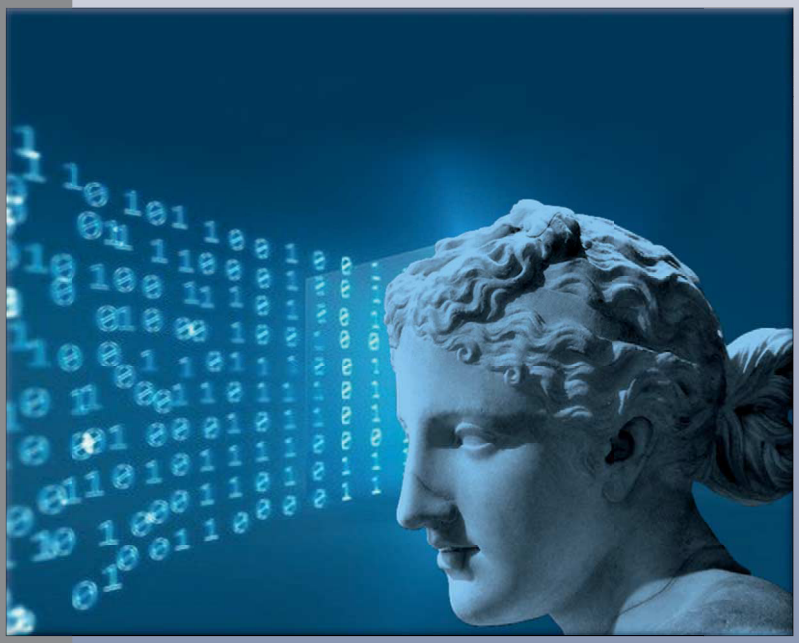
STUDIES IN HEALTH TECHNOLOGY AND INFORMATICS 262

Health Informatics Vision: From Data via Information to Knowledge



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The latest developments in data, informatics and technology continue to enable health professionals and informaticians to improve healthcare for the benefit of patients everywhere.

This book presents full papers from ICIMTH 2019, the 17th International Conference on Informatics, Management and Technology in Healthcare, held in Athens, Greece from 5 to 7 July 2019. Of the 150 submissions received, 95 were selected for presentation at the conference following review and are included here. The conference focused on increasing and improving knowledge of healthcare applications spanning the entire spectrum from clinical and health informatics to public health informatics as applied in the healthcare domain. The field of biomedical and health informatics is examined in a very broad framework, presenting the research and application outcomes of informatics from cell to population and exploring a number of technologies such as imaging, sensors, and biomedical equipment, together with management and organizational aspects including legal and social issues. Setting research priorities in health informatics is also addressed.

Providing an overview of the latest developments in health informatics, the book will be of interest to all those working in the field.

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HEALTH INFORMATICS VISION: FROM DATA VIA INFORMATION TO KNOWLEDGE

Studies in Health Technology and Informatics

International health informatics is driven by developments in biomedical technologies and medical informatics research that are advancing in parallel and form one integrated world of information and communication media and result in massive amounts of health data. These components include genomics and precision medicine, machine learning, translational informatics, intelligent systems for clinicians and patients, mobile health applications, data-driven telecommunication and rehabilitative technology, sensors, intelligent home technology, EHR and patient-controlled data, and Internet of Things.

Studies in Health Technology and Informatics (HTI) series was started in 1990 in collaboration with EU programmes that preceded the Horizon 2020 to promote biomedical and health informatics research. It has developed into a highly visible global platform for the dissemination of original research in this field, containing more than 250 volumes of high-quality works from all over the world.

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Preface

This volume contains the accepted full papers of the ICIMTH (International Conference on Informatics, Management, and Technology in Healthcare). The Scientific Programme Committee presents to the academic and professional community of Biomedical and Health Informatics the scientific outcomes of the ICIMTH 2019 Conference, which is being held from 5 to 7 July 2019 in Athens, Greece.

The ICIMTH 2019 Conference is the 17th Annual Conference in this series of scientific events, gathering scientists working in the field of Biomedical and Health Informatics from all continents as well as from the hosting country.

This year the Conference is focusing on increasing and improving our Knowledge of Healthcare in applications spanning the whole spectrum from Clinical Informatics, Health Informatics to Public Health Informatics as applied in the healthcare domain. Since Management and Organisational issues play an important role in the implementation phase of Biomedical and Health Informatics applications, topics related to the above themes are also included as an integral part of the overall theme of the Conference. We are examining the field of Biomedical and Health Informatics in a very broad framework presenting the research and application outcomes of Informatics from cell to populations, including a number of Technologies such as Imaging, Sensors, and Biomedical Equipment and Management and Organisational aspects, including legal and social issues and setting research priorities in Health Informatics. In essence, Data, Informatics, and Technology inspires health professionals and informaticians to improve healthcare for the benefit of patients.

This volume incorporates only the full papers accepted for oral presentation. It should be noted that the Proceedings are published in this series of the Conference as an e-book with e-access for ease of use and browsing without losing any of the advantages of indexing and citation in the biggest Scientific Literature Databases, such as Medline and Scopus that the series of Studies in Health Technology and Informatics (SHTI) of IOS Press provides.

At the end of the deadline we had 150 submissions, from which after reviewing we have accepted 95 as full papers to be included in the volume proceedings.

The Editors would like to thank the Members of the Scientific Programme Committee, the Organising Committee, and all Reviewers, who have performed a very professional thorough and objective refereeing of the scientific work in order to achieve a high-quality publishing achievement for a successful scientific event.

Athens, 30.05.2019

The Editors,
John Mantas, Arie Hasman, Parisis Gallos, Katia Kolokathi, Mowafa S. Househ, and Joseph Liaskos

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Contents

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Health Informatics Vision: From Data via Information to Knowledge
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Some Thoughts on Extended Collaboration of Entities with Natural and with Artificial Intelligence in Health Care and Beyond*

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Abstract. This lecture is dealing with new, future forms of collaboration and with its (hopefully existing) extended synergies, which may now will come in our era of digitization. Entities in this collaboration are we, the human beings, and other living entities such as animals with 'natural intelligence' as well as non-living entities, in particular functionally comprehensive machines, with 'artificial intelligence'. Based on lessons learned during the last years, among others in a task force on synergy and intelligence (SYnENCE) of the Braunschweig Scientific Society, five consequences for future health care with respect to this collaboration are put for discussion: (1) functional comprehensive 'intelligent' machines should be regarded as entities, not as modalities, (2) such machines have to become users of information systems in health, in addition to human entities, appropriate (3) legal and (4) ethical frameworks have to be developed, (5) extended collaboration in medicine and health care needs to be evaluated in accordance with good scientific practice. The statements of Karl Jaspers, made in 1946 on medicine and on technology, may help us to find a good way.

Keywords. Health care, digitization, natural intelligence, artificial intelligence

Introduction

This is my 5th keynote lecture at an ICIMTH conference. Such lectures provide opportunities to share and discuss topics, which might be relevant for the future of our societies in general and there in particular for health care. Topics which are of *originality* and *relevance* ([1], p. 260, df_6) on the one hand, and still to some extent immature on the other, as research maybe just at the beginning, and still without comprehensive results.

My first keynote lecture in 2003 gave me the opportunity to draw attention on 'information technology and the future of health care: the need for transinstitutional IT-strategies and information system architectures'. Today this might be subsumed under the term eHealth, in particular after the World Health Organization had in 2004 adopted its eHealth Resolution [2,3]. After successful developments on information systems architectures and strategies *within* health care institutions (hospitals, …), it became

* Written version of a keynote lecture, given at the International Conference on Informatics, Management, and Technology in Healthcare (ICIMTH), held from July 5 to 7, 2019, in Athens, Greece.

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necessary to now also focus on providing appropriate *patient-centered care*, not mainly institution-centered care. This problem still needs to be solved in many countries [4-6].

In 2013 there was the chance to address personal living environments as locations for health care, with the consequence that smart homes as well as health-enabling and ambient assisted technologies should become integrated parts of health care processes [7]. In 2016 under the title "my home is my hospital" [8] this was again the topic, as a just finalized review on such technologies could be presented [9]. This keynote lecture also gave the chance to remind of the term *engymetry*, proposed by Dietrich Peter PRETSCHNER,[10] and to suggest considering this term in this context

In 2017 reflections on informatics diagnostics and informatics therapeutics could be presented [11]. Originally suggested as research fields in [12], p. 606, they might today probably better be denoted as digital diagnostics and digital therapeutics [13].

1. Objectives and Contents

This keynote lecture is dealing with new, future forms of collaboration and with its (hopefully existing) extended synergies, which may now will come in our era of digitization. Entities in this collaboration are we, the human beings, and other living entities such as animals with 'natural intelligence' as well as non-living entities, in particular functionally comprehensive machines, with 'artificial intelligence'. These new, future forms of collaboration with all its potential opportunities and risks became more and more part of my research during the last years.

In section 3 I will report about lessons learned in some projects, I have been or still am involved in, being related to this topic. Consequences for future health care will be outlined in section 4. Some final remarks and conclusions will follow in section 5. Before I want to remind of two fundamentals, medical informatics is based on, in section 2.

2. On Two Fundamentals of Medical Informatics: Medicine and Technology

Medical informatics – you may also call this field biomedical and health informatics – is concerned with the systematic organization, representation, and analysis of data, information and knowledge in biomedicine and health care. The objectives of our field are twofold: to contribute to the progress of science and to contribute to high-quality, efficient health care, as well as to the quality of life ([1], pp. 256-257).

Two important fundamentals for our field are medicine and health care as well as information and communication technology. In this context I want to quote the philosopher and physician Karl Jaspers (1883-1969). In his essay 'on the living spirit of universities', published in 1946, he described the objectives of medicine and of technology [14]. Together with theology, law and philosophy, he regarded these two fields as the major building blocks of universities, usually organized within respective faculties.

Let me first quote his statements on *medicine*: "Medicine serves for the health and the well-being of individuals and for the hygiene of the conditions of populations. … Faculties of medicine live in the tension between the conception of humans as bodies, which can be fully understood by scientific means and which can be helped alone with these, and between communicating with humans as freedom of existence, to whomphysicians are companions in fate, not just assistants from natural science." ([14], pp 10-11,

translation by the author). On *technology* he wrote: "Technology serves for organizing our lives through mastering the natural forces, with the task of building environments of living, which relief humans from burdens and which finds beauty-enabling designs of human environments. … Faculties of Technology live in the tension between technical opportunities and human life orders. Being neutral in value they can be used as well for destruction as for construction. They are bound to natural sciences, but to be lead in their realizations by the freedom of humans, who know what they can and want, or who do not know." ([14], pp. 10-12, translation by the author). Let me come back later to these statements.

3. Lessons Learned on Extended Collaboration During the Last Years

Let me briefly report on some projects, being related with extended collaboration of entities with natural and with artificial intelligence. As already mentioned before, machines, which are functionally comprehensive, so that they can make or support decisions, which are comparable to those of human, are here called intelligent. This is of course debatable.

3.1. Health-enabling Technologies and Intelligent Homes as Servants

Since more than 10 years we at PLRI are doing research on health-enabling technologies. With the NATARS study, starting in 2011 we made first field tests with sensors in apartments of geriatric fracture patients after they have been discharged from hospital or rehabilitation centers. It turned out that by sensor technology (acceleration, motion), apartments could serve as diagnostic areas, with the potential to significantly improve health care processes [15,16]. This research continued with setting up research apartments as living labs and with additional research projects (e.g. [17,18]). With growing functionality, these apartments can be viewed as diagnostic and therapeutic areas [7,8]. Another view is to regard them as 'artificial servants' of their residents. Servants know a lot of the persons, they are serving, including many privacy matters. Good servants do not speak about these matters.

3.2. Robots in Operating Theatres and Questions on Shared Autonomy

Organized by the Braunschweig Scientific Society (Braunschweigische Wissenschaftliche Gesellschaft, BWG, [18]), on February 7, 2018, its 14th Bioethics Symposium was devoted to 'Robots in Operating Theatres'. From different viewpoints (surgery, robotics, medical informatics, law, and ethics) the challenges of novel team-machine interaction of surgery teams (physicians, nurses) and functional comprehensive robotic systems [19]was discussed, "in particular on how to adequately consider what hybrid actions can be specified, and in which sense these do imply a sharing of autonomous decisions between (teams of) humans and machines" ([20]). It turned out that from a surgical viewpoint already now decisions might be regarded are shared and not completely made by humans.

3.3. Questions at a Symposium on the Collaboration of Natural/Artificial Intelligence

Also organized by BWG, this time jointly with other institutions, on February 14 and 15, 2019, a symposium 'on the collaboration of natural and artificial intelligence' took place, with the subtitle 'on the collaboration of living and non-living entities in the era of digitization' [21]. Let me quote here the questions, raised at the beginning of this interdisciplinary symposium ([22], translated): "What will living together in times of increasing digitization look like in future? Which synergies arise from the now possible extended collaboration of humans, animals and plants on the one hand and of machines on the other? Can we distinguish between only contemporary and between appropriate forms of collaboration? And can recommendations be made in order to achieve appropriate forms, while avoiding timely but problematic forms?"

3.4. The SYnENCE Task Force and its Three Dimensions

Because of such questions BWG had in 2017 decided to establish a task force on 'synergy and intelligence' (SYnENCE, Synergie und Intelligenz, SYnENZ), the author of this keynote is chairing. To elaborate answers to questions, as mentioned in 3.3, the members of the taskforce decided to structure their work in three dimensions: Fields of application (one field being medicine and health care), methodological and technical aspects, as well as ethical and legal aspects. Let me mention the three instances of the dimension ethical and legal aspects and with the questions, raised in this context ([22], translated):"*Individuality and collectivity*: Will intensified communication and the extended use of assistive technologies lead to more cooperation and interdependence of individuals or of collectives? *Individualization and normalization*: Does the extended collaboration not only involve beneficial influences but also risks of normalizing human behavior and personal development? *Autonomy and responsibility*: What are the consequences for the autonomy of human decisions and for legal and ethical responsibility?

4. For discussion: Consequences for Future Health Care

What are or what might be consequences for future health care, considering both, respective research and respective practice? Let me put for discussion five themes:

Functional comprehensive 'intelligent' machines should be regarded as *entities*, not as modalities. In doing this, approaches on research and on implementing practice will probably become more appropriate. Just recall the topic team-machine interaction [20].

Such machines have to become *users of information systems* in health, in addition to human entities. When machines (intelligent houses, robotic systems, …) take care of patients, they may also need to know their diagnoses, signs and symptoms. Or they need to report about observations. Therefore they should have, as human health care professionals, access to their patients electronic health records. Details in [20], section 5.

Legal frameworks, today usually focusing on the responsibility of humans, need to consider this new and certainly for jurisdiction challenging development. This is in particular of importance for the ethical-legal instance 'autonomy and responsibility, mentioned in 3.4 Proposals have been made, see e.g. [20], section 6, of Susanne Beck.

Ethical frameworks need to be set in place, in particular with respect to the question, raised in 3.3, whether recommendations can be made in order to achieve appropriate forms of extended collaboration of living and non-living entities, while avoiding timely but problematic forms, and with respect to the ethical-legal instance 'individualization and normalization', mentioned in 3.4. Proposals have been made, see e.g. [20], section 7, of Arne Manzeschke.

Extended collaboration in medicine and health care needs to be *evaluated* in accordance with good scientific practice. In medicine we can fortunately base on a mature tradition of therapy research, with controlled trials as important instance (details in [23]).

5. Final Remarks and Conclusions

As mentioned in the introduction, such lectures provide opportunities to share and discuss topics, which might be of originality and relevance, but which to some extent still be immature and speculative. This is such a topic, which may have influence on our societies, not only on health care. Interdisciplinary research, including researchers in health sciences and informatics, but also from fields like ethics and law, is needed in order contribute to good future health care, and to not just sliding down a slippery slope of implementing new technologies without appropriate ethical framework. The statements of Karl Jaspers on medicine and on technology may help us to find a good way.

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Concurrent Execution of Multiple Computer-interpretable Clinical Practice Guidelines and Their Interrelations

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Abstract. Execution of multiple computer-interpretable guidelines (CIGs), enables the creation of patient-centered care plans for multimorbidity, which can be monitored by clinical decision support systems. This paper introduces an execution framework to manage multiple, concurrently implemented CIGs, also discussing the approaches used such as constraint satisfaction.

Keywords. Computer-interpretable Guideline, Multimorbidity, Personal Care Plan, Model-Driven Engineering, Constraint Satisfaction; Model Transformation

1. Introduction

Clinical Practice Guidelines (CPGs) [1] are evidence-based statements, which are used to support carers in supplying appropriate care, mainly for patients with a single disease. Patients, especially the elderly, may have dynamic and multiple health conditions (multimorbidity) [2], which use multiple formalised versions of guidelines. A computer interpretable version of these guidelines (CIGs) [3] can be used to achieve automated connections between CPGs and patient data, in order to for supply error-free and consistent care recommendations to maintain patient safety. To date, several CIG-driven Clinical Decision Support Systems [4] have been proposed to acquire, represent and execute guidelines, using different guideline representation languages with associated execution engines (e.g., Asbru [5], GLIF3 [6], GLARE [7], Prof*orma* [8]). CIG execution involves instantiation of CPGs with patient data, using a mechanism to extract information, and recommend appropriate patient-specific care recommendations, such as care options and clinical information.

MuCIGREF, which is a Multiple Computer-interpretable Guideline Representation and Execution Framework, is developed to represent and execute CPGs and their associated knowledge constructs in order to generate personal care plans for multimorbid patients. The application process of each guideline follows the semantics of the MuCIGREF ontology. As the care application proceeds, the personal plan is updated according to the recommended actions of guidelines. However, this is a challenging issue when multiple guidelines are concurrently implemented [9]. These can be induced by managing a set of constraints relating with, for instance, arranging concurrency and synchronisation relations between clinical activities, recommended by the same or

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different guidelines to avoid care conflicts (e.g., adverse drug interactions), or the need of multi-merging [10] of clinical activities to eliminate care duplications (e.g., inefficient use of resources). This paper presents the execution approach of MuCIGREF, mainly on alleviating challenges of parallel execution of multiple CIGs while generating a personalised care plan.

2. Model-driven Multiple Concurrently Implemented Guideline Execution

MuCIGREF implements the following three features:

1. **Elements of concepts and semantics regarding development of CIG models**: MuCIGREF uses the Eclipse Modeling Framework (EMF), which supplies a modelling and code generation architecture in Eclipse. EMF models are created to represent guideline elements and their interrelations. EMF-based CIG models are developed for each CPG. Once CIG models are created, they are executed in parallel to generate a unified personal plan model for each multimorbid patient. A model-to-model transformation approach (e.g., ATL [11]) is adopted, where source (individual CIG model) and target model (Personal Plan model) are complemented with a set of imperative logic, using the Epsilon Object Language (EOL) [12], a language imperative programming language to create, query and modify EMF models.

2. **Dynamic and flexible constraint satisfaction problems (CSPs) [13] over CIG models:** Actions of multiple guidelines may have diverse knowledge elements, their recommendations can be conflicting or overlapping, which may cause undesired patient outcomes. Constraints can be hard constraints, which must be satisfied at all times, like temporal constraints [14], or graph constraints to maintain care flow [15]; dynamic constraints like multi-activity management constraints to handle concurrency and synchronisation relations of guideline actions or to modify or optimise care to avoid conflicts or inefficiencies; or flexible constraints to handle user preferences. To do so, a new specialised CSP solving algorithm which is the extension of *backtracking* approach [13], is developed, which adopts to dynamic changes occurred in the CIG actions and their interrelations. Dynamic constraint satisfaction is used to support users to add new constraints (e.g., concurrency constraint), remove existing constraints or modify them during the solution process (e.g., care recommendation); flexible constraint satisfaction is used to relax constraints that must be satisfied, and enable users to make preferences on solutions (e.g., alternative care options).

3. **Consistent query answering [16] about these constraints:** Querying (e.g., specific time periods, patient information, lab results) and the constraint propagation technique [17], are used to reduce (filter) variables for the constraints, and extract information accordingly. Afterwards, this filtered information is recorded and used to update the model for further information extractions. Thus, step-by-step propagation and querying are applied in the entire personal plan generation process.

MuCIGREF's major execution functionalities are as follows: (i) checking execution status of each clinical activity to start care; (ii) identifying next clinical activities considering all the CIG models related with patient health disorders, by checking dependencies and constraints between clinical activities such as temporal constraints; and satisfaction of required conditions; (iii) adding, removing, or replacing clinical activities and/or their associated care elements; (iv) managing concurrency relations between multiple clinical activities to avoid harmful care advices, induced by recommendation conflicts (e.g., drug-drug interactions) and/or duplications (e.g., drug

overdose); (v) performing time-based synchronisation of clinical activities at the specific time point in order to be merged at the following care point as part of the care workflow; (vi) detecting unification care points to merge CIG actions; (vii) performing time-based care optimisation to avoid unnecessary resource (e.g., carer time, lab test) use and potential care duplications; and (viii) identifying conflicting clinical activities or potential conflicts and resolving them through modification of a clinical activity (e.g., activity start time, duration) or its associated care element (e.g., drug dose level).

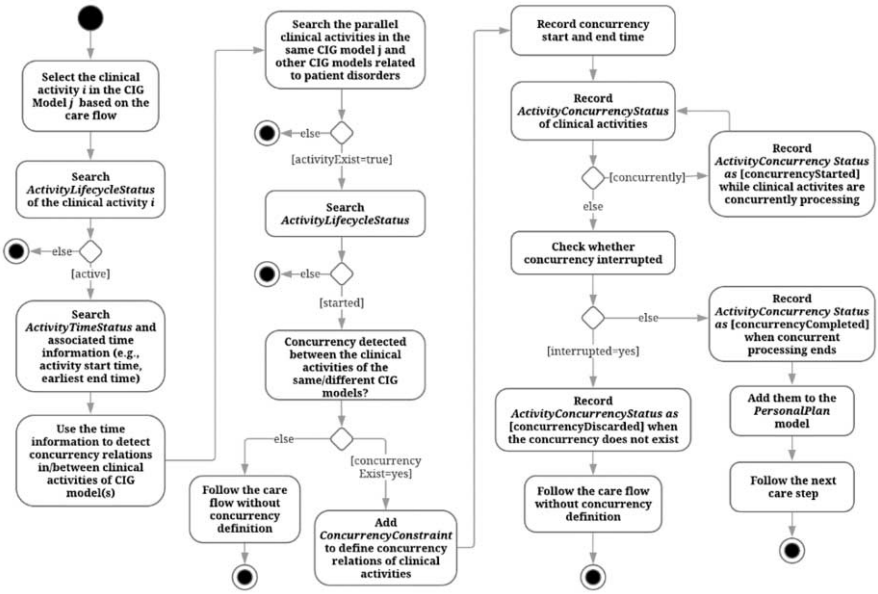

Figure 1. Concurrency management excerpt of MuCIGREF`s execution approach

3. Results

Several CPGs, from the UK National Institute of Care Excellence (NICE), are considered and, accordingly, personal plans are generated involving patient information. Execution framework meets the workflow requirements discussed in [18]. In Figure 1, an excerpt from the MuCIGREF's execution algorithm is presented, designed to handle concurrency relations between CIG actions. Validation is performed in the entire care process, in order to maintain consistent and error-free care plan. As part of the validation process, a set of model checking constraints are developed to comply with the requirements of execution regarding correctness, completeness, consistency and accuracy such as whether the defined care workflow has a cycle; each guideline has one starting activity and must have minimum one conclusion; or each decision must have minimum two conditional options. These constraints are applied in Epsilon Validation Language (EVL) [12] which check dependencies between the constraints specification of repairs that users can use to fix inconsistencies.

4. Discussion and Conclusion

In this work, conciliation of multiple CIGs with patient data to manage patients with multimorbidity, using a novel execution approach as part of the MuCIGREF, is introduced. Multimorbidity case studies were created with associated CPGs and patient data. Generating personal care plans for each patient by transforming individual CIG models; resolving challenges in coordination of complex knowledge sources and their interactions through satisfying a set of constraints with a new CSP solving approach; and adopting a dynamic model validation approach which supports users in each care step through supplying custom-built error messages, are the major contributions of this research. Future work will involve user validation and application in real-world cases.

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Usage of Accelerometers in the Medical Field of Application and Their Clinical Integration

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Abstract. We conducted a literature review on the use of accelerometers in medical context, on Pubmed and IEEEXplore. This includes 440 relevant articles. The subsequently identified publications were classified with regard to the medical context (prevention, diagnostics, therapy) as well as according to medical-informatics field of application, e.g. activity-tracking, fall prevention/detection and gait analysis. Furthermore, we analyzed their clinical integration or potential for the clinical usage, including both the technical integration into the clinical structures and respective claims and requirements, e.g. privacy or hygiene. This analysis shows five categories ("without indication" to "concrete implementation"). In 90% no statement was made on clinical integration. Only two articles could be found with concrete implementations, but these descriptions are limited to a more conceptual technical side. This poor situation in final clinical integration has to change in the future, because only by the premise "from workbench to bedside" the medical benefit is given.

Keywords. Accelerometer, Clinical-Infrastructure, Integration, Review

1. Introduction

Accelerometers have been a popular sensor technology within medical records for many years, for prevention and diagnostics, as well as therapy. The results from the recent literature search, over the years 2008-2018, shows how the use of accelerometers, especially in the medical field has changed within this time.

Figure 1 shows first the increase of relevant articles over this time. As can be seen here, the number of publications using accelerometers in the medical context has increased over the years, even considering the general increase in publications.

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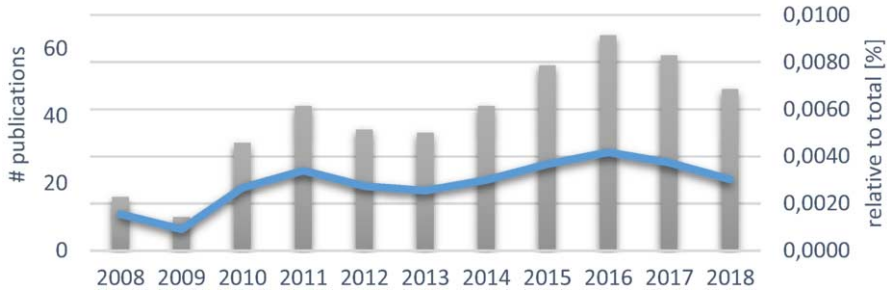

Figure 1. Found publications per year and relative number of findings to total publications

2. Method

To find the relevant publications we have used this search query,

(Accelerometer OR Acceleration Sensor) AND Monitor AND Health AND Human*

on the databases PubMed[2] and IEEEXplore[3]. After cleaning up duplicates we started analyzing the search results for relevance (according to PRISMA approach [1]); 440 articles could be found. These articles were then assigned to different groups (see **Figure 2**). The three largest groups are to be shown here in more detail.

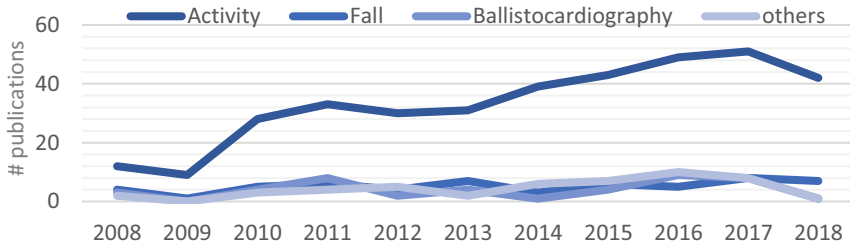

Figure 2. Number of articles on the respective field of medical informatics

Activity tracking: Activity detection seems to be a widespread application for accelerometers. There were 367 articles on this topic, which is 83.4 percent of the found articles. The number of articles distributed over the years shows a clear positive trend (see Figure 2). Taking into account the general publication growth, this means an increase in activity detection items from 2008 to 2017 of more than 100 percent.

Fall prevention/detection and gait analysis: We could find a total of 56 articles on this topic. That's a total of 12.7 percent. In relation to the activity detection articles, the number of these publications remains rather the same (see Figure 2).

Cardio-monitoring and ballistocardiography: 44 articles could be detected on this medical informatics topic, so 10 percent of the total found articles. Similar to the fall detection articles, the distribution over the years is rather steady.

A total of 515 assignments of the 440 articles were made, because some articles could not be neatly assigned to only one area, e.g. activity tracking and gait analysis or

[2] https://www.ncbi.nlm.nih.gov/pubmed/
[3] https://ieeexplore.ieee.org/

activity tracking and cardio-monitoring. In addition, 48 articles were found, which could not be assigned to the existing groups, e.g. sleep monitoring or eating habits, like rather small subgroups.

3. Results

But what is the situation of the actual clinical integration of these innovations or developments, in the published research results? In addition to the classification of the articles on the areas of application and topics, it was examined to what extent the integration of the technology into the clinical environment, as well as in the clinical processes, were realized. For this purpose, the articles were examined in a structured way and subdivided into five categories, "without indication", "future plans", "first ideas", "first developments" and "concrete implementations".

The aim of this work is to investigate the state of the publication on the medical use of accelerometers and their clinical integration. Within the identified articles (440 articles), as already described, five categories of clinical integration could be presented:

Table 1. Amount of papers in the integration classes and their medical field allocation

Category	Amount	Percentage	Allocation [amount]
without indication	396	90 %	prevention 20, diagnostics 328, therapy 58, others 4
future plans	15	3.4 %	prevention 1, diagnostics 12, therapy 2
first idea	19	4.3 %	diagnostics 15, therapy 4
first development	8	1.8 %	prevention 1, diagnostics 5, therapy 2
specific development	2	0.5 %	diagnostics 2

Biswas et al. have with their work, about the continuous monitoring of health and well-being with accelerometers, a possibility to implement a communication structure for sensor systems e.g. for activity detection and sleep monitoring [2], while Karunarathne et al. show the BioKin system for motion analysis, using also smart phones [3]. Both show more or less in detail the technical solution for the overall system (both cloud based data management and first general overall system description like raw interactions), including functionality or communication that can also be used for the clinical set up, but showed not all the needed properties for the clinical use, like staff interaction or data management.

4. Discussion

Some of the found articles refer to the development of first prototypes, e.g. for the measurement of previously non-medically used signals or basic research on the general use of accelerometers, but the step to bring research results and innovations to the patient bed should not be pushed aside. Especially the early consideration of constraints and limitations in the use of new technologies in a clinical context facilitates the integration. Only through the final premise "from workbench to bedside" is the medical benefit first given. Even the two found papers, that fulfil the actual development in terms of the clinical usability, did not describe all the needed details for the clinical integration. An example of the early involvement and the attempt of a clinical integration of accelerometers from research is shown by the INBED system [4]. Of course, clinical

research does not claim to develop ready-made tools, and so basic research is an essential component, but even in this section of research, future utility and usability should be kept in mind. According to Zubiete et al. one of the challenges of integrating sensor data is the lack of a general standard [5]. Sow et al. can also see this, despite the interoperable standards like HL7 or HIE [6]. Even in 2009, Marschollek was able to state that the biggest challenge of integrating new life forms into everyday medical life is not a technical one, but an interdisciplinary one [7].

Projects such as HiGHmed can make a considerable contribution, bringing sensor systems from research into everyday clinical practice, but data integration is not enough [8]. Both the technical requirements for the intuitive usability of such systems (e.g., communications infrastructure) and the clinical requirements (privacy or hygiene standards, e.g., for the cleaning of body-worn sensor systems) must be considered appropriate implementation.

With this literature trial, we make no claim to completeness. It is clear that we have not covered all relevant articles of the time, but a tendency can be identified.

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Creating Learning Opportunities by Using Videoconferencing in Surgical Education

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Abstract. Access to mentors for education in surgical subspecialties is a challenge in many hospitals. Videoconferencing (VC) provides real-time communication between mentors and mentees despite dispersed geographical locations. In Norway, an educational pathway of a specific laparoscopic surgical procedure was carried out using VC. The surgical training lasted for three months and was video recorded. The dataset covers the educational procedure, constituting of a trajectory of eight patient cases. During a model of stepwise distancing of the physical presence of the mentor, the collaborative work using VC leads the mentee to become an expert. VC is a tool for both collaboration and representation, as the picture on the VC offers the same information to both the mentor and the mentee. The communication is characterized by guidance and explanations of why specific actions are necessary for problem-solving. The use of VC was a presumption for becoming an expert in this procedure.

Keywords. Videoconferencing, learning, communication, surgical education

1. Introduction

Surgical training involves hands-on training, during which the surgeons who are being educated (mentees) are instructed by an expert surgeon (mentor). Access to mentors for surgical subspecialties is a challenge in many hospitals. Videoconferencing (VC) is a technology that provides real-time communication between mentors and mentees despite their different geographical locations.

An educational pathway of a hernia procedure was carried out using VC in a hospital in Norway. I followed the surgical training in the operating room (OR) of a mentee in a hernia procedure using laparoscopy. Laparoscopy is a technique that uses several small ports in the abdomen, with an instrument inserted through each. The procedure is visual, as a small camera is inserted into the patient's abdomen, and the image is transmitted to a monitor in the OR. VC occurs by connecting the laparoscopic surgery—the mentee, mentor, and the technological artifacts—to the monitor in the OR. The monitor is connected to the VC so that the mentor sees the same picture as the mentee.

Studies have stated that VC is well-suited for overcoming distance [1,2], allowing surgeons with no formal advanced laparoscopic training to benefit from expert advice during procedures [3] and providing better visibility and verbal accuracy in describing the procedures, as the instructor is not standing in the way [4]. These studies illustrated

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the outcomes possible with the technology, but few studies have reported on collaborative and communicative work in such settings. Related to the educational outcomes using VC, one review pointed out a strong focus on effectiveness in surgical mentoring and highlighted the need for in-depth understanding of instructions during surgical mentoring [5].

I report on the use of VC for instructions in real-time surgical education, where the mentor and mentee collaborated during the trajectory of becoming an expert. How is surgical training using VC organized, and what characterizes the communication? The hands-on training involved a mentee surgeon experienced with laparoscopy. Before practicing this specific procedure on patients, he had gone through the traditional education pathway for a new procedure, i.e., simulation using models and videos of the procedure.

2. Method

This research is related to a previous ethnographic study, which explored the mentor and mentee's views on the educational process [6] and was carried out during 2014–2016 in Norway, combining observations, interviews, focus groups, and field notes. Here, I present findings from three months of observations in 2014–2015, when the surgical training of a mentee in a specific hernia procedure was videotaped. The dataset covers the entire educational procedure, constituting a trajectory of eight cases and six hours of video observations. The whole dataset was transcribed. The presented excerpt is representative of this setting. The data protection officer at the selected hospital approved the study, and the study participants signed an informed consent form.

An interpretative analysis approach that uses an activity theoretical perspective [7] was used to conceptualize learning as a collective activity and a communicative process mediated by cultural tools, i.e., the VC. The analysis focused on the interactions between the mentor and the mentee where tensions appeared [7] and knowledge gaps needed to be closed, which directed the opportunities for learning.

3. Results

The educational practices in the OR were organized into eight sessions (Table 1) before the mentee became an expert.

Table 1. The organization of the educational practice and the use of VC.

The educational practice in the operation room (OR)								
Session	1	2	3	4	5	6	7	8
Mentor	Onsite operating	Onsite assisting	Onsite mentoring	Remote mentoring	Remote mentoring	Remote mentoring	Remote mentoring	Remote mentoring
Mentee	assisting	operating	operating	operating	operating	operating	operating	operating
Use of VC				In OR	In house	In house	Overseas	Overseas

The mentor performed the first operation while the mentee assisted. Then the mentee performed the operation while the mentor stepped aside, i.e., assisting and then observing and mentoring the mentee. The first session of mentoring observation (session 3) was done in the OR without using VC. In the fourth session, the mentor used the VC in the OR. In the fifth and sixth sessions, he moved to another room at the same hospital, and the last two remote mentoring sessions were done using the VC from overseas while the

mentee was in the OR. The first three sessions were onsite in the OR, preparing for the VC, while the next five sessions used VC. After the eighth session, the mentee was evaluated as educated as an expert in this specific procedure, terminating the use of VC from overseas.

What characterized the communication using VC is illustrated in Table 2. In this extract, we see the data about 20 minutes into the 5th session, which was videotaped for about 40 minutes.

Table 2. Content in the communication (A: mentee. B: mentor).

Extract from the 5th session:

1. **B**: Go a little more in, into the abdomen. Don't stay at the ring. Yeah, try that, inject.
2. Okay, if that's the vas you have to move the vessels, so the vas is still in there.
3. **A**: Oh.
4. **B**: I think, the opening in peritoneum, so now you're not gonna be [in the right spot].
5. **A**: Yes, it's sleekly [moving].
6. **B**: Yeah, exactly. Anyway, try that. Yes, nice, slide the needle forward, and it's easier to stay in the
7. abdomen instead of at the ring.
8. **A:** Yeah. I have to organize my needle first. Cause there's so much hydro dissection [fluid] here, I
9. can't see anything.
10. **B:** I know. So, you have to almost push the needle, all the way through (…) just get in that space and
11. push it forward. Keep going .... It's okay if you go out, go back in again now.
12. That's fine. That's nice, very nice. You got in. So you see how you …
13. If you take your needle out, and then take your Maryland [forceps].
14. I don't see your vas now, which means you did it nicely. Yeah. Very nice.

The mentor gave advice about moving into the abdomen [inside] and not staying at the ring [outside] (line 1). Then he recommended moving the vessels to keep the vas inside the ring (line 2). By referring to the opening in the peritoneum (line 4), he argued that the mentee was not in the right spot (line 4). The mentee explained it was sleekly [moving], and that's why he moved the forceps (line 5). The mentor recommended that the mentee slide the needle forward to stay in the abdomen instead of in the ring (line 6-7). The mentee had problems seeing, because there was too much hydro dissection [fluid] (line 8), and the mentor guided the mentee through by saying "push forward" and "keep going" (line 10-11). The mentee went out of the ring, and the mentor advised him to "go back in again now" (line 11) and advised him to take the needle out and use the forceps (line 13). At the end, he explained why he thought the performance was very nice—the vas was not visible (line 14) because it was left inside the ring.

The characteristics of the communication concerned the following: the mentor said what to do (lines 1–2, 4, 6–7, 10-14) and what not to do (lines 1, 4), explaining why (lines 4, 6-7, 11, 14). Both the mentor (lines 2, 12, 14) and the mentee (lines 9) referred to the picture on the monitor to reassure themselves of what was inside the abdomen (what they could and could not see).

4. Discussion

The organization of this educational practice using VC as a tool exemplifies instructional activities during surgical mentoring and how the mentor and mentee communicated, approaching new knowledge. After practicing for eight sessions in the OR, the mentee became an independent expert surgeon in this specific procedure. The sessions were organized according to the physical closeness–distance to the mentor. In the beginning, the mentor was in the OR, and thereafter there was a stepwise process of moving out of

the OR into another room at the hospital and then overseas. This model makes expert knowledge assessable despite geographical distances.

Widening existing studies', these findings report in-depth on collaborative and communicative work during surgical mentoring. The talk during the surgery illustrated how the mentor drew on his expertise, closing the knowledge gaps by instructing what to do and what not to do and explaining why. This communication pattern created opportunities for learning by sharing knowledge repertoires for medical problem-solving.

The VC was a tool for the activity, making the interaction between the mentor and mentee possible over great geographical distances. Additionally, the visuals on the monitor was of importance. Using a laparoscopic technique, the mentor and mentee approached the same video monitor, which made the physical presence of secondary importance. What became relevant in the interaction and communication was how the mentor and mentee contributed to the medical problem-solving and how these social practices for educating surgeons were organized.

5. Conclusion

During a model of stepwise distancing of the mentor's physical presence, collaborative work using VC helped the mentee become an expert. The communication in VC sessions was characterized, in the OR, in house, and overseas by guidance, explaining why the performance was necessary for problem-solving. The communication pattern during surgical training created opportunities for learning, while the VC was the tool and presumption for becoming an expert in this procedure.

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A Privacy Management Analysis (PMA) of Exchanging International Patient Summary

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Abstract. This paper provides a summary of the Privacy Management Analysis method followed for the analysis of the International Patient Summary exchange use cases of Trillium II Project. The objective is to recommend the required security and privacy measures by providing traceability from Regulations/Principles/Preferences to the recommended Security & Privacy Measures that needs to be implemented in pilots.

Keywords. Security and Privacy Controls, Privacy by Design, International Patient Summary

1. Introduction

The mission of the Trillium II project is to advance an International Patient Summary (IPS) standard [1] in order to ease accessing and sharing health information of people in case of emergency or unplanned care anywhere and as needed. Trillium II gives priority to immunizations, allergies, medications, clinical problems, past operations and implants in such cases. Thanks to IPS offering a window to a person's health, citizens gain health-awareness, while health professionals are better informed which causes fewer errors and better decisions. This paper summarizes the analysis of the selected IPS exchange use cases in order to recommend the required security and privacy measures that can be employed during pilot implementations. In this respect, it examines the regulatory challenges/barriers (introduced by EU GDPR, US Health Information Portability and Accountability Act (HIPAA)); identifies the information security and privacy risks concerning Personal Information (PI); identifies the needs for security and privacy controls and provides a 'catalogue' of security and privacy services and methods as a guidance to implementers of these selected use cases.

2. Methodology

We have carried out a Privacy Management Analysis (PMA) for the IPS exchange use cases which provides traceability from Regulations/Principles/Preferences to the recommended Security & Privacy Measures that needs to be implemented in pilots. As

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mandated by The General Data Protection Regulation (GDPR) [2], it is aimed to follow a Privacy by Design (PbD) approach for a standard based methodology utilizing the best practices established in the domain. For this purpose, we have conducted an analysis of a number of key studies in this field [3-5] providing guidance about how PbD approach can be successfully employed for analysing a use case at hand to identify the required security and privacy architecture that meets the expectations of the legal landscape and the security and privacy principles of all of the affected parties in the selected use case. Consequently, we have decided to follow a hybrid approach by exploiting the strengths of each of the mentioned references. Step by step demonstration of our methodology can be seen in Figure 1.

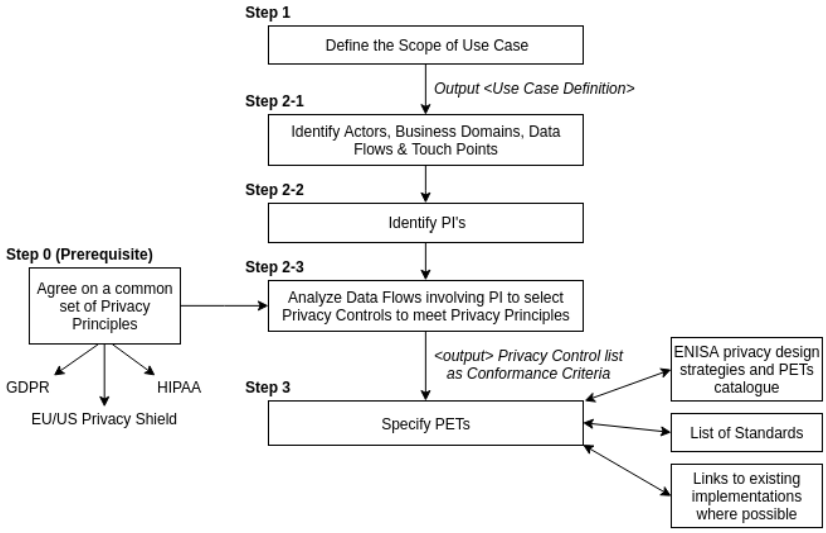

Figure 1. Trillium PMA Methodology

2.1. Selected Privacy Principle Set

Trillium II project aims the cross-border exchange of patient summaries between U.S. and EU countries. Within U.S., the processing and exchange of health information is subject to compliance to the Health Insurance Portability and Accountability Act (HIPAA) Security and Privacy Rules [6]. On the other hand, in EU regulation for the protection of natural persons with regard to the processing of personal data and on the free movement of such data depend on the EU General Data Protection Regulation (GDPR). ENISA Report in PbD, has thoroughly examined the new GDPR clauses and mapped these to nine Privacy and Security Principles, that can be used during Privacy and Security by Design procedures [5]. Those principals are; *Lawfulness, Consent, Purpose Binding, Necessity and Data Minimisation, Transparency and Openness, Rights of the Individual, Information Security, Accountability, Data Protection by design and by default.*

In the project, we carry out our PMA based on the ENISA principles, which has already been mapped to the EU GDPR clauses. On top of this, we have carefully analysed HIPAA Security and Privacy Rules to extract the security and privacy principles to be addressed and mapped these to the nine principles identified by ENISA [7].

3. Analysis of the Selected Use Cases and Results

In this paper we will focus on the analysis of the 'Cross-border Unplanned Care', which has been defined by epSOS project and will be operationalized via the eHealth Digital Service Infrastructure (eHDSI or eHealth DSI) enabling cross-border health data exchange under the Connecting Europe Facility (CEF). Each country is represented by a "National Contact Point for eHealth (NCPeH)" creating a Circle of Trust" (CoT) that enables inbound and outbound communication cross borders. It is assumed that within each country, through the agreements between point of cares (PoC) and NCPeH a national CoT is created, which leads up to building cascaded circles of trust. For the interactions between the NCPeHs of corresponding countries, either EU-US Privacy Shield (when cross border exchange between an EU member state and U.S. is targeted) or directly GDPR (when cross border exchange between an EU member states) would apply. Patient Summary used for the medical treatment of a patient and metadata needed to control the exchange of healthcare related data between NCPeHs and between NCPeHs and PoCs, respectively) are the Personally Identifying (PI) that have been identified for this use case. Among these, Patient Consent and Identity Claims can be categorized as Incoming PIs, the log data and administrative data as Internally Generated PIs, while Patient Summary can be categorized as both Incoming and Outgoing PIs. Having examined the system and identifying PIs, we identified a total of 53 different privacy controls as set of selected privacy conformance criteria that would apply to this use case to fulfill the above privacy principles. Afterwards, we presented pointers to the recommended security and privacy enhancing technologies in order to address the needs of the security controls identified (Table 1). The full list of recommended PETs can be found in our report available at [7].

Table 1. Example Security and Privacy controls and recommended PETs

Security and Privacy Controls	**Recommended security and privacy enhancing technologies to address these requirements**
Principle: Information Security *Privacy Controls: Identification (C.20) & Authentication (C.21, C.22, C.23, C24)*	* eHDSI Identity Management Service Specification description [8] * CEF eID building block (the eIDAS Regulation (EU 910/2014, 2014)) * HL7 FHIR security guidelines recommends OAuth and OpenID Connect to be used to authenticate and/or authorize the users.
Principle: Transparency and Openness *Privacy Controls:* C.9-C.14	The following transparency enhancing techniques can be implemented as recommended by ENISA Report [5]: * Privacy dashboards that presents the type of personal data collected, how they are used, to what parties they are made visible * Tools that extract by themselves the privacy information rather than depending on the declarations of the service providers, such as browser add-ons that analyses the events occurring when a user visits a website and continuously updates a graph showing the tracking sites and their interactions * Tools that rely on the effort of communities of peers (or experts) to evaluate privacy policies and track their evolution *Formal languages such as P3P, Privacy Bird, CI (Contextual Integrity), S4P and SIMPL can be utilized to make it easier for service providers and users to express their privacy policies and privacy requirements
Principle: Data Protection by design and by default *Privacy Controls:* C.52-C.53	Implement Minimize", "Hide", "Separate", "Enforce" and "Demonstrate" design strategies pointed out by ENISA Report. Guidance about the Privacy Enhancing Technologies (PETs) implementing these strategies can be found in ENISA Report [5].

4. Conclusions

In this analysis we have greatly benefited from the eHealth Digital Service Infrastructure (DSI) Security Service Specifications [8] as one of the analysed use cases is cross border "unplanned care". The eHDSI Security Policy specifications, and the accompanying Security Services Specifications very well addresses the requirements of *Information Security* principle (including identification, authentication, digital signatures, access control, confidentiality, system and data integrity, non-repudiation) and *Accountability* principle. On the other hand, the new requirements introduced by GDPR such as *Transparency and Openness,* and *Rights of Individuals (*online access to personal data and possibilities to exercise data subject rights such as withdrawing consent or requesting rectification, blocking and erasure of personal data) are not directly addressed eHealth DSI Security Services Specifications. Here we have utilized the guidance provided by ENISA report to point the implementers to the possible Privacy Enhancing Technologies (PETs) suggested by ENISA (e.g. implementing formal languages such as P3P, Privacy Bird, CI (Contextual Integrity), S4P and SIMPL for transparently sharing privacy policies). In addition to these, different from the eHDSI (exchanging Patient Summaries represented as HL7 CDA documents over an IHE XC*-based infrastructure), Trillium II intends to use HL7 FHIR resources to better reflect the new needs of the International Patient Summary [9]. In our analysis we have taken in to account these differences and provided references to security and privacy measures that is also applicable to RESTful HL7 FHIR resource exchange paradigm (e.g OAuth and OpenID Connect).

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Decision Support System for Inventory Management in Healthcare Organizations: A Case Study at the Brazilian National Cancer Institute

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Abstract. Nowadays, the great majority of the healthcare organizations has been criticized due to the high costs and low efficiency and are facing a critical situation aggravated by unmet demand and aging population. Availability of medicines is one of the clearest indicators that a healthcare organization is working efficiently. Medicines represent a large portion of the costs in the health services due to the significant value of these products and their storage and control requirements. Shortages of inventory have become a severe problem at the Brazilian healthcare organizations. The purpose of this work is to present the deployment of a Decision Support System which supports real-time inventory control and medicine tracking providing transparency and accessibility of this critical information at the Brazilian National Cancer Institute.

Keywords. Decision Support Systems, Medicine Inventory Management

1. Introduction

The healthcare industry has been under extreme political and public pressure during the last decades to control the increasing treatment costs. The expenses of healthcare are keeping on growing while the healthcare organizations are required to deliver a high quality of care. Despite the escalation of costs and relevance of this sector around the world, the medicine supply inventory management has been given little attention [1].

Medicine management and logistics have not been given high focus in hospital administration in the past. The Probable reasons are the high complexity of healthcare supply chains and their operational role in the hospital environment. However, in the last years, healthcare services have evolved into highly complex organizations, and logistics has been identified as a critical issue to control healthcare costs [2].

The major reasons that managers need to focus on inventory control are related to the fundamental differences between medicines and other kinds of products. Medicines

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are created, produced, and distributed according to strict regulatory requirements. By rising the efficiency of the supply chain, healthcare cost savings could be reached [3].

Availability of medicines is one of the most apparent indicators that a healthcare organization is working efficiently. It is one of the most critical supply and affects both health providers and patients. Medicines represent a large portion of the costs in the healthcare services due to the significant value of these products and their storage and control requirements. The primary purpose of medicine inventory management is to reduce treatment cost without sacrificing the quality of services [4].

The medicine shortages frequently impact cancer patients. Recently, a survey has been conducted to analyze the impact of drug shortages on cancer care that reveals 40 percent of oncologists had observed their patients die sooner and 95% of physicians had a patient who was unable to receive timely treatment due to medicine shortages [5].

Many reserachers have reinforced the relevance of Information and Communications Technology (ICT) tools in supply chain practices. Inventory management is a crucial decision-making process. The vast majority of the healthcare organizations has been criticized due to the high cost and low efficiency and are facing a critical situation aggravated by unmet demand and aging population. Drug stock-outs are identified as a global problem, and they severely affect all stakeholders of the healthcare services. [6]

Shortages of inventory have become a severe problem at the Brazilian healthcare organizations. Medicine shortages affect patient care by causing replacement of safe therapies by substitute treatments, compromising or suspending medical procedures and causing medication errors. The purpose of this work is to present the deployment of a Decision Support System which supports real-time inventory control and medicine tracking providing transparency and accessibility of this critical information at the Brazilian National Cancer Institute (INCA).

2. Methods

This study was developed through qualitative research to present a descriptive analysis of the implementation of the Decision Support System for Inventory Management at INCA. Qualitative data were gathered through observations and interviews. Semi-structured interviews were carried out with various hospital staff such as IT managers, supply chain professionals, nurses, pharmacist, physicians over the first four months of 2018. The INCA inventory management is a complex and critical process. The hospital's units run the risk of not being able to provide patients with the best medicine when it is required due to lacking proper medicine inventory management practices. Furthermore, pharmacies' dispensing medication choices may have a direct effect on the effectiveness of oncology treatment. Use medicines that are not on the clinical protocols may be risky and costly. Besides to patient safety and economic issues, rigorous regulatory requirements relating to drugs' traceability, inventory reporting, and inventory management increase the requirement of keeping efficient control over drug inventories ever-expanding in healthcare services.

The deployed real-time tracking functionality includes recommending items and quantities to be ordered based providing limits on excessive orders, and electronically placing orders after authorization. When setting the automated ordering, it is crucial to establish appropriate levels to organize the ordering process and reduce excessive supplies.

The Decision Support System for inventory management was developed with interoperability requirements to record and monitor medicine distribution and traceability at INCA as shown in Figure 1.

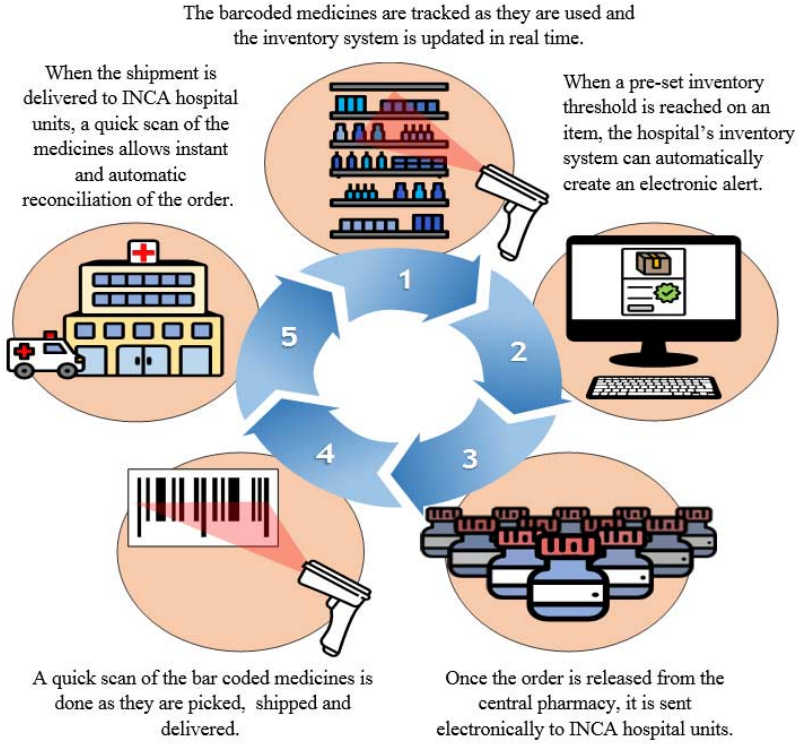

Figure 1. INCA medicine inventory management flow.

INCA had many reasons to effectively manage their inventory, including medicine tracking, investment protection, and goals compliance. Using barcode scanners for scanning have allowed managers conducted a physical inventory in fractions of the time. By managing INCA inventory in real time, substantial savings have been achieved in total inventory cost through the implementation of a new model to operate the hospital pharmacy inventories effectively and efficiently.

3. Results

Results found that the implementation of this system has improved the INCA capacity to manage its pharmacy inventory effectively and efficiently. The Decision Support System has allowed integrating real-time inventory tracking with purchasing functions reducing total inventory costs and stockout risks. Improvements in oncology medication inventory control can bring a significant impact on the efficiency of the INCA hospital units.

The Functionalities has included stock receipts, stock issues and adjusting stock levels. An inventory control module was developed to track medicines by generic name and to record batch number and expiry date. Reports on stock levels, stock to expire, and average monthly consumption were created.

The DSS implementation has greatly enhanced INCA operations. The flexibility of the system has allowed for automating and streamlining medicine tracking processes as well as reduces errors and the time spent correcting them. The system has addressed the tracking needs of INCA including managing inventory, supplies reordering, asset tracking and patient monitoring

The DSS has included detailed dashboards that present INCA managers with a graphical interface with key performance indicators like as total consumption per item, items to order and orders history.

4. Conclusions

The deployment of the DSS has improved the INCA' procurement processes, and inventory control besides offered several important insights for medicine supply staff. More efficient inventory management means cost not only savings but also better-quality patient care. The decision support system has enabled the managers to streamline how the staff managed medicines, tracking them most efficiently.

This research has demonstrated the decision support system deployment can provide healthcare organizations with a significant competitive advantage. However, careful implementation is necessary to explore the potential of the DSS fully. It is essential that managers who have involved with the decision support system deployment, understand how to use the system, and realize its potential benefits.

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Developing a Framework for a Healthcare Data Science Hub; Challenges and Lessons Learned

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Abstract. 'Research through innovation' is the current demand echoing throughout the healthcare industry, healthcare institutions tend to invest heavily in technology. Data Science being the major disruptor across industries is being incepted through establishment of innovation and R&D centers within their respective organizations. Data Science has become a critical component for the healthcare industry, supporting innovative approaches towards advanced clinical practice, clinical research and corporate management, serving to build an intelligent enterprise. Every healthcare institution maintains a good number of technical staffs with IT, Software, data management, BI and analytical capabilities, aiding the institutions to manage report and publish its data in some or the other way, grossly covering most aspects of data science knowingly or unknowingly. Setting up a new entity within the organization by recruitment of staff with Data Science based skill sets would be the first thought to strike the management, which in contrast would end up as disaster when it comes to understanding the organizational culture, processes, infrastructure, platforms, data etc. Hence in order to setup a data science hub, regrouping or realigning some of the existing institutional resources is crucial. With this approach, the Data Science hub would carry out three primary functions. The "Project Management & Data Sourcing", the "Data Management & General Analytics" and "Advanced Analytics". Current resources can be reorganized within the first two functions, further; it would be about establishing an advanced analytics group within the hub which would perform the Machine learning and AI functions.

Keywords. Data Science, Machine Learning, Advanced Analytics

1. Background and Introduction

In an intelligent world led by technology and innovation where the Modern scientific research is mostly data-driven, the healthcare industry -surprisingly- lags behind in the means of making full use of their resources using patients' historic data to improve patient care quality, the accuracy of diagnosis, lower the cost of chronic diseases expenditure on the government by early interventions suggested by prediction models,

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meaningful research can be performed, corporate decisions can be taken or altered, and corporate plans can be drafted and supported by evidence. Data science need to be leveraged in these areas if the healthcare industries want to lead in the field or even not be left behind which will be the case if not implemented correctly. Gartner reports that at most 20% of companies are engaged in real data science and predictive analytics. The greatest barrier to the non-adopters yet is simple, they don't know where or how to get started. There is so much unfamiliar jargon, press about multiple exciting new opportunities, and perceived risk of starting at the wrong place or taking the wrong direction which is keeping organizations at bay. Data and analytics must drive modern business operations, not just reflect them. Technical professionals must holistically manage an end-to-end data and analytics architecture to acquire, organize, analyze and deliver insights to support that goal [1]. Augmenting human decision-making at the enterprise level will bring us to the next level in growth [2]. The Data Sciences Hub within a healthcare and research environment would provide a focal point for programs dedicated to research and application of modern techniques to the management, storage, and analysis of complex data sets. In addition to fundamental research activities on data science, the Hub will include organization-wide discussions of data problems and consulting services to help investigators in defining and designing various hypotheses which can be investigated using the various platforms or available tools. The purpose of this paper is to document the experience with the best practices applied at the KFSH Research center, crossed with known Data Science functions and industry specific requirements within the healthcare sector.

2. Methodology

Healthcare and research setups since decades has been carrying out various statistics and descriptive analytics some or the other way, and these are the prime resources which would form the supporting pillars of the various functions under the data science hub, hence we do not follow a methodology of building a hub from scratch. Moreover, it would be about reorganizing the resources available with the organization in addition to the establishment of an advanced analytics group within the hub, which would include Machine learning experts or data scientist to formalize a core data science function. This alignment is mostly based on the physical setup at the KFSH Research center, in addition to the Machine Learning and AI functions.

3. Functions

Functions of the data hub revolve around the concepts and applications of data science, which is a holistic field encompassing data extraction, data preparation and data analysis, deriving insights, futuristic predictions and trends within the dataset. It can be further taken over to the next level of doing prescriptive analytics, contributing towards precision medicine. This generates demands for skills such as capturing data, statistics, mathematics, programming, problem-solving, data visualization, machine learning and AI. Further we will define each function within the hub in detail, as these functions act as the pillars of the Data Science Hub.

Data Sourcing and Data Project Management: It is crucial for the data science hub to function, supported by quality sourced data, it takes a considerable amount of

experience dealing with data management and sourcing. Secondly, this function would also be responsible to manage the data, architecture, hypothesis designs also covering all aspects of project management to ensure the desired quality output in a timely manner. This key function would include people with enough domain knowledge (healthcare) or expertise. Data sourcing would work hand in hand with the Data Warehouse team to ensure that the right data is available at the right time. Hence, the data warehouse acts as a service provider for the Data Sourcing function/section. Another function of this group would be to collaborate or rather connect the requesting department with the data science hub, helping them design a data strategy as a service to carry out research or desired data reporting.

Biostatistics and Computing function: This function would mostly be inclined towards research, grossly scientific projects, publications, precision medicine, etc. This function would be closely coupled with the Advanced Analytics function. It would be important for the Project Management group to rightly identify the projects or tasks which would need the biostatistics/scientific computing support.

Analytics, Data Visualization & Advanced Analytics Function: This function would act as an analytical arm for all the business units & functions within the institution, widely supporting the corporate side (non-medical) as well as clinical units. This function would cater to services starting from data preparation to descriptive visual analytics and reporting.

Machine Learning and AI: The primary purpose of Data Science is to build machine learning models, which are basically statistical models that can be used to extract patterns from data. Data science and machine learning can also be thought of as using the power of modern computing to leverage statistics. Some machine learning models, such as regularized regression and decision trees, lend themselves well to deriving insights and explaining patterns in data (e.g., which clinicians are over-utilizing costly materials). Other machine learning models, such random forests and neural networks (deep learning: image recognition, prescription reading which to pharmacy automation, facial and vocal recognition, diagnosis by image recognition "Medical Imaging" making it a lot easier to diagnose, (pain free, biopsy), are primarily used for prediction (e.g., each patient in a population's likelihood of readmission after discharge).Creating predictive model based on its own patient population.

Big Data Management: When we are talking about Data Science, we cannot afford to miss out Big Data. But healthcare and healthcare research data, although it justified the velocity, veracity, variety and value, but not as huge with volume and moreover is very well organized within the organization, with the help of EMR, Registries, imaging, other clinical systems etc. and hence can be extracted or queried in a systemic format. Hence the big data aspect for the data science for healthcare would be of consideration at a later stage, as and when the actual need arises.

4. Manpower Roles, Job Descriptions and Skill set

The Data Science hub does not just represent a core group of data scientists, rather this activity would be broken down into smaller functions, which will be easy to manage. Starting with the role of the Chief Analytics Officer/Chief Data Officer; success will be increasingly defined by leaders who understand & execute data science. As executives build and guide teams toward a harmonious, well-planned vision for healthcare improvement that fully harnesses data's capabilities [3], Followed by:

Data Scientist: A data scientist is a person who solves business tasks using machine learning and data mining techniques, briefly speaking a data scientist is the one who understands the complete data lifecycle and keeps the understanding of all the processes involved.
Data Analyst / ML Engineers: The data analyst role implies proper data collection and interpretation activities. An analyst ensures that collected data is relevant and exhaustive while also interpreting the analytics results. Organization requires data analysts to have visualization skills to convert alienating numbers into tangible insights through graphics.
Business Analyst: A business analyst basically realizes a CAO's functions but on the operational level. This implies converting business expectations into data analysis. If your core data scientist lacks domain expertise, a business analyst bridges this gulf.
Data Architect: This is a future role, when the data scope widens, and Big Data capabilities need to be implemented in order to scale up with the requirements. This role is critical for working with large amounts of data However, if you don't solely rely on MLaaS cloud platforms, this role is critical to warehouse the data, define database architecture, centralize data, and ensure integrity across different sources. For large distributed systems and big datasets, the architect is also in charge of performance.

5. Conclusions

The outcome of the above discussion would be the modality in which the Data Science hub would be structured within a healthcare or research environment. A two staged approach, stating with a centralized group followed by Center of excellence. The Data Science Hub would be a group/department catering to all the analytical needs within the organization, addressing both on the clinical and non-clinical sides.

Centralized Group: This would allow the organization to use analytics/data Science in strategic tasks; where the data science team as a group, serves the whole organization in a variety of projects. As a Department the group can look forward to a long-term funding & hence can manage the resources in a better way. The only pitfall here is the risk of transforming an analytics function into a supporting one.

Center of Excellence (CoE): Moving away from the centralized approach the group should innovate and educate other departments, in-order to establish a center of excellence. Down the line the DS Hub would keep the centralized approach with a single corporate center, but data scientists will be allocated to different units in the organization. This would form a balanced structure – data and analytical activities are well coordinated, but experts won't be removed from business units, or rather added wherever necessary.

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A Multi-Lingual Dictionary for Health Informatics as an International Cooperation Pillar

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Abstract. Even if, English is generally used for international communication, it is essential to keep in mind that research is running at the local level by local teams generally communicating in their local/national language. Bearing these in mind, the "European Federation for Medical Informatics Working Group on Health Informatics for Inter-regional Cooperation" has as one of its objectives, to develop a multilingual dictionary focusing on Health Informatics as a collaboration tool allowing improving international and more particularly European cooperation. This dictionary is implemented as a part of HeTOP (Health Terminology/Ontology Portal) which is currently integrating more than 70 terminologies and ontologies in 32 languages. The EFMI Dictionary main aims are helping medical librarians, translators, academic and industrial researchers understanding better one another and supporting students self-learning.

Keywords. Dictionary, Europe, Medical Informatics, Interdisciplinary Communications, Intersectoral Collaboration

1. Introduction and Background

The scientific projects, particularly in the Health Sciences and Technologies field, are nowadays more and more multi-centric by involving partners with different capabilities, skills and expertise from different countries. Even if, English is generally used for international communication, it is essential to keep in mind that research is running at the local level by local teams generally communicating in their local/national language.

The European Federation for Medical Informatics Association (EFMI) is built around more than 30 member-countries affiliated societies [1]. One of the objectives of EFMI is encouraging academic and professional collaborations and cooperation between all its members for enhancing health and medical informatics research, education, knowledge and industrial transfer. In this context of endlessly mutable scientifically, technologically and regulatory environments, the EFMI Working Group (WG) "Health

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Informatics for Interregional Cooperation" (HIIC) is actively dealing with promoting exchange of information, knowledge and experiences between Health Informatics field actors all around Europe and its neighborhood. Moreover, EFMI WG HIIC has for aims

1. Improving and facilitating interactions between students and researchers across Europe and World-Wilde and
2. Disseminating their productions – research results and documentation– across academics and practitioners [2, 3].

The 28 member-countries of the European Union has a population of more than 517 million inhabitants, and more that 750 million when including population of the geographical Europe and associated countries. Currently there are 24 official languages in the EU: Bulgarian, Croatian, Czech, Danish, Dutch, English, Estonian, Finnish, French, German, Greek, Hungarian, Irish, Italian, Latvian, Lithuanian, Maltese, Polish, Portuguese, Romanian, Slovak, Slovene, Spanish and Swedish [4]. Additionally, considering the EFMI member-societies which are not a part of EU additional languages must be considered from the EFMI WG HIIC perspective: Armenian, Bosnian, Hebrew, Icelandic, Luxembourgish, Macedonian, Norwegian, Romansh, Russian, Serbian, Turkish, and Ukrainian.

This language diversity is inducing number of research issues from the Management side and from the Informatics and Technology one. From a managerial perspective, international and multilingual working groups have to deal with misunderstandings due to mistranslations, and so any of the main five different steps of a project (initiation, planning, execution, performance monitoring, and delivery/closure) will be impacted and induce delays, overrides, bugs and major failures. From a technological and healthcare informatics point of view, developing a tool improving understanding and communication between non-English native speakers in a polyglot environment induce questions about usability and integration with existing terminologies, classifications and ontologies in health and engineering sciences.

Bearing these in mind, EFMI WG HIIC has one of its objectives, as a part of its continually evolving strategy, developing a multilingual dictionary focusing on Health Informatics as a collaboration tool improving international and more particularly European cooperation having as result less misunderstanding and mistranslation. This paper discloses the current status of the "EFMI languages Health Informatics Dictionary" (noted "EFMI dictionary") project.

2. Method and Results

The first step of the "EFMI dictionary" project has consisted in defining the list of the official languages of the EFMI member-countries. The second step has consisted in associating to each one of the 32 languages which have been previously identified the relevant ISO 639 code [5] in order to facilitate the next implementation steps.

Several initial main categories of terms have been defined such as "Computer-Hardware", "Computer-Software", "Biomedical Device", "System", "Programming", "Organization", "Journal", "Application field (Medical Specialty)", "Application field (Disease)". These categories will be refined, hierarchized and other will be added over time. They will support disambiguation for term having more than one meaning. The dictionary has been, as an initial step, populated by an initial set of 160 terms, and when relevant related acronym (e.g. International Conference on Informatics, Management and Technology in Healthcare, ICIMTH). This set has been established by the EFMI WG

HIIC members in English, French, Romanian, Hungarian, and Hebrew, which are the main languages they know at a native-speaker level. At a short term the dictionary will include at least 300 words translated in at least the five languages above. At the long term, it will comprise few hundreds of terms. Then, a simple automated translation process, using online multilingual machine translation service such as Google Translate supporting over 100 languages at various levels, has been implemented. The translation service was able to detect (with high accuracy) the language of the submitted term and then translate it to target languages according to the ISO 639 codes previously selected. As a result of this automated translation process a flat file has been generated and comprising 38 columns – the main category of the term, the term to translate, and the 32 translations –. However, as a part of the quality control point of this step, the EFMI WG HIIC members pointed out the lack of translated accuracy for at least half of the 32 languages due to the different levels of maturity of the translation capabilities of the service. Accordingly, human language speakers are and will be involved in the validation, improvement and expansion of the dictionary overtime.

Disseminating the information and the knowledge included into the "EFMI dictionary", a critical step was to define which kind of platform will be relevant for

- Hosting and maintaining it efficiently overtime,
- Supporting integration with other existing terminologies, classifications and ontologies in health, engineering sciences [6] and education [7].
- Providing to the end-user a user-friendly interface which will encourage using the dictionary as a day-to-day tool.

The HIIC workgroup interest focused on a cross lingual Health Terminology/Ontology Portal HeTOP (URL: www.hetop.eu), which contains more than 2 million health domain related concepts among more than 70 terminologies or ontologies (T/O) in 32 languages [8,9]. T/O are now widely used across the world for different kinds of applications and also generally specific to a domain (anatomy, rare diseases, medical devices, etc.) like the "EFMI dictionary". Moreover, with the same mindset, HeTOP is based cross-lingual since T/O are often available in several languages. Furthermore, HeTOP T/O' are mapped to each other and build a huge semantic network allowing the semantic interoperability. In the near future, this will allow improving and expending the EFMI dictionary. Accordingly, the flat file initially built with the first 160 terms only (without definition, at this time) and automated translation (partially validated by an EFMI WG HIIC specific language native-speaker) has been imported and integrated into HeTOP for empirically evaluating and validating

- Maintenance capabilities provided by HeTOP the EFMI dictionary,
- Usability of the dictionary in the HeTOP framework.

Figure 1 shows an example of HeTOP response for a query with the term "EFMI" which appears both in MesH as a drug and in the EFMI dictionary as the acronym of "European Federation for Medical Informatics".

3. Discussion, Conclusion and Perspectives

Developing inter-regional cooperation and collaboration is a challenging task which is now mainly based on the workspace virtualization and hugely using electronic tools. This

is a great opportunity for developing and improving scientific, technical, educational partnerships, in health informatics and technologies (HIT) in the Europe and around the world. Managing HIT related projects requires a basic but right understanding of the terminology from the technological, informatics and engineering side and from the health sciences and medicine side. The EFMI Dictionary has for goal to provide a multilingual tool focusing specifically on the health informatics and technologies arena. Its integration into HeTOP which allows in the future crossing and expending the EFMI Dictionary, (semi)-automatically with other health related terminologies and ontologies. Furthermore, the EFMI Dictionary as a part of HeTOP benefits of an environment helping medical librarians, translators, academic and industrial researchers, understanding better one another, and supporting students self-learning [10].

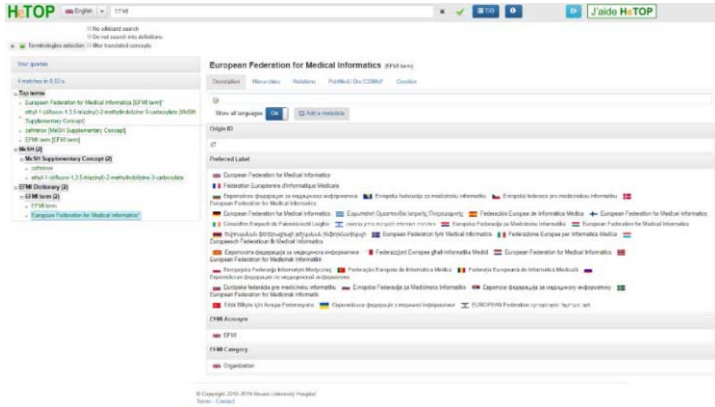

Figure 1. Example of HeTOP response for a query with the term "EFMI"

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Implementing an Oncology Decision Support System: The Case of the Brazilian National Cancer Institute

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Abstract. Brazil has a complex situation in cancer treatment services. The incidence rates have reached around 600.000 new cases each year. The development of an Oncology Decision Support System (ODSS) that support cancer treatment is amongst the priorities in the cancer control program. The purpose of this article is to study the ODSS deployment at the Brazilian National Cancer Institute. The implementation of this Clinical Decision Support System employed on the management, processing, and analysis of Brazilian cancer clinical data can be considered a disruptive innovation which changes the clinical decision-making process radically.

Keywords. Oncology Decision Support System, Clinical Decision Support System

1. Introduction

Nowadays, healthcare organizations are facing significant challenges due to demographic changes, technological advances, and scarce resources. The volume of data collected has surpassed the processing capacity of the clinical information systems. Additionally, this information comes from different sources and in diverse formats, which rise the effort to extract useful information. Managers understand that accurate and agile decision-making are vital to management efficiency [1].

Brazil has a problematic scenario in cancer treatment services. The rates of new cases have reached 600.000 each year. Cancer treatment is a long, multifaceted and risky process and involves different stakeholders. Therefore, the creation of an ICT environment that provides easy information access is critical to improve the clinical decision-making process and decrease the fragmentation of cancer patients' care [2].

Healthcare services have always been information intensive. Clinical Decision Support Systems (CDSS) are developed to deliver real-time information and have been often deployed to provide value to organizations. An essential function of a CDSS is to

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integrate data from a wide variety of internal and external sources, providing a suitable information framework for healthcare decision makers [3].

Innovations in Information Technology and Communication (ICT) will support healthcare executives to create the basis for improvements within the healthcare organization. Furthermore, allowing the physicians to communicate easily and quickly with patients and clinical staff will also rise patients' community' awareness of healthcare enhancements [4]. In oncology, physicians require electronic data collection of cancer-related information, in search of personalized care and to analyze real-time clinical research cases and, consequently, to improve the quality of oncologic patients' treatment. There is a need for specific software focusing on cancer treatment particular issues to make the system more useful and user-friendly to clinical staff [5].

Oncology Decision Support Systems (ODSS) are essential tools to ensure cancer treatment best practices, for improving patient security and facilitating research. In oncology, the growing volume of clinical data, the complexities of cancer care and the demand for real-time data underline the necessity for information systems to access, organize, and manage clinical oncology data [6].

This paper presents the implementation of an Oncology Decision Support System employed on the management, processing, and analysis of the Brazilian National Cancer Institute (INCA) data. The strategic importance of clinical data analytics has motivated INCA in adopting this CDSS for the medical decision-making processes.

2. Methodology

This study was developed through qualitative research to present a descriptive analysis of the Oncology Decision Support System deployment at the Brazilian National Cancer Institute and its adoption.

This single-case study aims to expand the knowledge of organizational phenomena, presenting an up-to-date description of the Clinical Decision Support System deployment, through an empirical inquiry. Data were collected through internal documents, participant observation, and semi-structured interviews. The data collection and analysis had been conducted over the last six months of 2018. The first author is the INCA's Chief Information Officer and associate professor at the postgraduate program in Business Administration that has been conducting this study.

3. INCA's Case Study

Cancer is possibly the most complex disease at present. Although the various types of cancer are well-established, the cases are never the same. A multidisciplinary approach is vital, with a healthcare team integrated and collaborating across the hospital. Oncology information environment can focus on cancer treatment specific data to make the system more useful for clinical staff. Nowadays, a Clinical Decision Support System (CDSS) that can manage patient treatment plans, treatment schedules, patient discharge summary, and results are extremely required. The CDSS can be used to control these data and encompass the information exchange between different departments and the overall healthcare organization.

The oncology information environment must be feed by all hospital information systems. The development of clinical information systems requires standardization for

quick deployment and facility of integration. By using standards, it is possible to share the patient data easily. And this interoperability will lead to improved medical safety and professional effectiveness. The significant volume of cancer cases in Brazil reinforces that the access of information about this disease is vital for patients and physicians involved in cancer treatment what opens a prospect for implementing an oncology information framework at the Brazilian National Cancer Institute. As responsible for the prevention and control of cancer in Brazil, INCA develops actions, campaigns, and programs nationwide in compliance with Brazilian National Health Policy. The Oncology Decision Support System has allowed INCA clinics to move beyond basic automation and transformed medical data into aggregated, multidimensional information to support critical decision-making in the cancer treatment improving patients cure outcomes. The INCA' ODSS has been implemented to help physicians cope with the information explosion. The ODSS information architecture was structured in a platform with different modules for data analysis compounded by legacy systems (OLTP); INCA Data Warehouse; Clinical Research Data Marts; Data Mining and Visualization tools (Figure 1).

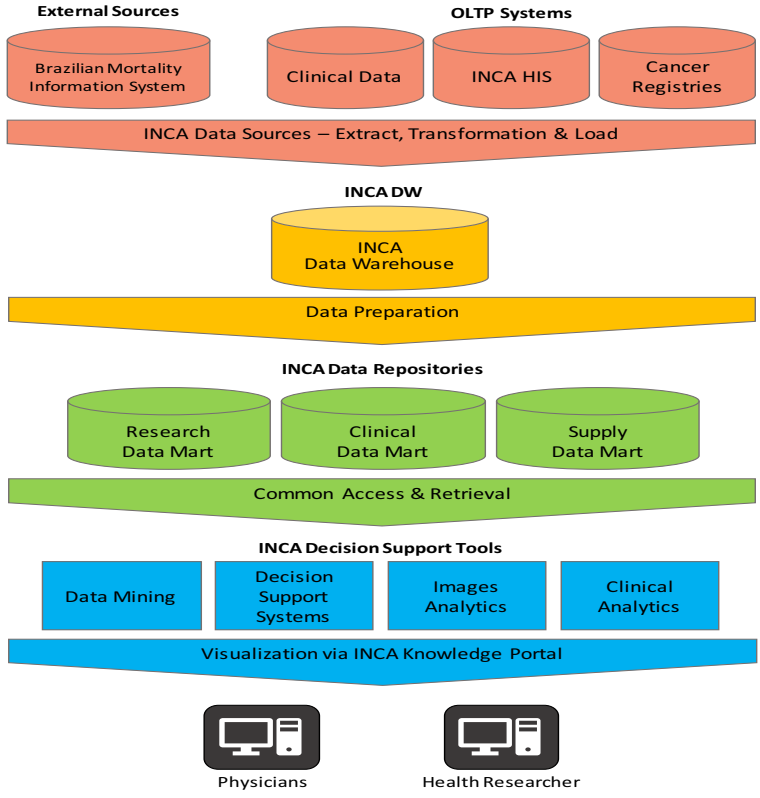

Figure 1. INCA ODSS Information Architecture.

The oncology information environment has developed using INCA's intranet that offers safe access to crucial information to improve cancer treatment. This solution has encompassed collaboration between physicians and managers, simplifying the clinician work. The ODSS has the potential to provide information to INCA physicians to make

evidence-based decisions to offer more efficient and personalized treatment while reducing the costs of cancer care.

4. Conclusions

Oncology Decision Support Systems (ODSS) are meant to support physicians in their decision-making process. Although the implementation of ODSS is not trivial and requires careful planning and significant work from a multidisciplinary group, the benefits that can be achieved by better informing and guiding decisions are expected to outweigh the costs. By providing on-demand answers to relevant questions, these tools will be an essential factor for performance improvement in medical practices. The development of Clinical Decision Support Systems increases requirements for information systems integration and data quality. Principally when legacy systems use data entry that is made by nurses, physicians, and other clinical staff, facing quality problems concerning data completeness, accuracy, and update. An effective strategy for managing change in healthcare organizations is to only ultimately deploy the change after trialing its fit with medical tasks. It was the strategy used at INCA. The physicians who benefited were actively engaged in implementing new functionalities to support their clinical practice. The main benefits derived from the deployment of this Clinical Decision Support System for cancer disease information management, so far, are real-time knowledge access, patient's focus and satisfaction, reduction in treatment costs, enhanced knowledge transfer and diffusion of best healthcare practices and finally quickness of cancer diagnosis. This study gives practical lessons that can be followed by healthcare organizations that are planning to adopt ICT innovations into clinical practice. Oncology Decision Support Systems are dynamic systems that involve an ongoing improvement process to support their development to meet the frequent changing of cancer care protocols.

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Mobile Phone Applications for Gestational Diabetes Mellitus: Appraisal and Perspectives

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Abstract. Gestational Diabetes Mellitus (GDM) has been associated with a plethora of maternal and neonatal comorbidities as well as adverse pregnancy outcomes. Evidence supports that identifying women with GDM and tight controlling of blood glucose (BG) levels are the fundamental steps for an effective management and prevention of risks associated with GDM. Recent advances in mobile phone applications have shown that they may offer personalized health care services, improve patient's care, independence and self-management as well as enhance patient's compliance to BG monitoring and treatment. Our aim was to identify and appraise main mobile phone applications that were evaluated by published clinical studies. Therefore, mobile applications that were accepted and deployed by healthcare providers, mainly hospitals, such as MobiGuide (Spain), Pregnant+ (Norway) and GDm-Health (UK) were reviewed herein.

Keywords. Diabetes mellitus, Gestational Diabetes, Mobile applications, Smart phone

1. Introduction

Gestational diabetes mellitus (GDM), which affects almost 6% pregnant women, refers to either glucose intolerance or diabetes mellitus being mainly detected during pregnancy [1]. Worldwide, the prevalence of GDM has been increased mirroring the increased prevalence of obesity and obesity-associated metabolic disorders in general population. Pregnancy constitutes a complex physiologic and metabolic condition being considered as a biological glucose tolerance test to detect glucose intolerance or insulin resistance earlier [1]. GDM has been associated with a plethora of maternal and neonatal comorbidities as well as adverse consequences comprising hypertensive disorders, preeclampsia, preterm birth, shoulder dystocia, caesarean delivery, type 2 diabetes mellitus risk in mothers as well as neonatal hypoglycemia, hyperbilirubinemia,

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hypocalcemia, macrosomia, etc. Evidence supports that identifying women with GDM and tight controlling of blood glucose levels are the fundamental steps for an effective management and prevention of risks associated with GDM [1]. Recent advances in mobile phone applications have shown that they may offer personalized health care services, improve patient's care, independence and self-management as well as enhance patient's compliance to blood glucose (BG) monitoring and treatment [2].

There are many commercial mobile applications where measurements are registered in the mobile phone and then transmitted via email in CSV file format. This type of applications facilitates the transfer of the laboratory exams of the GDM patient to the consulting physician. Healthcare providers such as hospitals that treat a large number of GDM patients need applications that are accepted by the patients and are supported by published clinical trials that certify their effectiveness and validity. The aim of the present study was to identify and appraise major mobile phone applications that were tested and evaluated by clinical studies published in MEDLINE and Scopus databases.

2. Methods

The present study focused on mobile applications that were accepted and deployed by healthcare providers, mainly hospitals. In February 2019, we conducted a literature search in two bibliographic databases (MEDLINE and Scopus) in order to identify mobile phone applications for GDM evaluated in published clinical studies. The combined advanced search of Gestational Diabetes AND (Mobile applications OR Smart phone applications) retrieved a small number of publications (N=31), since this is a relative new field in the GDM research. [1-2]. Twelve studies were excluded as they dealt with metabolic syndrome and diabetes in general.

3. Results

Nineteen studies were included in our study. Most of them referred to 3 main mobile applications accepted by hospitals. The mobile applications examined briefly herein are: MobiGuide (Spain), Pregnant+ (Norway) and GDm-Health (UK).

MobiGuide: MobiGuide is a platform developed as an EU-funded project under the Seventh Framework Program [3]. MobiGuide Project started in 2011 and had a four-year duration. The aim of the project was to develop Decision Support Systems (DSS) to assist patients with chronic illnesses including diabetes. The system uses sensors positioned on the patient body to gather and monitor critical signals such as blood pressure or blood glucose. The data are transferred to the mobile phone where an application has been developed. A server receives the data from the smartphone via an Internet connection. These data feed the DSS algorithms that provide medical advice to patients and physicians based on Clinical Practice Guidelines (CPGs) [4]. In the case where communication is lost between the smartphone and the server, some basic assistance is still provided taking advantage of the smartphone resources and increasing computational power. A smartphone User Interface has been developed for Google Android OS. Supported languages are Spanish, Catalan and English. The MobiGuide project has targeted two patient categories: women with GDM and chronic patients with atrial fibrillation. Patient data collected by the sensors are stored in the Personal Health Record (PHR) of the application and are integrated in a secure manner with the

Electronic Medical Record (EMR) kept by the Healthcare providers. There is a periodic synchronization of the necessary data between PHR and EMR. PHR gives the data that allow the DSS to provide personalized assistance to the patients. A small pilot study of 20 patients has shown: 1) the feasibility of the system; 2) the high degree of acceptance among patients and 3) the higher compliance of patients with BG monitoring compared to a group of 247 patients with similar clinical characteristics [4].

Pregnant+: Pregnant+ is a mobile application developed in Norway in order to assist women with GDM health problems [5]. The application has been developed for both Apple iOS and Google Android mobile phones. The protection of the patients' private data according to the Norwegian law was a first priority. For this reason, all data are kept in the mobile phone and are printed in a standard format when the patient wishes to consult her physician. Bluetooth was the protocol used for the communication of the BG metering devices with the mobile phone. Targeting multicultural female patient populations residing in Norway, the application which was initially supported only the Norwegian language was later translated into Somali and Urdu. Addressing security and privacy concerns, APIs (Applications Programming Interface) were developed for the communication between the mobile phone and the BG meters, since the BG meter device APIs involved the use of cloud services to temporarily store data. A number of studies have shown that the application contributed to the motivation of GDM patients for behavioral modification and the enhancement of their confidence regarding self-management [5-6]. The main problems included reported feelings of obsession and frustration, technical difficulties in the Bluetooth communication between the metering device and the smartphone and a lack of support for health-care professionals [6].

GDm-Health: GDm-health is an application developed by engineers and physicians in the British NHS. It has won the Oxford University Innovation Award and has been licensed to Sensyne Health plc. [7]. It is commercially available since September 2018. It uses English language and comprises of two main systems: a mobile application available for Android and iOS smartphones and a web application that is used by physicians to monitor the patients' health data. Data are transmitted wirelessly via Bluetooth and Near Field Communication from the BG meter. The data are then securely transferred to the web application and are available to the clinicians. The system is approved by the NHS and is included in the NHS digital apps library. Data are stored in the NHS cloud using Health & Social Care Network connectivity. The system targets women with GDM or pregnant women with pre-existing diabetes. The use of GDm-Health results in automated personalized communication and medical advice between pregnant women and healthcare personnel. The mobile app can be freely downloaded. A number of publications and congress announcements have reported on the positive effects stemming from the use of this application. [2,7-8]. Interestingly, in a recent randomized controlled trial (RCT) of 203 women, those using the app reported higher satisfaction while preterm births and cesarean deliveries were fewer than in the non-intervention group. Nevertheless, the direct health care costs, overall glycemic control and neonatal and maternal outcomes were similar between groups [8].

4. Discussion and Conclusions

In this study, we presented mobile applications used for assisting pregnant women with GDM by health care providers, published in MEDLINE and Scopus. The three applications presented herein, offer different approaches in the support of the patients.

Table 1. Main features of the applications and the respective differences

Mobile App	Key features	Communication with clinicians	Commercial availability
MobiGuide	DSS algorithms Part of a bigger suite EU project	Yes	N/A
Pregnant +	Smartphone based Focused on data security	No	N/A
GDm-Health	Mobile app and web-based application, NHS approved	Yes (via NHS Cloud)	Yes

Furthermore, there is also a limited number of other mobile applications in MEDLINE with very few data, addressing GDM patient's needs by research teams in Ireland, South Korea, Switzerland and China [2, 9]. Finally, a mobile application called M♡ther was developed at the CSIRO's Australian e-Health Research Centre and tested at Redland Hospital in Queensland, Australia [10]. M♡ther collects data via the mobile phone and uploads them to the clinician portal. No MEDLINE or Scopus published study concerning M♡ther has been found so far.

In conclusion, digital BG monitoring is a practical and useful methodology to face the global growing burden of GDM. More robust, clinical and economic studies, particularly RCTs, are warranted to critically evaluate the effectiveness of mobile applications in the self-management of GDM as well as in the prevention of adverse maternal and neonatal outcomes associated with GDM.

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Revisiting the Skills of a Healthcare Data Scientist as a Field Expert

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Abstract. The buzz words 'Data Science' and 'Data Scientist' are trending high in this age of information. The boundaries are still undefined, the exact skill sets are unclear, and the job description is still murky. This is an attempt to identify some mandatory or desired skills based on what data science demands from a data scientist. A very generic job description for a data scientist is 'A person who can perform advanced analytics on the institutional data", this gives a very unclear picture to the decision maker to identify the right resources within their data science activity. Practically the data scientist should be the one who can understand and moreover be involved with the data life cycle starting from inception > collection > operation > extraction > observation > preparation > description > prediction > prescription > Archival. Each of these aspects of data has a science behind it. An old team 'Jack of all trades' briefly defines this job description. A good data scientist essentially needs to be a good programmer, a good business/system/data analyst, a good statistician, one who can seamlessly visualize data, and is empowered with a vision to use and apply the necessary tools, techniques and methodologies in a scientific and applicable realistic way. Healthcare/Research environment is a complicated vertical when it comes to data, hence having domain knowledge is almost critical, complying with aspects of data governance such as patient privacy, consent, ethics etc.

Keywords. Data Scientist, Data Management, Machine Learning, Data Science, Advanced Analytics, Job description, Data science skills

1. Background and Introduction

Data science is a very broad term, and moreover a new field, every vertical has its own definition and the corresponding role of a data scientist within that domain. In this paper we will try to come up with a definition and a job description of a healthcare data scientist. Generally, Data Science refers to the collective processes, concepts, theories, tools and technologies that enable the review, extraction, preparation, analysis of historical and real-time data to gain valuable knowledge and insights. Data is only a provision within the data science domain, and data science is about the way of exploring your data. Hypothesis based thinking in data science is the key methodology that needs to be followed in order to guarantee success. The primary task for any data science project is to generate the necessary dataset that needs to be investigated to maximize quality, value and use it as a knowledge management tool that could be applied on different domains for development [1]. The second most important task is to find co-relations within the

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entities of this data set, which itself would provide a dissipated view of many feasible hypothesis, which the data scientist need to analyze to find the best hypothesis, technically various data subsets are generated based on the hypothesis, on which any machine learning (ML) engineer would be able to run various ML algorithms necessary to carry out further investigations. As far as data storage and sourcing is concerned, it is also an important aspect of data science, especially if its Big Data, otherwise data is generally made available through the data warehouse or various other providers within the setup. As a data scientist, one must have a deep understanding of the data on an organizational level; hence the domain knowledge is preferable if not essential. On the contrary, within the healthcare/clinical research environment domain knowledge plays a critical role as its not only the data, it is the terminologies/ontology, clinical standards, coding systems, knowledge of research process, patient privacy, ethical considerations, standard clinical systems, registries, genomic references etc. The aim of this paper is to define the role of a 'health care data scientist' by revisiting the skills and expertise needed to qualify a data scientist enough to suggest justified and strong hypothesis which can be further carried out and investigated upon.

2. Methodology

Working with the Biostatistics, Epidemiology and Scientific Computing Department in King Faisal Specialist Hospital and Research Centre has been a direct exposure to clinical and non-clinical data to provide outstanding statistical and analytical support to clinical, applied, translational, and biomedical researchers while advancing the reputation, research capacity, and commitment of the organization to advance the understanding, diagnosis, treatment, cure and prevention of human diseases. Nonetheless, it brought a realization that no standard job description within the region/organization was defined or available to refer to. Based on the essentials of data science aspects listed down in the introduction, these aspects would be mapped with the functions to come up with a skill set and a definite job description for a Healthcare Data Scientist. Moreover, the job description can be flexible based on the exact requirements for the institution and the analytical platforms being used within the institution.

3. Functions

In a healthcare setup a data scientist typically needs to address or carry out the functions such as data management general statistics, biostatistics, feature selection, hypothesis design, data visualization, problem-solving, ML and artificial intelligence (AI). Further we would define the required skill set for each function.

3.1. Domain Knowledge

In a healthcare environment, it is necessary for a data scientist to have adequate domain knowledge, if not the expertise. This covers the clinical research terminology and correlation between the domain entities in order to come up with strong hypothesis and reflective analysis.

3.2. Data Management

It is the most critical function as the data output of this function forms the foundation on the investigation that needs to be carried out based either on a hypothesis or the data. The idiom "Garbage-in: Garbage out" well support the above discussion, hence infusion of healthy sourced data forms the foundation of a data science project. This function covers the storage, sourcing, extraction, and preparation aspects of the data management. while enabling the Big Data capabilities the data management functions and skills would be a mandatory requirement for the job description.

Skill Sets and Tools/Platforms: SQL Skill, Handling an RDBMS system, Data extraction techniques, Data Conversion techniques, Data Transformation Techniques, Data Cleansing Techniques, Data warehousing knowledge. Experience with MS Excel, any RDBMS such as MS SqlServer or Oracle or mySQL, ProstGres etc., Scripting with python, R or any scripting language, tools such as rapidminer. Enabling Big Data capabilities would further require add on skills covering HADOOP components like Hive, Pig, HDFS, HBase, MapReduce, etc. NoSQL databases such as Couchbase, MongoDB, Cassandra etc., Apache Spark which is more straightforward and quicker alternative for complex technology like MapReduce.

3.3. General Statistics/Biostatistics

When it comes to statistics, a biostatistician stands out a greater chance of qualifying compared with a general statistician as in a healthcare setup the data science project would, grossly be scientific and health related in nature.

Skill Sets and Tools/Platforms: General Descriptive statistics / Analytics, designing hypothesis, validating hypothesis, identifying co-relations between various data entities, identify the significance of the data elements based on the hypothesis, should be able to apply mathematical & Statistical methods on the data whenever necessary. A Biostatistician would mostly utilize the power of SAS / SAS VA, JMP, JMP Genomics, SPSS, MATLAB and other statistical tools to carry out the necessary functions.

3.4. Analytics, Data Visualization

A good data scientist can formulate scientific hypotheses in such a way that disproving them lead to valuable conclusions that could be translated and put into action [2]. The output of this function contributes to the presentation layer of any analytical project, hence needs to be highly attractive, where the management/administration would be able to talk to the data in a very interactive manner, and enables decision makers to see analytics presented visually, so they can grasp difficult concepts or identify new patterns [3]. Organization requires data analysts to have visualization skills to convert alienating numbers into tangible insights through graphics.

Skill Sets and Tools/Platforms: High end analytical skills, generate visually attractive analytical output based on the dataset made available, juggling with facts, figures, and number crunching, Working with Geo-Spatial Data, proficiency with software tools etc. This function can be performed optimally by use of software tools such as SAS VA, Tableau, Microsoft Power BI, MicroStrategy, Alteryx, Python, R, MATLAB, Kibana, IBM Watson Analytics etc.

3.5. Machine Learning (ML) and AI

This function is dedicated to building machine learning models, which are basically statistical models that can be used to extract patterns from data. Mostly handles the predictive part of any analytical project. Using various ML algorithms prediction can be made for various data entities based on the available data and learning method used (Supervised, unsupervised or reinforced). Further the implementation of tried and tested, machine learning models would contribute to AI, which covers robust decision making. Based on its nature, the ML algorithms are grossly categorized as Regression Algorithms, Bayesian Algorithms, Clustering Algorithms, Decision Tree Algorithms, and Artificial Neural Network Algorithms. This function requires understanding of modern data science methods and familiarity with statistical or machine learning techniques [4].

Skill Sets and Tools/Platforms: An ideal machine learning engineer would be the one who is an excellent programmer, proficient in running various ML algorithms on the data provided in the most optimal way, the most common algorithms would cover Linear Regression, Logistic Regression, Decision Tree, SVM, Naive Bayes, kNN,K-Means, Random Forest, Dimensionality Reduction Algorithms like PCA/PCR(mostly used for feature selection), Clustering Algorithms and Gradient Boosting algorithms (GBM, XGBoost, LightGBM.. etc.). Proficiency in R or Python is desirable, SAS, MATLAB, Tensorflow, Keras, KNIME, RapidMiner etc.

4. Conclusions

Most critical data science functions, skills, software tools and platforms have been reviewed and suggested corresponding to a healthcare and research setup. Necessary job description can be abstracted by mapping the required functions and skills based on the software tools/platforms available within the organization. An ideal Data Scientist needs to carry the skills of a good programmer, data architect, statistician, data analyst, business analyst, data visualization expert and a Machine Learning engineer in order to harness the growth by developing and maintaining immense data assets from the real health experiences of individuals [4,5]. There are certain limitations to the study, as it is based on the experience gained with biostatistics, analytics and scientific computing department for over a period of 20 years, where are ML and AI are being incubated within the institutions, hence functions and skills are defined as per the study based on literature and the knowledge base.

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Nurses Acceptance of Automated Medication Dispensing Cabinets

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Abstract. The use of automated dispensing cabinets (ADCs) to enhance medication processes in hospitals has been increasing recently. Studies evaluated the effects of this technology on patient safety, workflow efficiency and cost reduction. To evaluate factors affecting nurses' attitudes and acceptance of using ADCs, an online survey, including seven categories with closed-ended questions and one open-ended question, was developed based on technology acceptance model and instruments used in previous studies. Response rate was 29.4% of 1,062 nurses at King Faisal Specialist Hospital and Research Centre, Jeddah, Saudi Arabia. Perceived usefulness, perceived ease of use, perceived usefulness to enhance control systems and training have positive effects on improving nurses' attitudes and increasing acceptance of using ADCs. Perceived risks had negative effects. The qualitative analysis of the open-ended responses supported these results and helped to identify many areas for improvement, especially in addressing perceived risks associated with the use of this technology.

Keywords. Acceptance, Automated Dispensing Cabinets, Hospitals, Nurses.

1. Introduction

Technology and automation in pharmacy practice are increasingly used to improve patient safety, enhance workflow efficiency and reduce healthcare costs [1]. The medication processes in hospital settings consist of three main phases; ordering, dispensing, and administration. One of the automation technologies that are widely used is the automated dispensing cabinets (ADCs) [2]. Based on a survey by the American Society of Health System Pharmacists; 97% of hospitals in USA are using ADCs [3]. In the UK, there has been a rapid adoption of pharmacy automation solutions over the past 15 years [4]. This was motivated by an audit commission report recommending the use of automation technology to reduce medication dispensing errors [5]. However, the adoption of this technology is still limited worldwide due to the high costs, where an ADCs implementation in a medium to a large hospital would cost over one million US dollars [1]. ADCs consist of drawers that contain secured storage compartments, each is used for a single type of medications. Access to the cabinets is computer controlled through finger prints or passwords. Restocking of medications is controlled by bar code technology which prevents errors in the

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replenishment process [6]. Nurses are the main healthcare professionals who use the ADCs daily and hence they have a key role in improving medications safety [7]. Despite the high costs and intensive work needed to implement ADCs, benefits could be limited because of the negative effects associated with lack of staff acceptance and compliance with the new workflow. The attitudes of healthcare staff towards technology are important factors in determining their acceptance and efficient use [8]. Successful implementation of health technology depends not only on designing or purchasing good quality applications, but mainly on the factors that lead end users to accept this technology [9]. In December 2013, King Faisal Specialist Hospital and Research Centre, Jeddah, Saudi Arabia (KFSHRC) started a project to install 31 ADCs in all inpatient wards. The project was completed in June 2014. This research aims at identifying critical factors that affect nurses' acceptance and attitude towards the implementation of ADCs at KFSHRC. The main objective of this research is to support the successful implementation of ADCs at this tertiary healthcare organization.

2. Methods

This study followed mixed methods approach and was initially based on two theoretical backgrounds. The Technology Acceptance Model (TAM); determining the factors that affect users' acceptance of information technology [10], and the Added Variables approach; adding more external variables to the original TAM, where the additional variables should be developed in the context of healthcare IT and specific systems evaluated [9]. A questionnaire was adapted from two previous studies discussing the attitude of nurses and their acceptance of e-prescriptions and automated medication storage and distribution systems [11,12]. The survey contained seven categories of closed-ended questions and one open-ended question. The constructs adapted include Perceived Usefulness (PU), Perceived Ease of Use (PEU), Perceived Usefulness to enhance Control systems (PUC), Training (T), Perceived Risks (PR), Experience Level (EL), Attitude toward using (A). Demographic questions included gender, age group, hospital unit, job role, and self-rated computer knowledge, and an introduction page with information on the study was included. The questionnaire was developed using Survey Monkey (www.surveymonkey.com) and was evaluated by three staff members, holding master degrees in health informatics. As part of a master's degree in health informatics, by the first author, at the University of Sheffield, UK, and implemented at KFSHRC, the research was approved on ethics background by both the University of Sheffield and KFSHRC. The study sample included all 1,062 hospital nurses who have access to ADCs and received the survey link via email. During the survey period of two months, seven reminders were sent to nurses in addition to one email to each head nurse to encourage nurses to participate in the survey. Data was analyzed using simple linear regression analysis in SPSS software. Thematic content analysis of the responses to the open-ended question using coding down technique.

3. Results

We received 312 valid responses from 27 nursing sections with a response rate of 29.4%. Despite that the number of responses was large, the response rate is still considered low, mainly due to the busy nature of nurses' work. Most respondents were

in the (30-39) age group (39.7%) and with Staff Nurse I job role (88.5%). Most of the respondents rated their computer knowledge as very good (46.5%). Level of experience with the use of electronic health records (EHRs) and ADCs was generally low. Most respondents reported less than five years of experience in both areas. Questions reliability was tested using the Cronbach's alpha coefficient, which showed acceptable levels for all the seven categories of questions. Correlation and consistency of variation between items in each construct was further tested using principal component analysis. The quantitative analysis showed, with a $P<0.001$, that Perceived Ease of Use is a significant predictor of Perceived Usefulness and Attitude toward using ADCs. Perceived Usefulness is a significant predictor of Attitude toward using ADCs. Perceived Usefulness to enhance Control systems is a significant predictor of Perceived Usefulness and Attitude toward using ADCs. Perceived Risks is a significant predictor of Perceived Usefulness and Perceived Ease of Use. Training is a significant predictor of Perceived Usefulness and Perceived Ease of Use. On the other hand, with a $P >=0.05$, Experience Level with EHRs is neither a significant predictor of Perceived Usefulness nor Perceived Ease of Use. The Experience Level with ADCs is also neither a significant predictor of Perceived Usefulness nor Perceived Ease of Use.

A total of 144 open-ended responses were received, answering the question "In your opinion what are the advantages and disadvantages associated with the use of ADCs?". Analysis showed that 28 responses were positive, 42 were negative, 66 were mixed, and 8 were invalid. Under Perceived Usefulness; ADCs helped saving time (n=33), enhanced patient safety (n=14), improved medications availability (n=11), increased efficiency (n=5), had some usefulness in emergency cases (n=5) and helped organizing work (n=3). On the other hand, some medications were unavailable (n=20), they were time consuming (n=13), and one respondent thought ADCs are not useful (n=1). Under Perceived Ease of Use; ADCs were easy to use (n=25), convenient (n=7), accurate (n=5), reliable (n=3), and user friendly (n=1). One respondent reported ADCs added more work restrictions (n=1). Under Perceived Usefulness to enhance Control systems; ADCs enhanced medication error control (n=26), improved inventory control (n=7), and improved control of narcotic medications (n=7). On the other hand, some respondents reported that ADCs lead to poor inventory control (n=4), and poor control over narcotic medications (n=4). Under Training category; only one negative response was identified which described training as inadequate. Under Perceived Risks; using ADCs is not suitable in emergency cases (n=33), had frequent hardware failures (n=22), frequent system failure (n=19), delayed urgent medication orders (n=16), delayed medications restocking (n=1), showed problems in storing liquid narcotic medications (n=1), medications restock errors (n=1), poor computer knowledge (n=1), system errors (n=1), and that the number of ADC machines in the unit is not enough (n=1).

4. Discussion and Conclusion

In agreement with other recently published research, nurses' acceptance of the use of ADCs is one of the main factors that lead to successful implementation of this technology in healthcare institutions [13,14]. Our research aimed to identify the factors that drive nurses' acceptance towards ADCs use and the factors that prevent this acceptance. The findings showed that perceived usefulness, perceived ease of use, perceived usefulness to enhance control systems and training were all positively affecting nurses' attitudes and acceptance of using ADCs. The findings also showed

that perceived risks are negatively affecting nurses' acceptance of ADCs use. Perceived usefulness is the most influencing factor on nurses' attitudes towards ADCs use and training is the most influencing factor on perceived usefulness. This indicates that healthcare management and ADCs implementation teams should focus on the usefulness and the benefits of this technology in the training programs in order to maximize nurses' acceptance and to ensure smooth and successful implementation. Perceived risks associated with the use of ADCs is a major factor that prevents nurses' acceptance of this technology. Hospital management and implementation teams should engage nurses in all phases of the implementation plan, get their feedback as end users on the perceived risks and work with them in order to mitigate the effects of these risks on their work and on patients' care. This research helped in identifying some of the perceived risks that were reported in the survey. The researchers and the implementation team at KFSHRC will work with nursing management and end users to find appropriate solutions to the reported issues. This research was done based on TAM theory. The findings showed the validity of this theory in predicting factors that affect nurses' attitudes and acceptance of using ADCs. However, additional variables were added to the original theory variables in order to create a model that can fit with the research setting specifically and healthcare IT context in general.

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Investigating Ethical, Legal, and Socio-Technical Barriers of Medical Data Donation and Developing a Concept to Address Them – A Research Protocol

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Abstract. Medical data are being generated in large quantities. However, these data are rarely used beyond their primary purpose. Big data methods to medical data offer the opportunity to transform healthcare. The healthcare industry has been a lot less successful than other industries in applying these new tools. Main reasons are privacy concerns and the fact that medical data in Germany are scattered across institutions. The method of data donation can offer a solution. The first aim of the proposed Medical Data Donation Enabler (MADE) project is to investigate ethical, legal and socio-technical barriers to data donation. The second aim is to develop a concept of a medical data donation process model that addresses the barriers by providing a data donation process model. The process model concept created through MADE could be provided for this purpose.

Keywords. Data donation, secondary data use, big data, process development

1. Introduction

Health data are being generated in significant quantities by personal health devices, healthcare systems as part of the healthcare delivery process, through public health measures and clinical trials and other research projects. However, these data are rarely used beyond their primary purpose.

Secondary use of health data is still scarce compared to the amount of health data that are being collected. The application of big data methods to health data offers the opportunity to transform healthcare [1]. However, the healthcare industry has been a lot less successful than other industries in applying these new tools. Main reasons for this are privacy concerns and the fact that medical data are scattered across institutions [2]. There are significant initiatives to foster the secondary use of clinical data. Examples are the Medical Informatics Initiative (MII) in Germany or at the University of California Medical Centers [3,4]. However, these initiatives are predominantly tailored for the

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extraction of data from large information systems. Legal, ethical and socio-technical barriers for data donation are high and significantly limit data from individuals, smaller systems or projects to be donated for secondary use by researchers. The most prominent barriers are ethical and legal concerns and uncertainty. For these reasons, scholars are arguing for medical data donation post mortem [5]. Patients should be encouraged to donate their medical data to research after their death, similar to posthumous organ donation.

The proposed project aims to investigate the ethical and legal barriers to medical data donation for research. Solutions to those barriers will be developed and included in an improved concept of a data donation process model. The unique aspect of the medical data donation process is that it will help to make medical data available for research, which is currently not accessible. These datasets are either not included in the larger databases targeted by secondary data use initiatives like MII or are entirely in the hand of patients (e.g., storage in mobile devices such as smartphones). As a result, these valuable medical data are currently not utilized for secondary data analysis. However, coming from a vast array of sources, the datasets can be highly relevant for research Examples are outpatient facilities, personal medical data on mobile devices or small-scale research studies containing participants with insightful medical histories. Thus, the concept of data donation contributes significantly to the completion of secondary medical records and thus prevents a possible evaluation bias due to data loss.

On the other hand, there are prerequisites for the data donation that affect both ethical and procedural aspects. A concept for implementation can also be a useful template for other projects in the healthcare sector. Ensuring transparency in the application of such methods has a positive impact on public opinion and can help form a basis for data donations and similar projects.

The result of the proposed project, a concept of a medical data donation process, could be used as a blueprint by initiatives such as MII to attempt to incorporate medical data from smaller data sources into their pool of data.

1.1. Scientific Objectives

1) Development of the concept of a process model for medical data donation by small- and mid-sized healthcare facilities, research projects and mobile devices of patients (Medical data donation enabler: MADE)
2) Identification of ethical, privacy-related and socio-technical barriers to medical data donation within the MADE process.
3) Development of social and technical solution resolving the barriers identified in objective two.
4) Development of a concept for the MADE 2.0 process model including the solutions identified in objective three to enable medical data donation by small- and mid-sized hospitals and research projects that adhere to ethical and privacy standards.

The project attempts to address the research objectives above using the following research questions:

- What are ethical, privacy-related and socio-technical issues in the data donation process by small- and mid-sized healthcare facilities, research projects and patients' smartphones?
- What are solutions to the issues identified and how can they be addressed in the concept of a data donation process model?

2. Methodology

The methodological approach can be divided into two phases: preparation and development/refinement of the data donation process concept.

The preparatory stage begins with a kickoff meeting to determine the timeline and align all project partners. A literature review followed by expert interviews aims to pave the way for the concept development by providing a theoretical basis on possible process-related and ethical challenges. The results of the initial data collection will be summarized and presented to the team during a workshop and shared with a broader scientific audience at a conference.

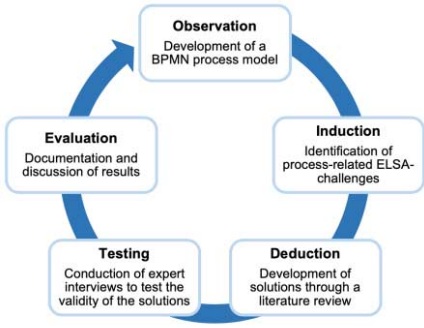

Figure 1. Process of concept development (based on the empirical cycle [6])

Building upon the results from phase one, step two is dedicated to the development and refinement of the final concept. The core of this is a two-step iterative cyclic procedure that is derived from the empirical cycle (Figure 1) which is used to answer questions of scientific knowledge [6]. The first task is the development of a process model based on the knowledge gained in the preparatory phase. The process will be modeled using the graphical notation standard BPMN (Business Process Model and Notation) and finalized in accordance with all project partners during a joint workshop. Comparable to the process of observation in the empirical cycle, this model forms the basis for the next step, induction, i.e., the development of hypotheses. In this project, the model will be analyzed to identify potential challenges related to the ELSA (Ethical, legal and social aspects) criteria. The next step, deduction, refers to the development of answers for the identified possible issues. Deduction includes a literature review on process feasibility, privacy and ethical issues of the process model to identify solutions for the challenges listed in the previous step. Subsequent expert interviews will help to verify the validity of these potential solutions. Interviews will be conducted with experts from various areas such as healthcare providers, health law, health ethics, medical informatics, and health policymakers. In the last phase, the results will be summarized, discussed and documented to set the stage for the process refinement phase two. Theories will be formulated on how the previous model can be optimized. The results and knowledge obtained will again be shared at a conference also to gain valuable input from the attending experts.

The process refinement cycle will be repeated a second time to adjust, improve and finalize the previous model. The data collection will be adjusted according to the lessons

learned in the first round. For the literature review, this means the use of new databases or keywords to identify further existing, useful research. If advisable, the selection of interview partners will also be revised.

The project will seek a broad dissemination strategy from the beginning to add input from as many stakeholders outside the project consortium as possible early on and be able to reach a broad audience with the results. Project results are aimed at the following stakeholders: patients, healthcare providers, health insurance companies, researchers, policymakers, and research funders.

The presentation of this research protocol serves the purpose of making relevant stakeholders aware of the upcoming work. Throughout the process development phase, preliminary results will be presented at scientific conferences. Publications in open-access journals about preliminary results of subtopics are planned. Through the engagement of project team members in specialized working groups, further dissemination of early results and external input will be fostered.

The final result of the project, the improved concept for a medical data donation process, will be made available to the scientific community through a flagship publication and will be presented at major international conferences to ensure broad dissemination of the findings.

The consortium works together with the German technology and methods network for medical research (TMF), which offers another excellent platform for dissemination of project results as it brings together most relevant stakeholders regarding the secondary use of medical data in Germany. TMF's existing infrastructure is dedicated to sustainable dissemination of results obtained through storage on the TMF portal server and dissemination to workgroup sessions and events. Our collaboration with the TMF ensures that the results of the project to be disseminated directly to the participants of the MI initiative and improves the chances of uptake of the concept.

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Challenges of Health Analytics Utilization: A Review of Literature

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Abstract. The last four decades witnessed a huge progress in digitizing health information, representing an unmatched opportunity for utilizing health analytics in improving the quality of healthcare and reducing its costs. To learn more about different challenges facing the successful utilization of health analytics, a careful review of literature was conducted, and a qualitative analysis was used to explore and classify these challenges. Three main categories of challenges were identified. 1) Technological challenges; hardware, software, and data content, 2) Human challenges; knowledge, experiences, beliefs and attitudes, and end user behaviors, and 3) Organizational challenges; managerial, financial, and legal barriers to optimal utilization of health analytics. The non-technological problems seem to be harder to solve as well as more time consuming, including the existence of a specific business need and a clear vision to guide the project. In addition, health analytics should always be built with the end users in mind.

Keywords. Big Data, Business Intelligence, Health Analytics, Hospitals.

1. Introduction

Over the last four decades, we have witnessed a huge progress in digitizing health information through collecting data of clinical practice and medical research in different types of electronic resources. Clinicians and healthcare professionals can now see new potentials in utilizing big data and health analytics to improve their healthcare processes and clinical outcomes. Health analytics can enhance evidence-based decision making; improving the quality of healthcare and reducing its costs [1]. Health analytics has the potential to identify valuable information and knowledge hidden within large masses of data. Healthcare researchers can analyze such big data to explore effective treatments for specific conditions or specific patients, explore hidden patterns of medications side effects, hospital readmissions, or emergency department crowding [2]. Bates et al. (2014) used predictive analytics to identify and manage six practical cases, as examples of achieved value through reducing costs, including high-cost patients, readmissions, triage, deterioration, adverse events, and treatment optimization for diseases affecting multiple organ systems. In fact, as many as one-third of the readmissions in the United States have been assumed to be preventable and, therefore, to present a significant opportunity for improving care delivery [3]. Proper health analytics can help professionals and organizations to monitor performance indicators on an ongoing and regular basis and support troubleshooting bad performance and to

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identify root causes of problems. Health analytics can help users to design, develop, implement and evaluate different key performance indicators that can help continuous monitoring, identifying reasons of performance deviations and eventually improving performance. There are many new unmatched opportunities to use such methods to improve the quality and reduce the costs of healthcare [4]. It is very crucial to learn about challenges facing successful utilization of health analytics.

2. Methods

A careful review of literature was conducted through searching four databases; MEDLINE, EMBASE, CINAHL and Google Scholar. The main search terms included Health, Analytics, Big Data, Business Intelligence, Utilization, and Challenges. The search identified 631 studies, after removing duplicates from the retrieved results of the four databases. Among these, 513 studies found non-relevant, after screening titles and abstracts and 94 studies found non-eligible, after examining the full text. Only 24 studies found eligible for the review. Inclusion criteria focused on studies describing specific challenges and categories of challenges of implementing and/or utilizing health analytics. References of eligible studies as well as recent studies that cited them were also examined. Qualitative thematic analysis was used, to classify main challenges of health analytics into different categories and types, through five steps; generating initial codes, searching for themes, reviewing, defining, then writing the challenges.

3. Results

We identified three main categories of challenges that face the successful implementation and utilization of health analytics. 1) Technological challenges which include hardware, software, and data content, 2) Human challenges which include knowledge, experiences, beliefs and attitudes towards health analytics, in addition to end user behaviors, and 3) Organizational challenges which include managerial, financial, and legal barriers to optimal utilization of health analytics. Each identified challenge, within the three categories, was discussed by at least two of the 24 eligible studies, so we included only 12 studies in the references. Figure 1 shows the three main categories and detailed challenges facing health analytics utilization.

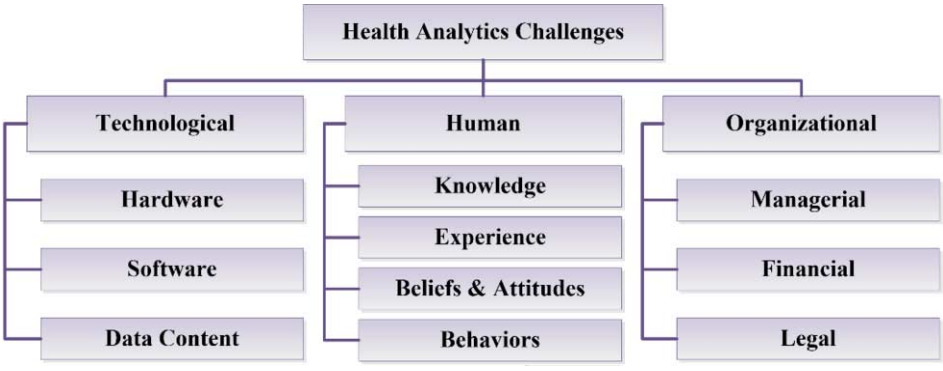

Figure 1. Health Analytics Utilization Challenges

4. Discussion and Conclusion

Even though health analytics can bring critical capabilities to healthcare, yet the implementation of such capabilities is often faced with many challenges. Health analytics projects are wrestling with different types of technological, human and organizational challenges. The non-technological problems seem to be harder to solve as well as more time consuming, including the existence of a specific business need and a clear vision to guide the project. Success depends on types of project funding, the value provided and the alignment of the project to the strategic vision of the organization [5]. Some studies classified challenges facing the implementation of health analytics and other informatics applications into six categories; human, professional, technical, organizational, financial and legal or regulatory challenges [6].

In the Human domain of challenges, we find it possible to explain the delay or unsuccessful implementation and utilization of health analytics by the poor acceptance or resistance of technology by healthcare professionals. The influence of the computers and IT knowledge, experience and skills of healthcare professionals and their beliefs about, and attitudes towards, using computerized systems in the healthcare environment can be considered among the major challenges to the successful implementation and utilization of such systems. Even highly regarded, industry-leading analytics and reporting systems can be challenging to use because of the multiplicity of functions, options and navigational tools [7]. Health analytics research often focuses on the design and implementation challenges, but not enough focus is given to how end users react to such systems. The success of systems lies beyond the level of a good design or the selection of a good technology. The degree of fitting the intended use by any system leads users to accept or reject such system [8]. Since health analytics is a newly emerging technology, it needs the efforts of highly trained, knowledgeable and experienced professionals with diverse new skill sets. These skills should not be limited to technical ones but should also extend to research, analytical, interpretive and creative ones, to support prescriptive analytics and advise organizations on possible outcomes and answer the question of what we should do next [9].

In the Technological domain we still can identify a lot of challenges related to data, such as the exploding volume, the velocity of data creation, which might be even more important than the volume, especially for the real-time analysis, and the variety of big data, in the form of text, voice, images and videos, which is a challenge for acquisition, processing and provision of useful information [10]. Technology related factors, such as hardware, software and data content, is more influential on descriptive analytics, while human related factors, such as knowledge, experience and skills can be more influential on prescriptive analytics. Similarly, the input of human knowledge and experience into strategic analytics is more important and influential than into operational analytics, which is more data driven [11]. The world of big data and analytics has two main challenge classes: engineering; efficiently managing data at large scales, where the technology challenges come first, and semantics; finding and meaningfully combining information that is relevant to our concern, where the human knowledge and experience challenges come first [12].

In the Organizational domain; developing and implementing health analytics is not only about technology, it is more about equipping organizations by tools that enable them to achieve their business objectives and providing users with technical capabilities that make new things possible and by engaging people into changing their behaviors to effectively use the new capabilities to generate the target results [13].

Leadership that sets smart goals, defines successful standards and asks the right questions is more important than having bigger or better data. The need for a human vision and insight will never be replaced by the power of analytics, since data content become cheaper and human input becomes more valuable. Changing the organization culture from "what we think" to "what we know" to identify organizational top-level management information needs [14]. The increased initial costs, operational and maintenance costs, and uncertain financial benefits of health analytics are frequently cited barriers. In addition, some ethical and legal concerns might be raised about the proper acquisition and utilization of systems, such as health information confidentiality [15]. Organizational leadership, managerial styles and other administrative and legal related factors, such as the financial issues, policies and procedures play an important role as mediating factors for other technology and human factors [16]. If the organization is not well prepared yet for transformation, in terms of cultural change and responsiveness, then all technology solutions and human efforts will not be enough to achieve this transformation and change, even if the best analytics were utilized and the most valid, accurate and comprehensive results are generated [17,18].

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Integrating GDPR in ISO 15189 for Medical Laboratories: Major Aspects and Perspectives

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Abstract. Medical laboratories process and store sensitive data during four major phases: arrival of patients in the laboratory premises and registration of their data, pre-analytical, analytical and post-analytical phases. ISO 15189 has specific requirements concerning the management of the laboratory data in terms of security, availability and protection. The aim of the present study was to examine major aspects of the General Data Protection Regulation (GDPR) integration in medical laboratories that comply with the ISO 15189 standard, including data breach and informed consent. To the best of our knowledge, this is the first study dealing with this subject in the healthcare sector. Accredited medical laboratories need to modify their ISO 15189 Quality System documentation and processes applying appropriate additions and adjustments in order to incorporate GDPR requirements in a clear manner.

Keywords. Accreditation, Data Breach, GDPR, ISO 15189, Laboratory

1. Introduction

General Data Protection Regulation (GDPR) has been in place since May 2018 for all EU countries, presenting a structured and concrete set of rules concerning the protection of personal data [1]. These set of rules apply to all industries and sectors. The Healthcare sector is very significant since a large volume of sensitive and sometimes classified data are kept and stored in hard copy as well as in digital format [2]. Medical laboratories at the Hospitals, including Biochemistry, Microbiology, Pathology, Hematology, and Cytology labs keep and process a large number of patients' personal data. These data are stored in Information Technology systems either inside the Hospital or in the Cloud [3]. Hospital Information Systems communicate with the Laboratory Information Systems (LIS) to get information that is very important for the patient's monitoring and treatment [4]. During the last 10 years, an

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increasingly large number of medical laboratories has been accredited to the International Organization for Standardization (ISO) 15189. ISO 15189 is the specialized ISO standard that covers the entire laboratory operation from the sample reception to the delivery of the results [5]. The introduction of ISO 15189 in the laboratory and the adoption of its processes contribute to the better performance of the laboratory and the improvement of the quality of services offered to the patients or customers [6]. ISO 15189 has specific requirements concerning the management of the laboratory data in terms of security, availability and protection. The aim of the present study was to examine major aspects of the GDPR integration in medical laboratories that comply with the ISO 15189 standard, including data breach and informed consent.

2. Methods

We performed a thorough search in the literature (PubMed, Scopus) for published articles concerning GDPR and ISO 15189. The initial search for GDPR and ISO 15189 produced N=57 and N=348 results respectively. The combined search of "GDPR" AND "ISO15189" produced N=0 (zero) results. We narrowed the field of our search in order to focus on medical laboratories. The combined search of "GDPR" AND "laboratory" produced N=0 results, therefore we searched for "GDPR" AND "health" to get as many results as possible relevant to the health sector. This combined search yielded N=37 results. We were interested in publications that dealt with data protection aspects of the standard. The combined search for "ISO 15189" AND "data" brought in N=71 results but only 2 of them were relevant [6-7]. Moreover, we consulted the accreditation authorities such as the Hellenic Accreditation System (ESYD) in Greece for relevant guidelines. ESYD developed a comparison matrix mapping out the GDPR requirements with the respective ISO 15189:2012 requirements [8].

3. Results

Medical laboratories process and store data during four major phases: arrival of patients in the laboratory premises and registration of their data, pre-analytical, analytical and post-analytical phases. Data are collected and stored in the Laboratory information systems as well as in corporate systems like Enterprise Resource Planning, Customer Relationship Management for billing, invoicing and customer relation purposes. ISO 15189 incorporates all requirements of the GDPR [8] as seen in Table 1. We analyzed two important issues that need further clarification in the implementation of the ISO 15189 quality system to strengthen GDPR compliance: Data breach and Informed consent. ISO 15189 addresses these points, but GDPR puts special emphasis on them. This emphasis needs to be taken under consideration for the laboratories that implement the ISO 15189 Quality System. GDPR requires a strict data breach process as well as a plan to deal with the consequences of the breach. The process includes a 72-hour notification deadline. The notification will be made to the respective authorities. The victims of the breach will also be notified. ISO 15189 incorporates data breach mainly in the framework of the laboratory Information Technology infrastructure and the proper maintenance of this infrastructure as well as in the Release of Results process. It is recommended that the specific GDPR requirements should be included in the Quality manual, the Quality documents and processes. ISO 15189 manual should deal with data breach in a clear and discrete manner. The IT

maintenance processes should pay special attention to the data breach. The responsible personnel should receive both a technical training (patching, antimalware software, and upgrades in applications, databases and operation systems) as well as a legal training concerning the procedures that follow the aftermath of a breach. This training process will be documented in the respective personnel file. ISO 15189 also includes the patients' consent in the various phases of the laboratory workflow. Informed or Valid consent and its withdrawal is very significant for GDPR [9]. It is recommended that Patient / Customer Consent should be clearly indicated in the ISO 15189 processes and identified as a separate sub-process, which is necessary for the laboratory to proceed with the handling of the samples, the storage and the processing of personal data as well as the delivery of the results. Table 1, which is based on GDPR versus ISO 15189 matrix by ESYD, depicts the GDPR interfaces with ISO 15189, including data breach and consent [8].

Table 1. GDPR and ISO15189 matrix [8]

GDPR Article	GDRP Requirements	ISO15189 Clauses
3	GDPR should be applied by any organization that processes data of EU data subjects.	4.1.1.3 Ethical Conduct 5.10 Information System Management
37-39	Appointment of a qualified data protection officer (DPO) (if required)	4.1.2.5 Responsibility, Authority and Interrelationships
35	Obligation to carry out risk analysis and privacy risk impact assessments	4.14.6 Risk Management
5, 89	Personal data must be collected for specified, explicit and legitimate purposes and not further processed in a way incompatible with those purposes. Personal data must be adequate, relevant and limited to those which are necessary; Where personal data are to be archived e.g. for research and statistical purposes, the privacy risks should be addressed through suitable controls such as pseudonymization and data minimization where feasible.	5.10.1 Laboratory Information Management 5.4.3 Request Form Information
17	Storage limitation (data should be kept for no longer than is necessary); Right to erasure ("right to be forgotten") including withdrawal of consent	4.5.1 Referral Laboratories and Consultants 4.13 Control of Records
Recital 39	Integrity and confidentiality appropriate security of the personal data (including protection against unauthorized or unlawful processing and against accidental loss, destruction or damage)	4.13 Control of Records 5.2.2 Laboratory and Office Facilities 5.2.3 Storage Facilities 5.10.2 Authorities and Responsibilities 5.9.1 Release of Results
33-34	Data breach notification requirements	5.9 Release of Results
7-9, Recital 161, Recital 33	Valid consent necessary (including process of children's data). Consent may be withdrawn easily at any time	5.4.4.1 Primary Sample Collection and Handling 5.4.2 Information for Patients and Users

Data breach and informed consent are in the last two rows of Table 1. All GDPR requirements are equally significant and are dealt within the ISO15189 Quality System in a clear manner. Data breach and informed consent are two main requirements that need special attention when a laboratory wishes to comply with both ISO 15189 and GDPR. It is worth underscoring that GDPR is a legal obligation, while ISO 15189 is a Quality System for medical laboratories that is not mandatory for their legitimate operation.

4. Discussion and Conclusion

In this study, we briefly presented two main issues concerning the simultaneous application of GDPR and ISO 15189 in medical laboratories: data breach and informed consent. To the best of our knowledge, this is the first study dealing with this subject in the healthcare sector. A full analysis cannot be performed due to lack of space. ISO 15189 focuses on the laboratory operation from the patient's arrival up to the delivery of the results. It is not an Information Security standard such as the ISO 27001 [10]. Therefore, Information Security issues are addressed but in the context of the laboratory operation workflow. On the other side, GDPR puts special emphasis on the data protection and privacy. As a result, data breach and consent are at the core of GDPR compliance. Organizations need to come with thorough plans and apply well-documented procedures for both data breach and informed consent. In that sense, accredited medical laboratories need to modify their ISO 15189 Quality System documentation and processes in order to incorporate these GDPR requirements in a clear manner. The incorporation can be completed relatively smoothly by appropriate additions and adjustments in the laboratory Quality management system. If necessary, the laboratories could utilize the services of specialized management consultants. In conclusion, medical laboratories may comply with both GDPR and ISO 15189 applying appropriate modifications to their ISO 15189 Quality System.

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Introducing a Research Management System to Speed Up and Streamline Clinical Research Activities

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Abstract. Clinical Research is a complicated process within a research institution or a tertiary care hospital, almost all research project proposal needs to get an institutional review board (IRB) approval before any research activity takes place. IRB approval involves various processes, in form of sub-committees through which the proposal is reviewed. It is of utmost importance to understand the complete functioning of an IRB, in order to automate the various processes using a management system. The Research office entity forms the central body managing the IRB functions. It provides all sorts of administrative support as far as guidelines, documentation, communication and co-ordination is concerned; hence the research office forms the administrative wing of the IRB. Further the IRB has several sub-committees such as the Ethics Committee, Basic Research committee and the Animal Care and Use Committee. Each committee has a chairperson and several members from different specialty to cover all the aspects of research. Each committee may have its own process/workflow of approval, but usually the process of each committee is somewhat similar to each other. Apart from these workflows process the things that needs to be digitized would include researcher's profile, pre-award and post-award management, publication management, graduate student management and research analytics for the organization.

Keywords. Research Management System, Research process, IRB

1. Introduction

Clinical Research faces multiple hurdles due to the complicated process starting from the research proposal preparation, submission, review by all relevant IRB sub-committees and approval till the execution of the project, and the most critical hurdle is the time taken at each step, hence there is great need to automate the process in order to leverage maximum benefits with respect to time. Currently the research proposal approval phase

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provides the maximum delay, where it generally takes anywhere between 3 to 4 months for a project to go through a full review. As the IRB process includes conducting physical meetings for proposal reviews for each of the committees, and due to the increased number of submissions only few are discussed until the committee schedules the next meeting. Hence decision making is affected in a big way, Ethics and governance approvals are burdensome for historical reasons and not because of the nature of the task. There are many opportunities to improve their efficiency and analytic depth in an age of innovation, increased connectivity and distributed working [1], hence there is a need to automate and streamline these processes using a software system, as whole of the institutional research would be managed using this system, we prefer calling it a research management system. There are a handful of commercial solutions available in the market which can offer a flexible, customized and dynamic implementation of the system within a research environment. The Aim of this paper is to generate a framework to organize institutional research in a digital repository or a Research Management System (RMS), this process would help us assemble the complete professional profiles for a complete and up-to-date collection of all teaching, research, and service-related activities. Providing an overview of all accomplishments, with advanced analytic reports of outputs and impact [2].

2. Methodology

Implementation is a challenge in this area. Initially the research areas needs to be defined, various IRB committees need to be identified and their internal process and workflows need to be mapped, next step is to streamline the system to fit into the organizational infrastructure along with key departments involved in the research proposal decision making, the legal, logistics, budget and resource management process are essential components to be considered in order to implement it within the RMS, Identify the user types and their corresponding roles and privileges, the workflow matrix for each of the entity which is a part of any workflow driven process, designing the information capture elements for each of the entities in the system, information management formats etc. Digitizing your research process is more about understanding and implementing the entities involved along with the related processes and workflows, more than just procuring a management system. Convaris from Clarivate Analytics [2] is the management system which was used as a reference for this case study.

3. Major Stakeholders / Entities

It is important to define the functional entities involved in the research process in order to study the functioning protocols of these entities followed by the defined processes maps followed by them, so as to come up with a plan to automate and streamline these in a 'lean' way. **The Research office:** This Office manages the operational activities related to conduct of all research at KFSH&RC, and provides administrative support to RAC and its standing subcommittees for Basic Research (BRC), Clinical Research (CRC), Animal Care and Use Committee (ACUC), and Research Ethics Committee (REC) [2]. It conducts pre-submission reviews, research applications managements, projects' budgeting, and Assurance and Compliance survey. In addition, it reviews, approves and authenticates publications and scientific meeting participation of clinicians

and researchers within the organization. It also manages Contracts and Agreements (in consultations with Institution's Legal Affairs. **Ethics Committee:** The Research Ethics Committee is charged with the tasks of reviewing all aspects of ethical considerations related to Human Subjects Research. It functions in compliance with local (Institutional code of Ethics) and National (generally the National Committee of Biomedical Ethics) and all applicable International Guidelines governing conduct of research in Human Subjects (e.g. Declaration of Helsinki, Good clinical practice etc.). This ethics committee structure, include members from various research areas, headed by the committee chair and a community member. **Basic Research committee:** is charged to evaluate the scientific aspects of all research proposals of basic nature including proposals that are conducted on animals or tissue cultures or that are based on basic science questions even if performed on materials obtained from human subjects. **Clinical Research committee:** is charged to evaluate the scientific aspects of all research proposals of clinical nature (e.g. human interventional studies, interview/ questionnaire studies, and retrospective medical records review studies). It evaluates the proposals for scientific merit, feasibility, and validity of design and methods. **Animal care and use committee:** is charged to evaluate all research proposals and activities involving the use of animals. It also oversees the institution's animal programs, procedures, and facilities to ensure that they are consistent with national and international standards. **Investigator:** is the one who initiates the project, Investigator's role is intense starting with the proposal, team formulation, budgeting and oversight of research compliance with the approved protocol.

4. Implementation and Automation Process

The first step of implementing any system is requirement analysis, that involves mapping the institutional requirements with the features and functions available in the system. The most important feature for a research management system is a dynamic and robust workflow, due to the involvement of multiple stakeholders at any given point of time. **Integrated system, user authentications and roles:** The system being implemented should be integrated well with the institutional setup environment; the authentication should be integrated with the organizational authentication within the IT setup. Where the various roles created for each of the stakeholders should automatically be mapped with the institutional organizational hierarchy within the human resource management system. Researcher role would be the default role for all the users, which would help the them create a research profile and import the corresponding research work using the web of science API/ORCID ID [2], this in turn would populate the institutional research portal to showcase its research achievements. **Digitization:** The primary purpose of implementing and RMS is to digitize the data fed and retrieved through the system, This would involve conversion of the manual paper forms into dynamic electronic data capture (EDC) forms based on the type of project, these forms include the proposal forms, inform consent, waivers, budgeting, reports, feedback, mandatory certifications [3] etc. This EDC would generally capture the data for a new research proposal, updating project reports, publications, Intellectual property rights, patents, graduate registration and processing etc. these would enable the stakeholders to input and manage their data electronically. **Workflow Processes:** Smart workflows need to be embedded in the system which may run in parallel as required. Other than the general research proposal submission and approval workflow, Each of the IRB sub-committee would be defined as

a separate entity carrying a separate workflow, running simultaneously. As an example, a complete research proposal workflow is defined further. Prior to the research proposal submission there needs to be acknowledgements from all the participating co-investigators, this will also act as a pre submission workflow, the supervisors of the participating co-investigators also need to approve their respective participation in the research [4]. Once Submitted, the supervisor of the investigator would approve the submission to the research office, where the proposal is reviewed as per the checklist and based on the nature of the research is referred to various IRB subcommittees, here on the proposal will be reviewed by all assigned committees and upon approval, the proposal would be ready to be initiated as a project. This workflow is multi-dimensional, where the research office or a committee member may ask for additional information from the investigator. The system workflow needs dynamism to incorporate the above narration. On each step proper notifications should be generated within the system and on emails, so that the next-in-line reviewer as the necessary information for carrying out the review. The system would allow the research office to schedule meetings (along with proposals to be discussed) which the members would attend physically, and all the minutes would be documented in the system. **Resource pricing, Budget & Logistics:** Master pricing information for all entities such as human resources, equipment, supplies, lab tests, imaging should be a part of the system or connected with the institutional Chargemaster database, so that the budgeting and resource allocation for a research proposal is automatically aligned with the institutional standards. The System should also provide logistical information such as shipment tracking, transfer agreements, customs clearance, tracking of material, equipment storage and retrieval in order to facilitate the project execution process, mostly to do with clinical trials and project requiring equipment and supplies.

5. Conclusions

Right implementation of a dynamic, flexible and scalable research management system would drastically cut down the processing duration for any research activity. It would also automatically govern the accountability on behalf of the stakeholders and help the institution in generating and showcasing its research output. The biggest challenge in such automation is the change management, which is a onus on the researcher, but it can be dealt through marketing the benefits it can bring to the researchers in cutting down the processing times, automatic showcasing of their research profile, research activities and CV without the need to update it manually.

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Speech Recognition Evaluation of a State-Of-The-Art Smartglass in the Use Case Pediatric Resuscitation

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Abstract. Emergencies involving children are rare events. Due to the associated lack of routine and special features in pediatric resuscitation, it is prone to errors and the results are unsatisfactory. One way of tackling this problem is to use assistance services. However, due to the process, these services cannot be easily integrated. One possibility is the use of Head Mounted Displays. These are often controlled via voice commands. With medical terms, the voice control implemented as standard can quickly become unusable. A wearable app was therefore developed for this paper and evaluated according to ISO/IEC 30122-2:2017 to determine the extent to which the voice control of a state-of-the-art smartglass works in quiet and noisy conditions for use during a resuscitation. Since the commands were well understood and the app could be reliably controlled, the use of voice control in an assistance service is conceivable.

Keywords. Emergencies, mobile applications, resuscitation, pediatrics/methods.

1. Introduction

Pediatric emergencies are rare events around the world, but they are still a serious problem. In the USA, for example, about 16,000 children suffer a heart attack every year [1,2]. In Germany, about 4,000 children are resuscitated every year, about 1,000 of them preclinically [3]. Although the survival rate has increased steadily over the last thirty years, far too few children survive with favorable neurologic outcome (2% preclinical, 17% clinical) [4-6]. The lack of routine, combined with individual dose calculation and time-critical procedures, make pediatric emergencies error-prone. However, the quality of cardiopulmonary resuscitation (CPR) is directly related to the survival rate [7-9]. It is therefore essential to have the guidelines [10] issued periodically by the European Resuscitation Council (ERC) at hand. However, the use of assistance services during resuscitation cannot be easily integrated into the process, even if physicians repeatedly wish to use calculators or computer programs, as this has been shown to minimize the number of calculation errors (e.g. medication dosage) [11,12]. The rescuers usually work with both hands under time pressure on the patient. Tablets or smartphones can combine all required information in a small device, but are only suitable to a limited extent due to the handling. A possible solution might be the use of Head Mounted Displays (HMDs).

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These devices can do much of what tablets or smartphones can [13], but there are some special characteristics. The display is rather small, and they cannot be operated as usual. HMDs are often controlled via voice commands. However, this might quickly become unusable with medical terms. Using the Vuzix M300 smartglass as an example, this paper evaluates how good the standard voice control of a state-of-the-art smartglass is in the field of pediatric resuscitation today.

2. Methods

As a first step, a systematic literature search according to the PRISMA scheme was carried out in PubMed and Google Scholar in order to identify related work or preliminary work. Subsequently, a study according to ISO/IEC 30122-2:2017 [14] was designed to evaluate the quality of speech control of the Vuzix M300 in the case of pediatric resuscitation in a test environment. In a first step, voice commands were constructed that conform to both [14] and [10]. The basis was the Pediatric Advanced Life Support according to [10] (see Figure 1).

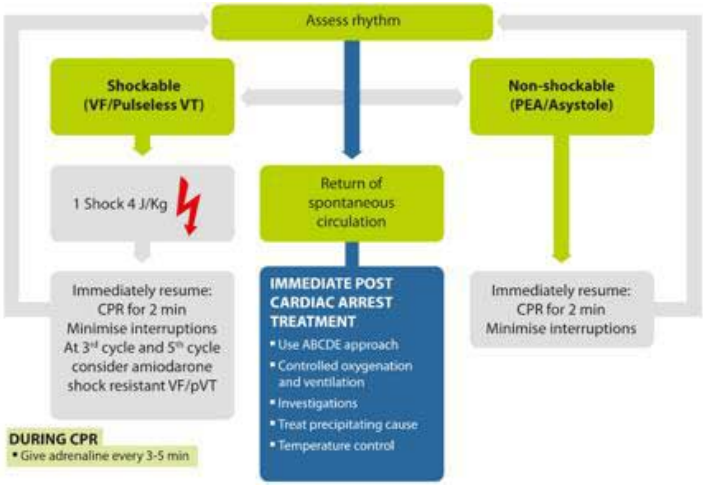

Figure 1. Pediatric Advanced Life Support [10].

Afterwards a wearable app was programmed using the newly constructed voice commands (see Figure 2 for example).

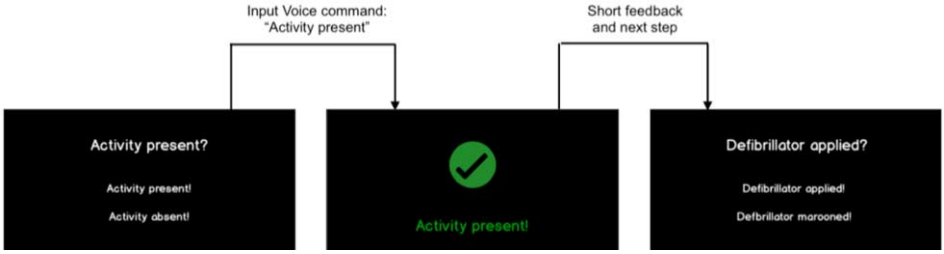

Figure 2. Mock-up of the function "next step" of the Wearable App.

This app was then evaluated after [14] with the help of 19 people in two settings (low volume (LV; Ø51±1,4 dB) and road noise (RN; Ø76,1±1,4 dB)). The following key figures were determined in each case:

$$Word\ recognition\ ratio = \frac{(Number\ of\ correctly\ recognized\ words)}{(Number\ of\ all\ testet\ words)} \quad (1)$$

$$Word\ accuracy = \frac{[(Number\ of\ correctly\ recognized\ words) - (Number\ of\ inserted\ error\ words)]}{(Number\ of\ all\ tested\ words)} \quad (2)$$

The 19 participants were 13 men and 6 women aged between 21 and 30. All participants were not native English speakers and had little experience with entering voice commands. There were 10 iterations per person in the mentioned two settings with 14 defined voice commands each (7 approving, e.g. "Activity present" and 7 disapproving, e.g. "Activity absent", according to the use case (see Figure 1)). That means there were 5320 voice commands in total.

3. Results

3.1. Related Work

There have been many papers dealing with speech recognition and Natural Language Processing (NLP) in medicine since the late 90s. In most cases it is about entries in an electronic health record (e.g. [15,16]). In most cases, specially developed software solutions are used. But there are still several problems as a paper by Google from 2017 shows [17]. Publications that test voice control without specially developed software were not found. Nor were there any papers dealing with voice commands in emergencies.

3.2. Speech Recognition Evaluation

The total word recognition ratio WRR_{total} after (1) is 95.43%. Looking at the individual settings, the word recognition ratio is 97.14% for low volume (WRR_{LV}) and 93.71% for road noise (WRR_{RN}). None of the voice commands was detected in less than 89% (low volume) of the cases respectively 88% (road noise) (see Figure 3). Since there were only 4 insertion errors overall (words that were recognized but not in the test samples), the word accuracy (WA_{total}) after (2) is approximately equal to WRR_{total}.

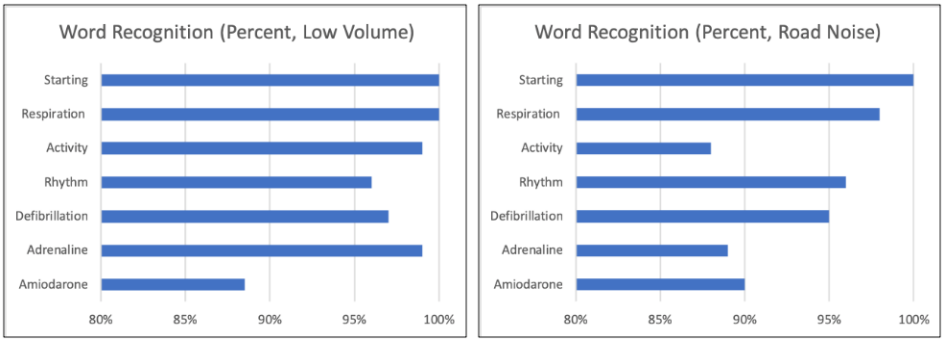

Figure 3. Word recognition per step.

4. Discussion

To ensure sufficient accuracy of the measurement results, ISO/IEC 30122-2:2017 proposes a minimum of 10 participants [14]. For this setting, 19 persons were interviewed who are heterogeneous in age and gender. Overall, the test result looks very good, a WRR_{total} of 95.43% would still be within a 95% confidence interval. However, the result must be interpreted in such a way that in practice it will be used primarily under difficult acoustic conditions and not at low volume. The result of $WRR_{RN} = 93.71\%$ is just outside this range. If these results are good enough for reality can't be said due to the setting. At least repeated speaking was not perceived as annoying in this test setting. It is striking that commands with a strong medical character (amiodarone, defibrillation, adrenaline) are less well recognized but still detected at a high percentage (≥88%). In addition, the results for street noise improved over time, people may have become accustomed to the ambient noise level and may have spoken commands louder. An interesting side observation of the data is that the use in ambient noise became worse especially with female participants (Δ♂: Ø7,9%; Δ♀: Ø14,2%). In order to transfer these results to real environments, a further study is necessary under almost real conditions in a simulation center but the results are promising from a technical point of view.

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A Vision Utilizing Gamification to Enhance Patients' with Chronic Shoulder Diseases Adherence to Rehabilitation

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Abstract. Although adherence is a key factor for successful treatment of chronic diseases, only about 50% of patients achieve good adherence. However, health enabling technologies and gamification offer new possibilities to enhance patient's motivation. In physical rehabilitation, various applications exist. As these often stress a specific part of the rehabilitation process, we introduce a six-step new holistic approach to apply game design elements in the entire rehabilitation process, while focusing on patients with musculoskeletal diseases of the shoulder.

Keywords. Musculoskeletal Diseases, Shoulder, Rehabilitation, Treatment Adherence and Compliance

1. Introduction

Gamification has gained a growing importance in research and practice [1,2]. Its basic idea is "*[...] the use of game design elements in non-game contexts*" [2]. In the context of health care, gamification is applied to enhance motivation and support therapy in general [3]. Especially in the case of chronic diseases, adherence is a key factor for successful treatment [4]. According to the World Health Organization (WHO), only an average of 50% of all chronic patients achieve good adherence [5]. Non-adherence in long-term care processes could jeopardize the effectiveness of treatment [5]. Different factors such as lacking knowledge about the disease, forgetfulness, low degree of motivation, and lacking personal interest, contribute to discontinued or irregular rehabilitation processes [5,6]. Previous studies have already shown the potential of gamification to increase motivation and adherence in therapeutic settings [3]. In physical rehabilitation, the range of approaches and applications is numerous. However, most applications focus on specific parts of the process. Furthermore, assistance is often limited to the provision of information, the possibility for documentation and the evaluation of subsequent rehabilitation services [7,8]. Against this background, it is sensible to investigate a holistic approach to actively increase the patient's motivation

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and empowerment and, thus, the adherence over the entire rehabilitation process. Consequently, this paper proposes a corresponding conceptual framework to enhance adherence through game design elements, while focusing patients suffering from musculoskeletal diseases (MSD) of the shoulder, more specifically shoulder lesions.

2. Methods

To support patients playfully during their entire rehabilitation process, game design elements and supplementary methods such as eLearning will be used. In this work, a rehabilitation process is defined as the whole treatment of a patient from diagnosis to acute treatment – conventional or surgical – to inpatient or outpatient medical and/or vocational rehabilitation. This also includes preventive measures and alternative medicine, as well as administrative sub-processes such as the application of rehabilitation services and the reimbursement of costs.
The methodology to develop the framework will comprise six steps described hereafter.

3. Results

A future direction for the long-term management of rehabilitation processes by the patient themselves is to be shown. In the following six consecutive steps, including their respective aims, are described.

Step 1 Process Analysis. The process analysis will define the conditions for the development of the conceptual framework. The scope of the analysis is to identify and describe weak points in the rehabilitation process. The status quo of care will be established. Data will be gathered by literature analysis, complemented and verified by interviews with caregivers and patients. Due to the complexity of the underlying intersectoral care process, a service blue print will be modeled initially. Thereby, relevant process sequences will be established, aggregated and prioritized to identify characteristics of the process. A detailed visualization, based on the business process model and notation (BPMN) or extended event driven process chains (eEPC), will be used to elicit causes and effects of several motivation barriers.

Step 2 Motivation in the context of Rehabilitation. To explore motivation in the context of rehabilitation, concepts influencing the patient's adherence need to be determined. A literature research will identify general and specific adherence factors to the chosen rehabilitation process. Existing motivation models will also be considered and analyzed. Based on the results of the process analysis, adherence and motivation factors will be classified. A tree of problems will be used to visualize various motivation barriers. To represent the relations between individual motivation concepts and factors dependent of the rehabilitation phases, a structure model will be defined.

Step 3 Gamification in the context of Rehabilitation. Existing gamification theories will be analyzed to collect game components, dynamics and mechanics. Supplementary, a scoping review will identify game design elements specifically for rehabilitation of patients with MSD of the shoulder. The main analysis is intended to figure out when which kind of game design element is useful within this specific rehabilitation process (scenario analysis). Therefore, it is necessary to identify and describe the operational environment as well as basic conditions for the appropriate usage of individual game design elements. This may include factors of the International Classification of

Functioning, Disability and Health (ICF), target groups, safety requirements as well as the integration into standard care processes.

Step 4 Model development. Building on the tree of problems, it is planned to represent the context between motivation, gamification and the rehabilitation process as a tree of aims (see Figure 1). The intention is to identify, describe and easily visualize possible solutions for individual motivation barriers. Once initial solutions have been found, various evaluation criteria will be defined to analyze them with regard to their applicability and appropriateness to enhance motivation and patient empowerment in specific rehabilitation phases. Requirements for the use, preconditions, and technical, legal or ethical aspects will be taken into account. The tree of aims will result in a formal representation of the conceptual framework containing internal and external motivation factors, various game design elements, causes and effects as well as relations between the modeled entities in dependence on the rehabilitation phase and the operational environment.

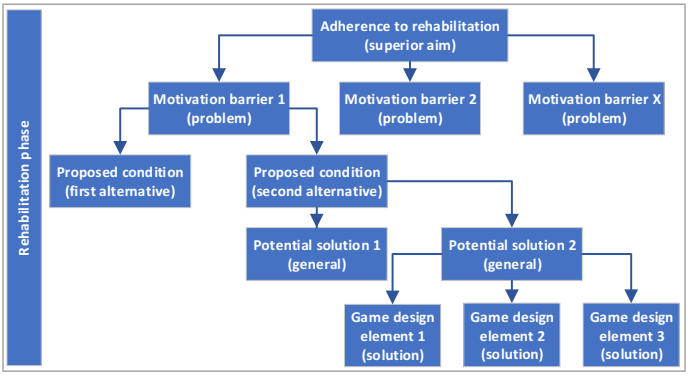

Figure 1. Generic tree of aims

Steps 5 and 6: Exemplary instantiation and evaluation. Based on the conceptual framework, an app will be implemented. The idea is to give patients the opportunity to easily navigate themselves through the rehabilitation process without predetermined paths. The self-management skills of the patients will be strengthened by giving timely advice and encouraged by giving rewards for even small achievements. The app will present the rehabilitation phases and related interventions, provide additional information, as well as guidance by pointing out possible pathways. To provide further functionalities for assisting patients, it should be possible to integrate health enabling technologies as exergames or tele-monitoring systems. The app prototype and the framework will be evaluated in a study. To restrict the study, the use case "*home-based exercises*" as part of the subsequent rehabilitation process will be focused. The priority is testing the hypothesis, whether patients who are supported by the implemented app will train more often than patients without. By this, conclusions on the motivation and adherence may be drawn. The evaluation study will also cover the technical feasibility, acceptance and usability.

4. Discussion

We propose a methodology for the development of a conceptual framework to enhance motivation and patient empowerment through game design elements in the

rehabilitation process of patients with shoulder lesions. Therefore, we described six consecutive steps.

There are some limitations to the described work. Although the objective is to develop a holistic approach for the entire rehabilitation process, the exemplary instantiation will be more specific. However, as many adherence problems occur, the patient's support is particularly important at this stage. It may be reasonable to assume that adherence issues occur in patients also in the early rehabilitation phases, rather than only later. Accordingly, all rehabilitation phases should be supported with a focus on subsequent rehabilitation services. Furthermore, the evaluation with a single prototype might worth discussing. However, we assume that both using the framework for the design of the app and the focused evaluation should surface substantial problems. Once the framework is finalized, the evaluation method might change.

5. Conclusion

Gamification offers possibilities to enhance motivation and adherence in the therapeutic area. A wide range of approaches and applications already exist. However, the focus is mostly on a specific part of the rehabilitation process without taking the individual patient pathway into account. In this paper, we presented the comprehensive methodology for the development of a new holistic approach to use game design elements to enhance motivation and patient empowerment in the entire rehabilitation process of patients with MSD of the shoulder. Although some modifications and amendments to individual steps can be expected, we are confident that the described methodology will be suitable to archive the overall objective of this work.

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Patient Reported Reasons for Surgery Cancellations Do Not Necessarily Correspond with Hospitals' Representation of the Same Problem

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Abstract. Surgery cancellation is a well-recognized quality problem within hospitals. The e-Team Surgery project addressed the problem of elective surgery cancellation at a Norwegian hospital and explored the potential to reduce surgery cancellation by providing a tool for secure online communication between the hospital and the patient. This communication would occur before surgery while the patient was still at home. The causes of elective surgery cancellation are divided into two major categories: hospital- and patient-related reasons. As part of the e-Team Surgery project, this study addressed patient reasons for cancelling surgery through qualitative interviews with 11 patients who fit these criteria. The study found that most patients called the hospital to reschedule, not to cancel, their upcoming surgery. The patient interviews had significant implications for the e-Team Surgery project. They affected the overall understanding of the surgery cancellation problem and made more clear the data and information needed when developing sustainable systems to reduce elective surgery cancellation.

Keywords. Surgical cancellation, patient perspectives, online communication, qualitative research, technology development

1. Introduction

For most hospitals, a surgery department is simultaneously a major investment and their greatest revenue source [1-4]. However, 10%–40% of elective surgeries are cancelled [4,5]. The causes for surgery cancellation can often be divided into two major categories, which are based on who made the decision to cancel. These categories are hospital- and patient-related reasons. Most surgery cancellations are due to existing, necessary information that was unavailable to health care providers during the planning process [6-8]. Up to 50% of cancellations might be avoidable [1,6,9].

The e-Team Surgery project (2015–2019) [1,10] addressed the problem of elective surgery cancellation at a university hospital in Norway and explored the potential to reduce surgery cancellation by providing a new tool for secure online communication between the hospital and the patient. This communication would occur before surgery while the patient is still at home. An interdisciplinary research team studied whether and

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how electronic communication before hospitalisation could actively involve the patient. This would occur during the pre-operative planning process and, therefore, reduce cancellations by providing necessary information at the appropriate time. In this case, necessary information refer to information patients often have access to and that might affect surgery. This includes whether the patient has a cold or other virus infection, allergies or chronic conditions; if they are taking pharmaceuticals; if they are prone to anaesthetic reactions; if they have surgery-related anxiety or distress and other factors.

Hospitals, including the hospital that constituted the research site, often use the cancellation code 'patient wish' to refer to patient-related causes for surgery cancellation [7,11]. This term indicates that the patient did not wish or want to have surgery. At the hospital, professionals expressed concern about the cancellation rate and discussed the use of tools such as SMS notifications to remind patients about upcoming surgeries. However, to this study's knowledge, the hospital had not asked patients about their reason for cancelling. This representation of the problem, in which the patient is held responsible and not the hospital, corresponds with research on cancellations performed in outpatient clinics that addressed the problem of patients failing to show up for or forgetting about their appointments [12,13]. Patient perspectives has been little explored.

To gather empirical knowledge on patient reasons for cancelling surgery, this study designed a qualitative interview inquiry that asks patients why they cancelled their elective surgery. The aim was to use the knowledge to develop an online tool for communication between the hospital and the patient before surgery. The results of the patient inquiry were surprising and had major implications for the health informatics vision and the technology development of the e-Team Surgery project.

2. Methods

During the e-Team Surgery project, an interdisciplinary team explored the potential to reduce surgery cancellations by providing secure online communication between the hospital and the patient. The project applied a mixed-method approach.

To gather patient perspectives on why they cancelled surgery, a health professional identified patients who had done so within the past three weeks. To maintain the patients' anonymity, the health professional mailed letters of invitation to the patients requesting their participation in qualitative telephone interviews. Of the 48 letters of invitation, 11 recipients stated that they were available for an interview. The participants were adults ages 32 to 70 and included six men and five women. The conducted, structured phone interviews lasted 10–60 minutes each.

The data protection officer at the selected hospital approved the study, and all the participants signed informed consent forms.

3. Results and Analysis

During the interviews, most patients stated that they wanted surgery, but, unfortunately, the operating date provided by the hospital was inconvenient and ill-timed for them or their families. Most patients called the hospital to reschedule immediately after receiving the admittance letter that set the date of their surgery. This letter, which the hospital mailed, was the first piece of information the patients received about the fixed date for

their surgery. The letter also contained general information about the surgery, vital pre-surgery behaviour and the name of the responsible surgeon.

When asked why they cancelled their surgery, one patient said, 'I didn't cancel for the fun of it!' (Patient 1, P1). This patient said she was troubled by her condition and wanted surgery but twice had family obligations that made it impossible for her to have the surgery at the time set by the hospital. Another patient said that the admittance letter informed her that the surgery was not recommended for pregnant women. 'I called the hospital and said I was pregnant and that I could not undergo surgery as it was not recommended for pregnant women' (P2). A third patient said, 'I cancelled. I had to work that day! It was not possible for me to be hospitalised at the assigned date' (P3). A fourth patient cancelled because his wife was scheduled for a caesarean delivery on the same day. He said, 'I got a daughter [on] the assigned date. It was a planned caesarean delivery, and I wanted to be there!' (P4). These statements illustrate how the patient reasons for cancelling surgery varied. Nevertheless, the overall findings demonstrate that the patients wanted surgery. Most called the hospital to reschedule, not to cancel, their surgery.

One patient criticized the current surgery scheduling system. 'The booking system, it definitely has constraints. As a patient, you cannot reschedule! The surgery gets cancelled! In a digital society, is it not possible to change an appointment and go through with the surgery?' (P5). Another patient said, 'I think it [the surgery cancellation rate] is related to the lack of coordination. Currently, the hospital schedules blindly, solely based on doctor and operating room availability rather than a quick phone call to the patients [to ask], "These dates are available. Which is better?"' (P6). As these quotes illustrate, the patients saw the scheduling system as rigid and outdated. The patients wanted to be involved in the scheduling process and to have a say in the timing of their elective surgery.

4. Discussion

This study on patient perspectives on surgery cancellation demonstrates that, contrary to the hospital's assumptions about the 'patient's wish', these patients wanted their surgery. They simply sought to reschedule the surgery date set by the hospital. Their reasons for cancelling surgery were not related to a lack of interest or willingness to undergo surgery as the 'patient wish' concept indicates. Instead, they cancelled due to the hospital's poorly functioning scheduling system.

This study illustrates the advantages of shifting analysis from an attempt to develop solutions to an exploration of how different actors represent the problem [14]. Investigating the surgery cancellation problem from the patients' perspectives yielded new knowledge on surgery cancellation that hospital required but lacked. Today, there is no rescheduling category in the system. In addition to uncovering patient reasons for cancelling elective surgeries, this study sheds light on the differences between the problem for the patients and the representation of the problem by the hospital.

5. Limitations

A limitation of this study was the low response rate (11:48). Participants may have been particularly frustrated with the scheduling system as compared to non-participants. However, the patient interview data correspond with interview data from secretaries

working with the scheduling system. Both groups indicated the limitations and constraints of the scheduling system though from different perspectives.

6. Conclusion

The results of this study were surprising. They affected not only an overall understanding of why patients cancel surgery but also future approaches towards developing the e-Team Surgery solution. This study also provided information necessary to create sustainable systems that will reduce the number of surgery cancellations. The e-Team Surgery project sought to address the problem by facilitating secure online communication between the hospital and the patient prior to surgery. However, this vision has been put on hold. The project's new health informatics vision is to improve the surgery scheduling system. Although this is not as innovative as the initial vision, it will hopefully provide a first step towards reducing surgery cancellations at hospitals.

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Dynamic Survival Analysis Using In-Memory Technology

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Abstract. In the field of oncology, survival analysis is one of the most important tools in terms of measuring therapy success, evaluating risk or prognostic factors. Within this work, a variety of common survival analyses were embedded into a real-time analysis platform based on a comprehensive oncological dataset. The analysis platform utilizes an in-memory database, therefore allowing spontaneous adjustments of the survival curves to selections and stratifications. In contrast to classical statistics, where individual scripts have to be formulated for every possible request, the running system allows the deduction of instantaneous results.

Keywords. Survival Analysis, Data Warehousing, Medical Oncology

1. Introduction

Within oncology, keeping track of a patient's course of disease allows to calculate the time between diagnosis and specific events like e.g. death. If this follow-up (FU) information is known for most patients of a given cohort (different sources advise a FU rate of 80%-100% [1,2]), meaningful estimations about the survival can be made. The university hospital of the Ludwig-Maximilians-Universität in Munich is documenting oncology-relevant information into its tumor documentation system (CREDOS [3]) where each patient is comprehensively described by a set of records resulting in more than 1000 possible attributes. The software captures all organ entities (e.g. stomach) and the documentation is driven by federal laws (Bavarian Cancer Registry Law: BayKRegG, Art. 4, §1) and certification requirements [2]. While CREDOS is a tool for gathering data, the site developed an analysis platform [4], based on the in-memory software QlikView, allowing to examine the data in real-time [5]. The most complex module within this platform is the survival module, which, in comparison to classical statistics, allows the dynamic formation of arbitrary patient cohorts, stratifications and types of survival analysis by simple clicks.

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2. Methods

For building modules, QlikView offers a scripting section as well as a graphical toolbox. Within the scripting section the tables, data fields and interconnections are defined. In the running system (user interface), all connected tables dynamically, in real time react on any selections [5]. For example, if an end-user clicks on a specific field value, e.g. a diagnosis code, consequently all other tables and charts dynamically only display cohorts with the given diagnosis code. The analysis platform's main data model was leaned on the CREDOS data. Linked to this model, via the tumor-id, was a large table labeled SURV, which was built up in a stepwise manner. Every type of survival analysis contains a specified starting and endpoint, from which the survival time was calculated. Additionally, the binary field 'type', being either a censorship or an event was defined. In the given context a censorship describes the situation when there is a FU time but the given event has not yet occurred or is not known to have occurred [6]. For each event or censorship, a date of occurrence was stored within the table. Due to the scope of this work, we cannot go into full detail about all preparatory steps. Finally, the time in days up from the starting point until the previously defined endpoint - event or censorship - was calculated and stored within SURV. In summary, for every tumor in the dataset, the times and the types needed for calculating each of the six types of survival curves (see below) were stored. If no such information was available, the corresponding fields were left empty and in the later-on calculations of the curves, these cases are not included in the cohort. After the data model was loaded in QlikView, the graphical development toolbox was used to create the dynamic Kaplan-Meier (KM) curves by accessing SURV. One chart was created, which can display six different curves: OAS, survival after progression (PPS), local recurrence-free survival (LRFS), recurrence-free survival (RFS), metastasis-free survival (MFS) as well as progression-free survival (PFS). The chart was designed in a way that the survival is estimated at every FU time, starting from zero. As has been mentioned, these times are calculated in SURV. The general formula of the KM-estimator is well-known (see [6; 7]). The implementation of this formula might differ depending on what programming language or software is used. In our system, the formula was implemented as follows:

*[S(t)]: if(isnull(Above([S(t)])), 1, Above([S(t)])) * propSurv*

The given formula is recursive and utilizes the proportional survival at time *t*. We refer to it as *propSurv*. We utilized QlikView's "Above" function instead of writing a "for" or "while" construct, as is common in other programming languages, to access the cumulative survival at time *t-1*.
The part, which we refer to as *propSurv* is another expression and was implemented as:

[propSurv]: if((([Amount of Events]=0) and ([Under Risk]=0)), 1, 1-([Amount of Events]/[Under Risk]))

In Bewick et al. [6] it is defined as the proportion of surviving time *t* having survived up to time *t-1*. The cumulative function of those makes up the KM curve. In square brackets are additional expressions, which were derived from the SURV table.

Aside from the main KM-chart, we added helpful features like confidence intervals (Greenwood's formula [7]) or overviews about the FU rate for a selected cohort within a given timeframe.

3. Results

As part of an interconnected analysis framework, the presented survival module sits on top of a persistent oncological data model. Based on simple mouse clicks, arbitrary selections and stratifications are possible in real time. The main part of this module is a KM chart. Currently it supports six different types of KM-curves, as described above.

QlikView itself is a continuously running system, automatically updated on a daily basis and reachable by interested physicians via a web browser (intranet). A video showing the main functionalities of the survival module is provided at:

https://www.ibe.med.uni-muenchen.de/organisation/mitarbeiter/070_drittmittel/nasseh/survival_final.mp4

4. Discussion

The in-memory database is not a technology exclusively used by QlikView but instead can be found in many modern business intelligence solutions like microsoft's Power BI or SAP-Hana [8,9]. Implementing survival analysis within these tools should be seen as an innovative technique for quickly examining arbitrary cohorts. In comparison to classical statistics, the in-memory technology allows a fast, real-time view on arbitrary stratified data. In software like R or SPSS [10,11], even if a preliminary working script had been established, one would need to alter scripts for every new selection or stratification. Thus, the big benefit within our system does not lie in the performance, which can be even better in static scripts, but instead within the absence of any need of preparation, allowing to spontaneously browse into the data and generate knowledge. One pitfall though within in-memory systems is that there is a tradeoff between runtime and allowing flexible interaction of the user, hence the system may not get too complex. Currently within our system (12.0 GB RAM, Intel Xeon 2.4 GHz dual core), generating one curve for 1000 patients takes 5 seconds. Although physicians should be able to understand and explain KM-curves [12], in order to protect against misuse, when entering the survival module there is a collection of information: Buttons, pop ups and tooltips which give insight about used formula definitions, FU rates as well as technical limitations. Concerning the used formulas, there are ongoing debates about the correct specifications, where e.g. different definitions have been used in publications [13]. Along the recommendation of the FDA [14] we clearly state the used definitions. Furthermore, references were provided, as e.g. the RECIST criteria [15], definitions of our local tumor registry or the demands of the certification committee [2,16]. Although there are alternative ideas [17], quantification of FU was calculated along ONKOZERT and CONSORT guidelines [18,19]. Finally, it has to be mentioned that a system like this is not meant to replace a statistician or IT professional. The goal is rather to facilitate translational research by simplifying the access to the oncological database for physicians, who often do not have the computational skills and time to extract the knowledge from pure data tables, but who have the expertise to generate new research hypotheses [20]. As the system was just recently released to physicians, besides positive feedback, it has not been used for extensive research projects yet. Still it has been utilized within our annual audits and in general creates a lot of interest into our data, which has not been the case before. As for future perspectives, further refinements of the module are envisioned as e.g. adding FU rates of other curves than the OAS, log-rank test or Cox-regression models.

5. Conclusion

Despite the limitations and risks, the merits of a real-time, flexible survival analysis tool, compared to classical statistics, are obvious. In-house, the software has been used, with, the last couple of years for proposals, analyses, etc., while the survival module in particular offers a great facilitation during the annual audits and could serve as an inspiration for other centers which are interested in novel ways of data discovery [21].

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Implementing eHealth Technologies: The Need for Changed Work Practices to Reduce Medication Errors

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Abstract. Medication errors are a significant health problem and a serious threat to patient safety. In Norway, an estimated one-third of the elderly population has been exposed to potentially inappropriate medications. The Norwegian government has assumed a pivotal role in reducing medication errors and providing safer medication management for its citizens, particularly through the national eHealth system's e-prescription and Summary Care Record. In the present study, we depart from the governmental eHealth initiatives and examine why access to pharmaceutical information is not sufficient to solve the problem with medication errors. Empirical data were collected from 2015 to 2019 through the conduction of 56 qualitative interviews that were transcribed, thematically coded and analysed. The results illustrate how eHealth systems are helpful, at the same time, we emphasise changed work practices and professional knowledge-sharing as a basis for solving the issue of medication errors.

Keywords. implementation, eHealth, Summary Care Record, e-prescription, shared pharmaceutical list, medication errors, work practices, qualitative method

1. Introduction

The Norwegian government has assumed a pivotal role in providing safer medication management for its citizens by reducing medication errors through eHealth system efforts, such as e-prescription, the Summary Care Record (SCR), Multidose in e-prescription and the future Shared Pharmaceuticals List [1]. However, medication errors are still a significant health problem and a serious threat to patient safety. In Norway, as in the rest of the Western world, medication errors are a key societal challenge. One-third of the elderly Norwegian population has been exposed to potentially inappropriate medications [2], and it is estimated that 1,000 deaths yearly are due to medication errors [1]. Taking the wrong medicine, an incorrect dosage or the wrong combinations of drugs can lead to poor health outcomes, including premature death and reduced quality of life [3,4].

In this paper, we depart from e-prescription and the SCR, two national systems that collect data from a database called the Prescription Mediator, and provide access to information about the prescribed pharmaceuticals that the patient has received from

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Norwegian pharmacies. Here, we *examine why access to information about the patient's pharmaceuticals is not sufficient to solve the problem with medication errors.*

2. Methods

Empirical data were collected from 2015 to 2019 using a qualitative research method. We interviewed 56 professionals working with the SCR or the e-prescription solution. This presentation is based on knowledge gathered from all interviews. Since we are discussing governmental efforts in reducing medication errors, we have provided quotations from nine interviews with health authority representatives. The representatives were strategically selected for their professional involvement with the SCR or the e-prescription solution and consisted of designers, developers, implementers, health care providers and leaders. Empirical data from the other interviews are presented elsewhere [5]. All interviews were recorded, transcribed, thematically coded [6] and analysed. The selected quotations are translated from Norwegian to English.

3. Results and Analyses

We approached the challenge of medication errors through qualitative interviews with health authority representatives deeply involved in two national systems for accessing pharmaceutical information: e-prescription and the SCR. Our interviews, illustrated by quotations A–F (Figure 1), show that the health authority views e-prescription as a successful initiative. Digital prescribing and access to prescription information is regarded as a national quality improvement for Norwegian health and care services (Figure 1A).

A: The [governmental] aim has always been a shared pharmaceutical list in Norway. Numerous studies demonstrate the poor pharmaceutical situation: a number of mistreatments and 1,000 deaths annually due to pharmaceutical errors. The [governmental] aim is to do something. E-prescription was probably the first major initiative introduced by the authorities. It was a huge improvement—from paper to digital. E-prescription was a big step forward. We see quality improvement on [the] national level with digital access [to prescriptions].

B: However, there is a challenge: what I call a bad [prescription] practice—the practice of paper [prescriptions]—continues. You [the doctor] do not access the system to check the patient's medication; you just write a new prescription. Here you go! You are welcome! Go to the pharmacy and get the medicines. You [the doctor] do not know—[Was] this medication prescribed to the patient previously [by another doctor]? Does the patient have the same medication at home or ...? That is how we get double prescriptions.

C: E-prescription [the system] visualises the practice of double prescriptions ... Now, we have statistics; we can follow the development; there are numerous double prescriptions out there.

D: There [are] so [many] systems going on, without coordination and an understanding [of] the overall picture. A [next] step is [giving nurses] access to the Summary Care Record. The nurses will get access to the same information though the SCR, as doctors gets in E-prescription.

E: [The] Summary Care Record was adjusted to receive this information about pharmaceuticals, so, all together, the Shared Pharmaceutical List [a new service] ... the doctors could use the prescription mediator and send information about the patient's pharmaceuticals there. The nurses can use the Summary Care Record because they have no access to the prescription mediator.

Figure 1. Quotes from health authority representatives.

The health authority representatives claimed that a shared pharmaceutical list has always been the government's goal; e-prescription is merely the first step towards it (Figure 1A). At the same time, the health authorities acknowledged continuing challenges with medication errors and described them as connected to the continuance of work practices established though the use of paper prescriptions. Prior to e-prescription, there was no proven system for looking up a patient's pharmaceutical history. After e-prescription,

however, the work practices from paper continue. Doctors continue prescribing medications, now digitally, without checking the patient's pharmaceutical history. Therefore, Norway still has medication errors, particularly related to double prescriptions (Figure 1B). E-prescription visualizes these errors, which were not as noticeable when using paper prescriptions (Figure 1C).

The health authority representatives claimed that national, digital systems for shared patients' pharmaceutical histories have had their attention for a long time, and stressed that the medication challenge is not regarded as solved by e-prescription (Figure 1A). Several systems have been developed and implemented so that new groups of professionals can access pharmaceutical information that they were unable to access earlier (Figure 1D). Nurses can access the SCR, doctors can access e-prescription and all professionals will have access to the future shared pharmaceutical list (Figure 1E).

E-prescription is a success as a digital system that provides doctors at various institutions and levels of care in Norwegian health and care services access to the same prescription information. However, the quotes illustrate that such systems for accessing information are not sufficient for solving the problem, neither in regards to double prescriptions nor to mistreatments and deaths due to medication errors. E-prescription is the first of several tools for accessing information about the patients' pharmaceutical history, and new systems are forthcoming, all with the purpose of providing information to diverse professionals at various levels of care to meet the issue of medication errors.

4. Discussion

To reduce medication errors, Norwegian health authorities have developed and implemented several national eHealth systems that provide healthcare professionals at diverse institutions and levels of care access to the same pharmaceutical information. The findings illustrate that the authorities perceive e-prescription and the SCR as useful quality-improvement initiatives but also recognise that these national systems are not sufficient for solving the medication challenge. Therefore, the governmental eHealth vision is to develop and implement a new, digitised, national system—the shared pharmaceutical list.

Digital systems for accessing pharmaceutical information are often linked to automatically generated data, as in the case of e-prescription and the SCR, which both collect data from a national database the Prescription Mediator. The national mediator provides information about all the prescribed pharmaceuticals that patients have received from Norwegian pharmacies. We believe that to get the patient's medication right, health professionals need to go through each patient's medication prior to prescribing new medication and determine whether they contain the correct medication for the patient. This will create an additional workload and require changed work practices for professionals.

With paper prescriptions, it was possible for doctors to prescribe medicines in a single action. Making this information digital allows them to check the information in the Prescription Mediator to prevent writing double prescriptions, prescribing incompatible medications and so on. Hence, the prescribing process should include extended collaboration and discussions among professionals. To address the problems of erroneous medication, incorrect dosages and patients taking the wrong combination of drugs, professionals must process the information from the digital systems to acquire

correct information through collaboration and knowledge sharing. This includes changed work practices.

Systems for accessing pharmaceutical information are useful; however, to fulfil the promise of digital systems and solve the issue of medication errors, new work practices are essential, including extensive knowledge sharing and defined responsibilities. It is not enough that individual practitioners change their habits, whether writing or pushing a button. All the involved professional groups, institutions and patients must collaborate and share knowledge to solve the issue. It is essential to look beyond technological optimism and focus on professionals and work practices to understand and reduce medication errors.

5. Conclusion

We have studied why implementing eHealth systems for accessing information about patients' prescribed pharmaceuticals does not solve the problem of medication errors. The results demonstrate that increased information sharing is crucial, but solving the problem of medication errors demands changing established work practices and the way that professionals collaborate. We recommend that health authorities look at professional work and knowledge practices rather than at technology. Digital technologies are helpful in addressing the medication problem, but the main challenge may be related to establishing new routine work practices among health professionals. We believe that healthcare providers have the greatest potential to bring about change and solve the issue of medication errors.

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Impact of Students' Presence and Course Participation on Learning Outcome in Co-Operative Online-based Courses

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Abstract. Socio-constructive instructional designs for online-based learning focus on interaction and communication of students to allow in-depth learning. The objective of this study is to analyze whether increased interaction of students in online-based learning settings may contribute to better outcome. We developed indicators for presence, participation, and interactivity of students. We extracted log data from the learning management system for 31 students in 10 online courses (n=123 course attendances). We correlated indicators to final grades and also applied a decision tree based machine learning approach. We found only weak to moderate correlations between the indicators and final grades, but acceptable results concerning prediction of students' success based on the indicators. Our results support the theory that student presence and participation in online-based courses is related to learning outcome.

Keywords. Learning, distance, health informatics

1. Introduction

Socio-constructivist theories of learning are built on the assumption that learning is only possible by interaction and communication. From this perspective, learning advances through collaborative social interaction and through the social construction of knowledge [1]. Research indeed provides evidence that course engagement and interaction with peers are related to better learning outcomes [2,3]. The Austrian University UMIT started a fully online-based postgraduate master program in Health Information Management in 2017 [4]. The program contains only asynchronous activities and peer discussions, for details of the instructional design see [4]. We were interested to understand whether sustained engagement and interaction between students contributed to learning outcomes, as we wanted to inform new students on the need and the benefits of regular engagement and interaction. Our research question is therefore: Is course presence, course participation, and course interaction positively correlated to learning outcome as measured by final grades?

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2. Materials and Methods

We extracted log data of successful students from our learning management system Moodle. In addition, final grades were documented (60 – 100 points, as 60 points was the pass mark in every course). For a sub sample of courses, manual workload documentation on a daily base was available from the participants. After data integration, the dataset was pseudonymized for further analysis.

We used indicators on student's presence in the online-based environment, student's participation, and student's interactivity [5] (Table 1). For this study, only standard log data was available; the indicators for interactivity as proposed in [5] could not be calculated. We thus added two further indicators that are easily available from Moodle log data: Course dedication that describes the overall online time, and course activity that counts the overall number of logged activities (Table 1). We added these indicators as earlier research found that they are related to learning outcome [6,7]. All indicators were calculated as an "index" with minimum = 0% and maximum = 100%. Overall, we extracted data from ten online-based courses in the master program Health Information Management at UMIT that took place between October 2017 and July 2018. Each course had a duration of six weeks and was given fully online. Data from 123 course participations (31 distinct students) was included in the analysis. Manually documented workload data was available for 54 course participations. For this subset, we analyzed correlation between this "subjective" workload self-assessment and the "objective" log data (course dedication), to learn about the validity of the log data. We also assessed the correlation between all indicators and the final course grade as well as the correlation between the different indicators both statistically and using visual analytics techniques.

Multivariate analysis was not yet performed due to dependency of the data (single students participated in several courses and half of the courses were taught by two lecturers) and the small sample size. However, to test, if it is possible to predict students' success (i.e., belonging to the better half of the students) depending on the indicators we applied a decision tree based machine learning approach (CRT Trees, gini index, 10-fold cross validation). We used R (version 3.5.1) to calculate and statistically assess the indicators that are presented in Table 1. Tableau Desktop Professional (V 2018.2.3) was used for the visual data analytics part and IBM SPSS Statistics (V 24) for the machine learning approach. The study was approved by the ethical board of UMIT (2309/17). Students provided informed consent. All data were pseudonymized before data analysis.

Table 1. Indicators for course engagement [5]. * = New indicators added for this study. † = Indicators not available for this study

Indicator	Description
Student's presence	
Access Index	Number of online days in relation to course duration.
Access Pattern Index	Number of days that belong to a group of at least three days in a row in which a student was absent from the course, in relation to the duration of the course; the result is then subtracted from 100%.
Dedication Index*	Overall time spend online (Moodle course dedication), in relation to the maximum dedication of a student in the given course.
Activity Index*	Number of activities (reading, writing) conducted online, in relation to the maximum number of activities of a student in the given course.
Student's participation	

Reading Index	Number of reading activities, in relation to the maximum number of reading activities of a student in the given course.
Writing Index	Number of posts written by a student, in relation to the maximum number of posts written by a student in the given course.
Contribution Index	Number of days with at least one post, in relation to all own online days.
Student's interactivity †	
Answer contribution Index†	Number of replies in relation to all own posts.
Connectivity Index †	Number of unilateral relationships in a course, in relation to the number of possible unilateral relationships
Reciprocity Index †	Number of bilateral relationships in a course, in relation to the number of possible unilateral relationship

3. Results

We found a strong positive linear relationship between the automatically calculated workload estimate ("course dedication" with default options) from Moodle and the manual daily workload documentation provided by the students ($r = 0.74$ [CI 0.59 0.84], $df=54$, $p<0.0001$). We can thus use dedication as an indicator for individual workload.

From the available seven indicators, we found a positive correlation with final grades for all of them. However, the correlations were only weak to moderate (Spearman's ρ ranging from 0.092 to 0.480). The correlations was highest for the following three indicators: Access Index ($\rho=0.426$, $p<0.0001$), Reading Index ($\rho=0.472$; $p<0.0001$) and Writing Index ($\rho=0.092$; $p=0.31$). Finally, we tested the possibility of predicting students' success with the available indicators. Students' success was defined here as belonging to the better half of students in the course (i.e. final grade (range: 0-100 points) above or equal the median grade of all students in the course). Consequently, we obtain a binary classification problem with two classes. The decision tree model yielded a classification performance in terms of accuracy of 78 percent. A students´ success (i.e., success = TRUE) could be correctly predicted in 73.5 percent of the cases (50 of 68). Students with grades below the median (i.e., success = FALSE) were classified correctly in 83.6 percent of all cases (46 of 55).

4. Discussion

We found weak to moderate correlations between indicators for course presence and course participation and the final grade in online-based courses. The dedication index, showing the overall time online, has the highest normalized importance for predicting the success and also correlates strongly with activity index, read index, and write index. Analysis of self-assessed workload revealed that dedication time and individual workload are strongly correlated, allowing using dedication time as surrogate for workload. We assume a somewhat logical chain from presence (being in the course) to participation (being active in the course) and finally to interactivity (being active together with peers in the course). We haven´t analyzed yet whether this hypothesis can be validated from the data; this can only be done when larger sample sizes are available. We focused on successful students; unsuccessful students may show different patterns.

Gunawardena (1997) described how online learners arrive at a higher level of critical thinking through different stages of interaction with peers: (a) sharing/comparing of information, (b) discovery of dissonance, (c) co-construction of knowledge (d) testing

and modification of proposed synthesis, and (e) agreement of newly constructed meaning [8]. Salmon (2013) postulated in a comparable way a Five Stage Model for successful collaborative online-based learning [9]. All these frameworks have a strong focus on interaction and communication of students as a precondition for successful learning in common. Our indicators are not yet able to mirror these complex stages. A qualitative and quantitative content analysis of forum posts would be needed for this. Our results need to be interpreted with some caution: First, correlation does not imply causation. As we did a retrospective observational study, we cannot conclude that high student presence and participation cause higher grades. An alternative interpretation could be that motivation, self-regulation or intelligence impact on both participation and grades. Second, using grades to measure learning outcomes has some limitations. Third, in our online courses, participation in the courses has an influence on final grades. In all courses, 10 – 20% of final grading were given based on quality (but not quantity) of interaction. Thus, students who interacted strongly got partly higher grades. This may have contributed to the identified correlation. Fourth, our results are not easily generalizable to other instructional contexts.

5. Conclusions

We were able to calculate indicators for student presence and student participation in online-based courses from routine log data. Results show a small to medium correlation with learning grades. We plan to conduct further multivariate analysis to better understand how the different indicators may predict success, failure or final grades, as soon as more data are available. In addition, we will develop indicators of interactivity that can be calculated from standard log data in an automated way.

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Digital Oblivion (The Right to Be Forgotten): A Big Challenge for the Public Hospital Management in Greece

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Abstract. The purpose of this study is to ascertain the readiness of the public hospital in Greece to comply with the new Regulation for protecting personal data (GDPR). A qualitative research was carried out by using structured interview with experts and relevant hospital executives of the 2nd Health Region for collecting the data. Despite the mandatory application of the new Regulation by Hospitals, the right to be forgotten and the other rights on personal data in healthcare are virtually not applicable.

Keywords. General Data Protection Regulation, rights, public hospital, Greece

1. Introduction

General Data Protection Regulation (GDPR) 679/2016 is a new European law. Its purpose is to protect the personal data of individuals, giving persons greater control over their data. The new Regulation is designed in two pillars. The pillar of Regulatory Compliance (Legality) regarding the Principles and Rights of Processing Entities and the Technical Conformance Pillar (Security) concerning the technical capability of the Information System to support and satisfy are the principles of GDPR. The question is how this purpose can be achieved in the public hospitals. This study aims to ascertain the readiness of the public hospital in Greece to comply with the new Regulation for protecting personal data.

2. Methods

The methodology for conducting qualitative research was based on the six-step development model in order to extract as relevant and safe conclusions as possible [1]. An interview with three hospital experts in 2nd Health Region of Greece took place on October 2018 structured into five modules: A) the demographic information of respondents, B) the actions for the implementation of the Fundamental Authorities of GDPR, C) the actions for the implementation of the right to be forgotten etc., D) the

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security of the physical archive and technical capability of the Integrated Hospital Information Systems, and E) the attempt to learn the personal view of the respondents for the application of the Regulation and general questions about the policies that the hospital has made [2,3]. Data Analysis was done by encoding the questions of the interview. The qualitative research encountered difficulties such as fear and denial of the hospitals for authorization of the survey, lack of experience from the public hospital from a prior application of a similar procedure, lack of previous similar research to conduct safe conclusions and the contrast of principles and rights of the new Regulation with the current health legislation.

3. Results and Discussion

The deviations of Regulatory Compliance showed that public hospitals are not complied with: the Object and Transparency Principle, the Minimization of Data Retrieval and Processing Principle process of automated erasure of personal data (when the necessary time has elapsed), the Integrity and Confidentiality of Data, the Limitation Authority and the Accountability Authority. The rights on personal healthcare data (the right to be Forgotten, data portability, the right to Automated Individual Decision Making, including Profile Forming, Opposition as well as the Consent) are virtually not applicable due to several exceptions, in the relevant articles of the Regulation, mainly on grounds of public interest, for scientific or statistical reasons. There is no up-to-date list of the personnel's physical access rights in the premises where the data is located, there is no physical security in the data areas and there is no registered Personal Data Management Policy. The deviations of Technical Conformity showed that there are no specific roles and responsibilities for the management of data security, there is no active encryption method, and furthermore there is no sufficient troubleshooting of operational systems and knowledge of information systems' security issues.

4. Conclusion

After the qualitative research, it was found that despite the mandatory application of the new Regulation by Hospitals, rights on personal healthcare data are virtually not applicable. In general, while providing instructions on the maintenance or processing of personal data, technically the Regulation raise specific requirements without specifying the technical measures to be taken in order to protect personal data and enable the rights of individuals. Future research will be necessary for further results.

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Using Equivalent Classes of an Ontology to Understand Care Pathway in Amyotrophic Lateral Sclerosis

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Abstract. To understand the home-based difficulties encountered in the health care pathways of patients with Amyotrophic Lateral Sclerosis (ALS), we must annotate a large amount of textual data, from a database created by the ALS Île de France coordination network. For this purpose, we have developed a modular ontology, consisting of four modules, and a semantic annotation tool integrating the created ontology. The specificity of our approach is the creation of equivalent classes at different levels of the ontology. These equivalent classes represent variables of interest allowing a statistical approach and a clinical analysis of comprehension of care pathways ruptures causing.

Keywords. Equivalent classes, care pathway, Amyotrophic Lateral Sclerosis

1. Introduction

Amyotrophic lateral sclerosis (ALS) is a progressive neurodegenerative disease of motor neurons, leading to a worsening of the weakness of voluntary muscles. The median survival time after symptoms onset is usually 3 years [1]. Because of progressive paralysis of the muscles, patients will be facing many disability situations. Beyond medical aspect, the patient and their loved ones will require different types of help such as (1) assistance for the realization of life's daily activities, (2) technical aids to movement or for communication, but also (3) social support for setting up funding. However, problems can arise at home resulting in interruptions in the care pathway and hospitalizations. These incidences can have an impact on the health and quality of life of the patient and his family and have a financial cost. However, we do not have any data on the origin of the problems leading to these interruptions. This lack of understanding of failure causes is a problem. If the causes of interruptions of care were understood,

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measures could be taken to prevent them. In Paris, associated with the expert center hospital, a regional coordination network has been created: the IDF SLA network, which coordinates various professionals involved in care and social assistance. The SLA network has created a textual database collecting (1) all the requests and needs issued by the patients or the local professionals, and (2) the coordination action put in place to address these needs. The hypothesis of our work is that by analyzing this corpus, it will be possible to (i) understand the difficulties of patients and families in their homes, (ii) understand coordinated actions, (iii) identify indicators of ruptures, or typologies of patients at risk. In this case, we suggest the use of a modular ontology and the creation of equivalent classes. After semantic annotation, these will serve as variables of interest in the statistical analysis of the data extracted from the texts. We will thus be able to obtain an analysis with a clinical dimension. The second section of this article will describe the ontology built, its various modules, as well as the equivalent classes. Finally, the third section will present the first results obtained, perspectives areas or improvement to be developed.

2. Material and methods

2.1 Creation of the ontology modules

To develop ontologies, we followed the generic methodology illustrated by Charlet et al. [2] which combines a top-down approach using a top-ontology and a bottom-up approach by finding candidate terms from corpora. This method provides the terms representing the concepts used. Each concept of the ontology is designated by a preferred term in English and French, as well as alternative terms (synonym terms, acronyms, abbreviations considering the spelling specificities related to the coordination context). The analysis of the candidate terms allowed us to define four main dimensions: (1) a dimension containing the generic concepts common to all fields, (2) a medical dimension related to the pathology, (3) a socio-environmental dimension related to the patient's family and geographical environment, and (4) a coordination dimension related to the activities undertaken by the SLA IDF coordinators. Each dimension leads to the creation of a specific ontological module [3], (i) a kernel module (343 classes) which contains all the high-level concepts common to the three ontologies, such as ideal objects, agents, processes, modalities, (ii) a medical module (969 classes) which contains medical agents (doctor, neurologist, ...), medical processes (consultation, hospitalizations ...), medical objects (drugs, probes ...), and anatomical structures, (iii) a socio-environmental module (779 classes) which brings together all the concepts related to the person's life in his family and social environment, and finally (iv) a coordination module (295 classes) which is composed of specific coordination missions as communication, assessment needs, resource research.[2]

2.2 Creation of the equivalent classes

The organization of knowledge in the form of an ontology allows us to create equivalent classes, to link all the concepts present in the different modules and belonging to a common theme. This theme makes it possible to group all the concepts satisfying the

[2] Ontology available at http://bioportal.bioontology.org/ontologies/ONTOPARON

same property. This equivalent class is called a *defined concept* (http://mowl-power.cs.man.ac.uk/protegeowltutorial/resources/ProtegeOWLTutorialP4_v1_3.pdf). When using the reasoner HermiT in Protégé, all the related concepts will be inferred under the equivalent classes. These equivalent classes are constructed and created as variables of clinical analysis interest of care pathway and their frequency will be an indicator of the "problems" encountered by patients. The functioning of the SLA network is based on the solicitation of the network, by the agents (patient, family, professionals...) when they need it. Each of these solicitations will generate one or more event, according to the actions that will have to be set up by the coordinators. The goal of our work is to understand what are the elements involved in the care pathways of patients. For example, we would like to know if the presence of certain markers such as "caregiver burnout" or "pain" have an impact on patients' health care pathways. In an attempt to answer these questions, we have decided to create equivalent classes. Figure 1 shows the equivalent classes of high-level. Other equivalent classes at lower levels are present in the various modules such as: (1) Coordination Action in the coordination module, which groups together all the actions of guidance, communication, search for resources carried out by the coordinators. (2) In the social module we created the equivalent classes Social Problems which gathers all the requests and actions made in the social domain. (3) In the medical module we created the equivalent classes Cognitive State which gathers all the concepts referring to clinical signs, symptoms and diagnosis related to a cognitive alteration of the patient. A total of 33 equivalent classes were created in the different ontology modules.

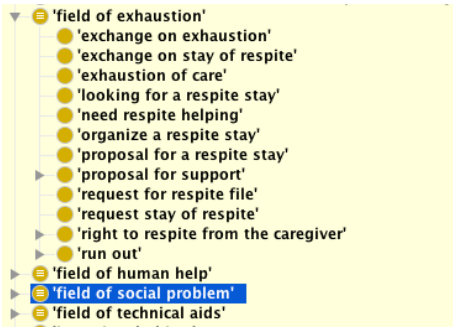

Figure 1. View of the kernel ontology containing the defined high-level concepts.

3. Results

A semantic annotator was developed in the laboratory on a GATE (https://gate.ac.uk) platform that uses the ontology as a semantic repository [4] .We carried out the semantic annotation on 611 patient files, that is 28 052 primary and secondary events. These patients were included in the netwoork between 2013 and 2017, and had already died when the documents were annoted in 2018. The choice to take only deceased patients allowed us to have all the events generated in their health care record. The number of events for these patients ranged from 1 to 188 with a median of 23 and an average of 31.6 events per patient. We wanted to divide patients by "homogeneous group" according to the number of events. Using a logarithmic distribution we obtain three groups with 171, 216, and 224 patients and, respectively, 1 to 13, 14 to 32, and 33 to 188 Events. We used the JMP software to perform the different statistical data treatments. It

is observed that between these three groups the equivalent class field of exhaustion is very present for group 3 and not very present in group 1, the question that we ask is why?

In order to illustrate the contribution and the interest of the defined concepts in our project, we will take the example of the field of exhaustion, it includes all concepts related to the exhaustion of the family caregiver. We will present one example of existing correlations between this concept and the other variables of interest, and we will explain their contributions in the clinical vision of care pathway.

In view of the literature and some studies [5], we hypothesized that family caregiver burnout might be correlated with the presence of clinical signs indicating an impaired cognitive status of the patient. The presence of cognitive disorders is referenced in the literature on ALS, such as the presence of behavioral disorder, or the presence of a frontotemporal dementia. To test this hypothesis, we carried out a statistical test to evaluate the degree of correlation between these two variables, which are the concepts of *Field of Exhaustion* and *CognitiveState*. The value of correlation coefficient is 0,23 with p-value is $p < 0.0001$. We can validate the hypothesis that there is a correlation between the presence of cognitive disorders in the patient and the appearance of exhaustion phenomenon in the caregiver. These results are in line with studies on the exhaustion of caregivers in Alzheimer's disease.

4. Conclusion

In this article, we wanted to present our approach using the ontology modularization, reasoning and possible inferring abilities in the ontology, to create equivalent classes which be on the semantic aspect, have a real dimension and clinical expression. This structuring of knowledge, allows us to use the tools we have developed to annotate corpora and extract knowledge. The identification and the presence of these markers present in the courses of care (exhaustion of the caregiver, presence of social problems, ...) in certain patients can allow us to search for the triggers, is it the difficulty of access to social assistance, lack of local professionals? The correlation between the presence of sign of a cognitive alteration and the exhaustion of the caregiver is one of the tracks. Some improvements are still to be made in two directions: improving performance of semantic annotator and, deepen correlation searches between events.

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Evaluation of Perceived Usability and Utilization of a Virtual Care Program Among Adolescents and Geriatrics

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Abstract. The advancement of telemedicine has allowed to reach users of various demographics. In this paper we compare two cohorts, adolescents and geriatrics at a virtual care clinic. We calculated frequent chief complaints, modality of communication, and the distribution of gender. Our findings show that elderly female population prefers telemedicine more than men, and adolescents are more likely to use video calls than the geriatric population.

Keywords. Telemedicine, Adolescents. Geriatrics.

1. Introduction

Telecommunication technology has immense potential to revolutionize the way healthcare is delivered. Literally meaning "healing at a distance" [11], telemedicine is an umbrella term used to define the utilization of technology to increase access to care, thereby improving patient outcomes [9]. In recent years, due to the introduction of the internet, there has been tremendous advancement in the scope and utility of telemedicine. Videoconferencing has allowed synchronous exchange of information which is facilitating innovative healthcare delivery. In an urban setting, a telemedicine reading center remotely evaluated retinal images to screen diabetic patients for diabetic retinopathy (DR) [7]. This led to DR being identified early in 94.1% of all participants, thereby affirming the potential of such programs to mitigate negative outcomes by instituting interventions early. At another pilot telemedicine program in a clinic in Rochester, NY, 86% of participants cited a reduction in loss of work time and a trip to the emergency department due to the telemedicine consult [5].

While telemedicine can be effectively applied to a variety of medical matters, the rapidly aging population in the United States, dubbed baby boomers, can benefit greatly from this care modality. As they age and become more frail, driving skills and transportation barriers may prevent visits to the doctor's office. Hence, telemedicine can

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play a huge role in geriatric care. In a younger study cohort, children with acute illnesses were 22% less likely to visit the Emergency Department when prior care was availed through telemedicine at daycare centers and schools [2]. Slusser et al. assessed a pediatric obesity telemedicine clinic in a metropolitan area where 93% of respondents were satisfied with the video appointment [10]. In terms of clinical outcomes, both blood pressure and body mass index Z-score either stabilized or decreased at follow-up.

Our study was designed to evaluate the perceived usability of an on-demand urgent care service via telemedicine services between geriatric and adolescent populations by comparing common chief complaints, modality of consultation, and gender distribution.

2. Methods

This study was based at a virtual care program that utilizes a web portal to conduct patient consultations. The virtual care visits were available 24 hours a day, 7 days a week, and was staffed by physicians from various primary care disciplines. Patients were able to log into the portal from a desktop or a mobile device and choose a provider based on their needs and select either video or audio consultations. Participants of the study were divided into two cohorts: the adolescent group aged ≤18 years, and the geriatric group aged ≥55 years. The two cohorts were evaluated based on variability in gender, preferred consultation methods, chief complaints, and their areas of residence. Data was collected through the web-portal and imported into a secure, HIPAA compliant business intelligence server. The server provides a flexible architecture that enabled the research team to run complex queries, generate reports, and run analyses. Data was cleaned using *Microsoft Excel,* and duplicated results were eliminated. Similar chief complaints were grouped together to avoid redundancies. Attributes to be analyzed were tabulated using STATA. These included the sample size in each group, common chief complaints, mode of encounter, gender distribution, and the area of residence.

3. Results

A total of 1675 encounters were recorded since this portal went live in October 2018, of which geriatrics and adolescents combined accounted for 20.76% (180 encounters for geriatric patients, and 168 encounters for adolescent patients).

Table 1 shows that there was an equal distribution among genders in the adolescent cohort. However, the geriatric group was composed of 76.1% women. Elderly women were also more likely to use telemedicine, and 63.5% of the total encounters among adolescents and geriatrics involved female patients. More than 90% of geriatric (177 out of 180) and adolescent patients (159 out of 168) were from North Carolina.

Table 1. This table shows distribution of gender amongst adolescent and geriatrics

Gender	Female	Male	Total
Adolescent	84(50%)	84(50%)	168 (100%)
Geriatrics	137 (76.1%)	43 (23.9%)	180 (100%)
Total	221(63.5%)	127 (36.5%)	348(100%)

The chief complaints of both cohorts were recorded. Table 2 shows that UTI (urinary tract infection), sinus, and sore throat were the most common reasons for the visits and make up for 27.22% of the total encounters in the geriatric cohort. Sore throat, cough,

and rash accounted for 30.04% of calls among adolescent patients. Between the two groups, infections such as sore throat, and cough were the common complaints.

Table 2. Top 5 Chief Complaints among geriatrics and adolescent patients

Adolescent	Freq.	Geriatric	Freq.
Sore throat	21	UTI	18
Cough	15	Sinus	17
Rash	15	Sore Throat	14
Ear Pain	13	Cough	8
Fever	11	Cold	7

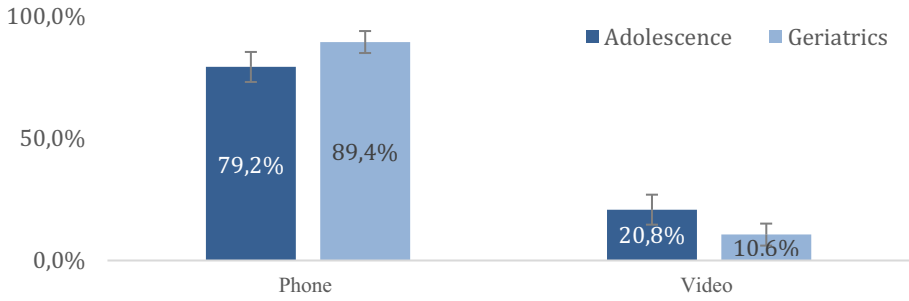

Figure 1. This figure shows the preference of modality amongst adolescent and geriatrics users, with error bars showing 95% confidence interval.

Users in this web-based portal were given the option to choose between a video or audio call for consultation. Figure 1 shows that while audio calls were unanimously preferred by both cohorts. Geriatrics Patients (SD) 89.4% (±4.50%) were more likely to choose an audio call as compared to 79.2% (± 6.14%) of adolescents (SD). On the other hand, 20.8% (± 6.14%) of adolescent users (SD) were twice as likely to choose video call than 10.6% (±4.50%) of geriatric population (SD).

4. Discussion

While both patient populations opted for phone consultations by a wide margin, our first finding indicates that adolescents were twice more likely to use video calls than geriatric patients. This finding correlates with previous findings that shows only 29% of young adults prefers video consultations over 63% phone consultation [3]. This could be attributed to several factors, such as, common clinical complaints among adolescents such as rashes, ear pain, were due to vision issues necessitating video conference for assessment. Due to a shortage of specialists in rural areas, telemedicine serves as an important healthcare provision for children and adolescents living in remote localities, and young adults prefers video consultations over phone consultations [8]. In addition, the geriatric population may not be as adept at and comfortable with using video technology [6].

Our next observation shows female geriatric patients were three times more likely to use telemedicine than male geriatrics. Previous study confirms older women are twice more likely to live alone than older men, thereby considering in-person health services a burden to attend [4] As a result, female geriatric patients are more prone to using virtual

urgent care as an alternative. In addition, female patients living alone in small rural communities tend to save $150 with telemedicine by avoiding travel, missed days at work, and other expenses [1].

One limitations of this study includes data from a single state only. Geriatric population was considered as over 55 years of age to have similar number of distribution of observations across two cohorts. In addition, subsequent studies could identify social determinant factors affecting the use of virtual clinics and the ways in which they can be utilized in future designs.

This study investigated the perceived usability of telemedicine amongst adolescent and geriatric populations. Video calls is a more popular option amongst adolescent than geriatrics, and elderly female population utilizes telemedicine more than the male population. Future work may investigate telemedicine disparities among different generations and way to improve telemedicine acceptability and usability.

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Decision Support Systems for Tuberculosis: Protocol for a Scoping Review

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Abstract. Tuberculosis (TB) represents a global challenge in terms of prevention, care and control. Decision support systems (DSS) can supply the necessary knowledge basis to underpin investigators, policy makers and health personnel actions and to provide crucial elements that can help reducing TB burden. Thus, the objectives of this work are to present the protocol to be followed for carrying out a scoping review to identify topics where DSSs are used, to define appropriate categories and to clarify main outcomes and research gaps. As part of the protocol, five electronic bibliographic databases will be searched for articles from 2006 to 2019 and two investigators will independently screen each work using the study inclusion criteria. Data extraction will be performed, and findings will be reported. The results will be used to provide a broad understanding of how DSSs for TB are being used.

Keywords. Decision support systems, tuberculosis, protocol, scoping review

1. Introduction

Tuberculosis (TB) is a bacterial infectious disease that remains as a major public health problem in the world. Despite the success of some strategies to reduce the global burden, TB remains as a leading cause of mortality worldwide. It is estimated that in 2017 approximately 10.5 million people got infected with drug-sensitive TB, rifampicin-resistant (RR-TB) or multidrug-resistant (MDR-TB) [1]. The World Health Organization (WHO) End TB Strategy, a global strategy for tuberculosis prevention, care and control, aims to halt the TB epidemic by 2035 [2]. Technological innovation will strongly underpin the reduction of the global TB burden. Delays in diagnosis and the lack of clinical support tools not only result in poor treatment outcomes, but also in longer infectious periods resulting in sustained transmission at the community level [3].

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Also, policy makers and managers depend on crucial information to make difficult decisions about which available tool to implement and how to apply it considering the existing health care infrastructure and regional particularities [4]. Aiming to support decision making in both clinical and managerial scopes, Decision Support Systems (DSS) plays a relevant role. DSS is a general term for any information system that enhances a person or group's ability to identify problems and to make decisions that could help to solve such problems [5]. It usually allows knowledge extraction from several sources of information and guide clinical and administrative decision-making, directly affecting the management and quality of health services.

The main goal of this work is to present the steps to be followed for carrying out a scoping review, i.e., a protocol, that will formally verify, for the first time, the available literature that present the development and/or implementation of decision support systems for Tuberculosis. The methodology presented is this paper is based on studies from the literature, which provide guidelines for conducting reviews that can be applied to several research domains sin a nonspecific way.

2. Methods/Design

The protocol presented in this paper was established according to the methodology developed by Arksey and O'Malley [6] and other guidelines provided by the Joanna Briggs Institute [7], which recommend a five-stage framework for scoping review. The Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) [8] flow diagram will also be used to a better comprehension of study selection.

2.1. Stage 1: Identifying the research questions

The following research questions were drafted for the scoping review:

- What does DSSs for TB usually address?
- How to categorize DSSs for TB?
- What are the main outcomes and research gaps regarding DSS for TB?

2.2. Stage 2: Identifying relevant studies

2.2.1. Eligibility criteria

The scope review will include research (full papers, conference papers) and non-research studies (editorials, narrative reviews) that present a prototype or a fully functional computerized tool, regardless a graphical user interface, that could be applied to any subject related to TB. Thus, studies with only theoretical approaches without a practical implementation, such as models' definitions (operational, predictive) or ontologies, will be excluded. Also, selected works must address pulmonary tuberculosis (PTB) in humans.

2.2.2. Search strategy

The following databases will be searched: PubMed/MEDLINE, ACM Digital Library, IEEE Xplore Digital Library, Elsevier Scopus and Cochrane Database of Systematic

Reviews. Bibliographies of the retrieved articles will be searched for additional relevant works and experts in the field will be contacted to identify others. The search strategy will use combinations of the following terms: decision support, decision making, system, tuberculosis, drug-resistant, latent and diagnosis. The searches will include international articles, but only works in English language will be considered. The time frame will range from March 2006 (start of the WHO End TB Strategy [2]) to February 2019.

Detailed search strategies from each database will be available from the authors on completion of the scoping review. Bibliographic details will be downloaded into Mendeley software (https://www.mendeley.com/).

2.3. Stage 3: Study Selection

After performing searches using the terms in the mentioned databases, two investigators will independently screen each retrieved article based on title and abstract for eligibility according to the inclusion criteria. Then the full text will be retrieved, and the investigators will independently perform another round of review to determine if these full texts meet the eligibility criteria. Disagreement between the two reviewers will be resolved in consultation with the principal investigator.

Search results and eligibility screening process will be reported using the PRISMA diagram to detail the results of the search, study selection, addition of studies, and a final summary of included articles [8].

2.4. Stage 4: Charting the data

An extraction strategy was defined to capture relevant data from the selected studies to be further discussed in the scope review, such as: study descriptive information, main target audience, type of technology used to deliver decision support features and main outcomes and limitations. Data extracted must be enough to answer the research questions established in Stage 1. Table 1 summarizes the data that will be extracted from each included article.

Table 1. Data extraction strategy.

Scope	Data to be extracted
Summary	Author(s), title, citation, publication type, country of origin, aims/objectives, if it is a fully functional tool and if it contains a graphical user interface.
Question 1: addressing topic	DSS main applicability (clinical, epidemiological/managerial)
Question 2: DSS categorization	Type of technology used
Question 3: outcomes and gaps	Outcomes of interest, limitations

2.5. Stage 5: Collating, summarizing and reporting the results

Since scoping studies seeks to present an overview of all material reviewed [6], data will be organized thematically according to the identified topics and DSS categories, summarized and presented in a table ordered alphabetically. This table will contain narrative content with data obtained in Stage 4, that is, the metadata of all selected studies and written commentaries based on the following headings: objectives, type of

applicability, type of technology, research methods, stage of development, public availability, existence of a graphical interface, outcomes and limitations.

3. Final Considerations

The protocol proposed in this work may result in the first scoping review conducted to provide an overview of Decision Support Systems for Tuberculosis. The results will be used to provide a broad understanding of usability to a better dissemination. Furthermore, by applying a consistent approach to report findings, a valuable identification and comparison of relevant aspects of DSSs will be achieved, including topics of applicability, implemented technologies and the public availability.

Thus, once the scoping review is completed, it will be possible to determine the topics that the DSSs addresses in the line of TB care, to define categories, to point out main outcomes and possible research gaps and to identify where there is a lack of tools to underpin decision making processes of relevant stakeholders. Results will be published to make it available to all interested audience. In addition, consultation with health service providers, policymakers, health professionals and other stakeholders will be carried out to effectively disseminate the findings and to provide expert knowledge.

As possible limitations, relevant non-English language publications can be excluded. Also, due to the research design, the quality of articles will not be assessed.

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PhD Students and the Most Frequent Mistakes During Data Interpretation by Statistical Analysis Software

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Abstract. Correct choice and administration of a statistical test are absolutely essential for meaningful interpretation of research data, yet mistakes are still frequent and could be easily found in published scientific papers or PhD theses. The aim of this study was to analyze mistakes made by PhD students in statistical analysis of data collected during research within the framework of their thesis. PhD students frequently use Excel and SPSS for data processing, while SAS, Stata and R are also available. The study was designed as cross-sectional analysis of random sample (n=15) of PhD theses in pre-approval stage at Faculty of Medical Sciences, University of Kragujevac, Serbia. In total 14 (93%) theses had at least one mistake. The most frequent mistakes were as the following: insufficient statistical power due to small sample size, inappropriate presentation of results at tables and graphs, andinappropriate choice of statistical tests. In order to improve the situation, training courses in statistics during PhD studies should be re-evaluated and improved in regard to relevance, delivery methods and motivating potential, and mentors should invest more effort to review the data and guide students through statistical analysis.

Keywords. Data Interpretation, Statistical, Data Accuracy, Scientific Experimental Error.

1. Introduction

Correct choice and administration of a statistical test are absolutely essential for meaningful interpretation of research data, yet mistakes are still frequent and could be easily found in published scientific papers or PhD these [1]. There is an increasing trend of incidence of statistical mistakes, which was recently described in several studies analyzing methodology of previously published research results [2]. Regardless of the motives, statistical mistakes lead to invalid conclusions, which, if taken for granted, may lead to waste of resources, human work and time. PhD students are

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among those who make mistakes, and theyusually need additional guidance by their mentors in order to avoid misuse of statistical methods and thereafter misinterpretation of the data collected [3]. Recent survey of training practices of PhD students in biostatistics among USA-based physiology PhD programs showed that not all of them included statistical course (just 67.5%), and significant proportion of the courses was offered as an elective [4]. When the courses were offered, their contents were rarely tailored to needs of the students, but according to the principle „one size fits all". Such practice was reflected in frequent statistical mistakes found in papers published in physiology journals, like using incorrect tests, asuming normal distribution of data without testing it, treating nonindependent data as independent, etc. Knowing what statistical mistakes are the most frequent and what confuses the students is helpful when planning and designing new biostatistical courses. The most frequently used statistical softwares for data processing in medicine are Excel, SPSS, SAS, Stata and R (Table 1). Excel has basic methodological capabilities (it should be used for descriptive statistics at most), SPSS moderate, and SAS, Stata and R advanced. Only R software is freeware, and it could be installed on any computer system; however, it requires considerable learning effort, as it is script-based software, and one first has to learn the R language itself, and then how to use it for a statistical problem. While SAS, Stata and R are script-based softwares, which makes them not that easy to use, the SPSS has graphical interface which is very user-friendly; however, this could be a problem, since activation of elaborate statistical tests is possible regardless of their appropriateness for particular dataset, and inexperienced investigators may get results which then will be wrongly interpreted [5]. The aim of this study was to reveal and analyze the most frequent statistical mistakes made by biomedical PhD students in their theses.

Table 1. Comparison of statistical softwares [6]

Software	Advantages	Disadvantages
Excel	Free Simple to use	Limited number of tests available
SPSS	Graphical interface Easy to learn, intuitive Large number of available statistical tests	Expensive Limited options for transformation of data
SAS	Can process extremely large datasets Can perform advanced analyses	Script based, so it demands considerable learning Expensive
R	Free Can perform advanced analyses	Script based, so it demands considerable learning
STATA	Has both graphical and script interface Can perform advanced analyses	Expensive More difficult to learn than SPSS

2. Material and Methods

This cross-sectional study was made on a random sample (n=15) of PhD theses submitted for approval by University of Kragujevac, Faculty of Medical Sciences, Kragujevac, Serbia. The theses were publicly available at the University web site. The available theses were numbered, and than 15 random numbers were generated using the function in Excel 2007. Theses from the sample were read and statistics described in Methods section and used in Results section analyzed against principles of good analytical practice published in medical journals by statisticians [7,8]. Detailed results

of the analysis are shown in the supplementary table, and summary data in the table within the text of the article, as counts and percentages.

3. Results

There were 8 theses with results from clinical trials, 6 theses with results from experimental studies on animals and one thesis with epidemiological data. All theses from the sample were submitted within the time period from January 2013 to November 2018. The results of the analysis are shown in the Table 2.

Table 2. Classification of statistical mistakes in the analyzed PhD theses.

Category of a mistake	Mistake	Number of theses with the mistake	Percent of the total number of theses
Inadequate choice of a statistical test	Mann-Whitney test used for comparison of dependent data	1	7%
	Wilcoxon test used for comparison of independent data	1	7%
	Chi-square test used when count in a cell was zero or less than 5 in at lest two cells	4	27%
	Linear regression of mean values instead of individual data	2	13%
A test used without demonstration that assumptions are met	MANCOVA used without proofs of normality of data distribution and homogeneity of variances	2	13%
Inadequate presentation of results in figures or tables	Number of subjects not shown	4	27%
	Data variability not shown	3	20%
	Data variability shown as standard error instead of standard deviation	5	33%
	Shown only p-value without a test results	1	7%
	Wrong axis title in a ROC graph	1	7%
	Unclear tables or graphs	2	13%
Achieved statistical power	Less than 80%	8	53%
	Not enough data presented to be calculated	2	13%
Non-transparent presentation of data	Details about quality of regression model lacking	3	20%
	Statistical test used not specified	1	7%
Incomplete analysis	Validation of a questionnaire lacking temporal stability, divergent validation and mulimethod matrix	1	7%
	Reliability testing of a questionnaire lacking split-half	1	7%

4. How to avoid mistakes

Our study showed that majority of the analyzed PhD theses had at least one mistake in statistics, inadequate choice of a statistical test, insufficient power of the study and inadequate presentation of results in figures or tables being the most frequent.Types and frequency of errors in statistics found in our study correspond in general to errors reported by other authors who analyzed published articles in biomedical journals or

theses [1,4]. Such results reflect insufficient competence of biomedical PhD students concerning statistical skills, which could be consequence of at least two types of problems in practice: low quality of teaching statistics practices at PhD programs and negative attitude of PhD students towards statistics. Statistics is taught to biomedical students mostly in a traditional way, and modern teaching techniques that stimulate acquiring skills, like problem based learning, are rarely employed even in the most developed settings [9]. Majority of students do not recognise the value of contents that are taught during courses of statistics, and later on, when practical problems are raised by a research data, they lack skills to solve them [10]. Although necessity to place greater emphasis on applying statistics and interpreting data during biostatistical courses was recognized long ago, it is still rarely done, leaving statistics at a margin of medical education on both undergraduate and postgraduate level at numerous university setting [11]. On the other hand, biomedical students frequently feel unable to master statistical techniques and underestimate their cognitive competence when faced with learning statistics; with such attitude their learning outcomes become lower than they might be even with the same educational efforts [12]. Kiekkas et al. showed in their study that positive attitudes towards statistics among nursing students were linked with higher marks and improved ability to solve statistical problems later in research practice [13]. Key factor for achieving good mastery of statistical skills for PhD students is attending a course in biostatistics which offers both relevant, practically applicable knowledge delivered in a user-friendly way and strongly motivating approach to individual students which would reverse negative attitude towards statistic [14]. Main limitations of our study are small sample size and unicenterdness, which may introduce bias of local practices; therefore its results should be taken as preliminary. However, we could conclude that mistakes with statistical analysis made by PhD student are frequent, and may lead to misinterpretation of the data. In order to improve the situation, training courses in statistics during PhD studies should be re-evaluated and improved in regard to relevance, especialy at universities which insisted on use of Bologna model of education, delivery methods and motivating potential, and mentors should invest more effort to review the data and guide students through statistical analysis [14-18]. However, the most certain way to avoid errors is appropriate use of available statistical softwares, in line with their instructions, usually given in the help files.

5. Conclusion

PhD students are at the beginning of their research carriers, and it is of outmost importance for them to master adequately statistical skills. Right interpretation of research results depends on adequate statisticall processing. Although statistical softwares enable swift and relatively easy administration of statistical tests, they are also prone to misuse, as an automatic checking whether assumptions of statistical tests were met before activation of certain test is not available. Much should be invested and improved in statistical education during PhD studies if statistical errors and misinterpretations are to be avoided.

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Strong Recommendations Are Inappropriate in Person-Centred Care: The Case of Anti-Platelet Therapy

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Abstract. A 'Rapid Recommendation' has been produced by the GRADE group, in collaboration with MAGIC and BMJ, in response to an RCT showing Dual Anti-Platelet Therapy (DAPT) is superior to Aspirin alone for patients who had suffered acute high risk transient ischaemic attack or minor ischaemic stroke. The interactive MAGIC decision aid that accompanies each Rapid Recommendation is the main route to their clinical implementation. It can facilitate preference-sensitive person-centred care, but only if a Multi-Criteria Decision Analysis-based decision support tool is added. A demonstration version of such an add-on to the MAGIC aid, divested of recommendations, is available online. Exploring the results of different preference inputs into the tool raises questions about the strong recommendation for DAPT.

Keywords. anti-platelet therapy, transient ischaemic attack, MAGIC, GRADE, person-centred decision support, preferences, Multi-Criteria Decision Analysis

1. Introduction

A 'Rapid Recommendation' has been produced by the GRADE group, in collaboration with MAGIC and BMJ [1], in response to an RCT showing Dual Anti-Platelet Therapy (Clopidogrel and Aspirin) (DAPT) was superior to Aspirin monotherapy for patients who have suffered acute high risk transient ischaemic attack or minor ischaemic stroke [2].

In the systematic review and meta-analysis undertaken as part of the Rapid Recommendation production process [3], it was confirmed that DAPT was not a dominant option, i.e. it was not best or equal best on all criteria. The Rapid Recommendation was nevertheless a 'strong' one in favour of DAPT, to be started within 24 hours in patients who have had a high risk transient ischaemic attack or minor stroke and to be continued for 10-21 days, at which point patients should continue with aspirin alone. In GRADE 'Strong recommendations mean that most informed patients would choose the recommended management and that clinicians can structure their interactions with patients accordingly.' (p1051, italics supplied) [4].

When there is no dominant option any recommendation is necessarily preference-sensitive, reflecting the relative importance weights assigned to the various criteria. The preferences elicited in the GRADE study were those of the guidelines panel:

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> *... the patient-important outcomes were defined by an international guideline panel [of 19 persons, which] judged death, non-fatal stroke, major extracranial bleeding, functional ability, and quality of life as critical outcomes. Myocardial infarction, recurrent transient ischaemic attack, and minor extracranial bleeding were judged less important* (p.3) [1].

In person-centred care that meets the requirements for informed consent the relevant preferences are those of the individual patient elicited at the point of care. These may be out of line with the average ones reflected in the recommendation of a guideline panel.

2. Method

We introduce an add-on to the interactive online MAGIC decision aid, presented as the main route to clinical implementation of the rapid recommendation. The add-on enables the criteria importance weights to be varied, to produce a personalised opinion available at the point of decision. It transforms the aid from being simply a set of excellent - but cognitively challenging - infographics, for example Figure 1, into a personalised preference-sensitive decision support tool.

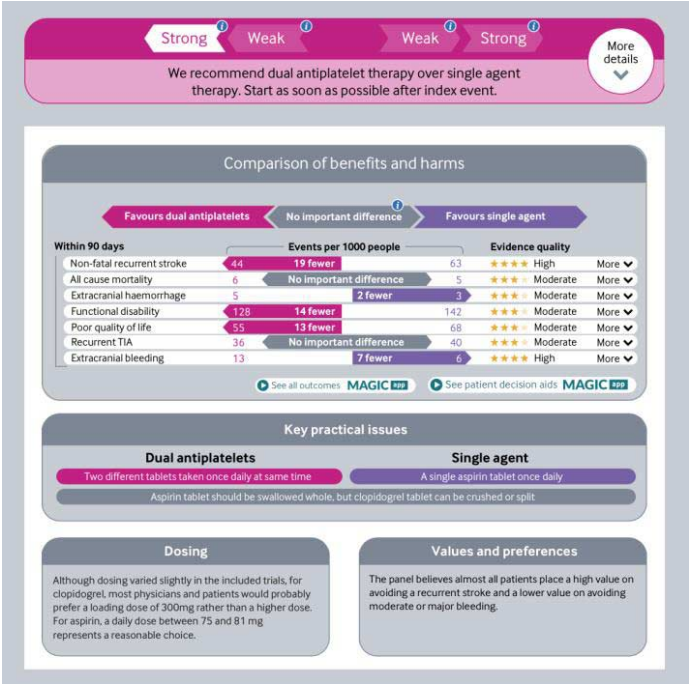

Figure 1. Infographic in MAGIC aid [https://www.bmj.com/content/363/bmj.k5130]

The basic inputs into the decision support tool are the seven featured criteria in the MAGIC decision aid, along with the evidence on how DAPT and ASPIRIN perform on them, as their Ratings. A treatment burden criterion is added, for which the individual is asked to supply their personal difficulty ratings, based on the 'Practical Considerations'

section of the aid. Most significantly, they provide their percentage importance Weightings for the eight criteria. The Weightings and Ratings are integrated in expected value calculations to generate a preference-sensitive opinion - pair of Option Scores - for the person to discuss (Figure 2). Having seen these scores they then have the opportunity to revise their Weightings in the light of the displayed Ratings. The tool is built in the Annalisa implementation of Multi-Criteria Decision Analysis (MCDA) [5].

GRADE use four verbal levels to classify the quality ('certainty') of the evidence. In our conception of a decision support tool, adjusting for this is not a task to be left outside the tool for 'consideration'. MCDA requires quantitative inputs, so the levels are here mapped as Very low = 0.1; Low = 0.4; Moderate = 0.7; High = 1.0. Certainty-adjusted scores are thereby also calculated and displayed as a second pair in the interface.

3. Result

To engage with the tool, on a demonstration-only basis, go to https://ale.rsyd.dk and enter 1499 as survey ID. A sample output screen appears in Figure 2.

Figure 2. Screen capture from decision support tool

The criterion importance weightings in the figure are in line with those of the guideline panel but they actually produce an opinion favouring aspirin monotherapy, albeit at the third decimal place. But such near-equipoise is produced by many sets of weightings and it remains after certainty adjustment. (These results are best confirmed by engaging with aid.) The *strong* recommendation for DAPT is therefore very surprising, since for GRADE this makes option discussion with the patient unnecessary.

4. Discussion

In addition to wider concerns regarding GRADE [6],

> *It is difficult to personalise recommendations from guidelines ... Usable decision aids should now be seen as one of the most important end products for evidence based medicine.* (pp1-2) [7].

However, the well-established difficulties arising in attempts to introduce decision aids into clinical practice need to be recognised [8].

5. Conclusion

In keeping with that of GRADE, MAGIC, and the BMJ, the aim is to provide support for more transparent and accountable clinical decisions, made within typical time and practice constraints and cognitive limitations of all parties. Person-centred care involves serious elicitation of individual's preferences at the point of care - as provided for in this add-on aid. The resulting opinion may legitimately deviate from expert-based guidelines.

Acknowledgment

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Conflict of Interest

Jack Dowie has a financial interest in commercial use of Annalisa.

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Why a Global PROMIS® Can't Be Kept

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Abstract. Composite multi-dimensional constructs, such as 'global mental health' and 'global physical health', in PROMIS® instruments and ICHOM standard outcome sets, are formative, not reflective. Their preference-insensitivity means they are potentially misleading in both clinical and policy decision making practice. Their frequent validation by reflective psychometric tests is also improper methodologically. The spread of these instruments is occurring without sufficient awareness on the part of patients, clinicians, researchers and policy makers that the need for group-specific preference bases ('tariffs') for such measures rules out any possibility of 'international gold standard metrics'.

Keywords. Patient Reported Outcome Measures; preference-sensitive, formative, reflective, PROMIS

1. Introduction

"PROMIS® is increasingly recognized as the international gold standard for patient-centered assessment…" suggest Evans and colleagues (p345) [1]. PROMIS® is a large and expanding bank of patient-related outcome items and instruments, operating under the aegis of the PROMIS Health Organisation (PHO), with an associated user community. PROMIS® is the registered trademark of the U.S. Department of Health and Human Services. (http://www.promishealth.com).

"The Patient-Reported Outcomes Measurement Information System (PROMIS®) is a National Institutes of Health initiative to develop state-of-the-science self-report measures to assess functioning and well-being in physical, mental, and social domains of health. PROMIS measures are potentially useful to screen for disability, identify health care disparities, enhance communication between patients and clinicians, and improve population health… PROMIS includes item banks that can be administered using computer-adaptive testing, short forms for individual domains, and profiles that yield information about multiple domains for use in clinical trials, observational studies, and clinical practice. The PROMIS-29 v2.0 profile measure assesses pain intensity using a single 0–10 numeric rating item and seven health domains (physical function, fatigue, pain interference, depressive symptoms, anxiety, ability to participate in social roles and activities, and sleep disturbance) using four items for each domain. [It] is analogous to the most widely used profile measure to date, the SF-36. But the PROMIS-29 v2.0 profile items were selected from PROMIS item banks calibrated using item response theory (IRT) analyses and all items in a domain are scored on the same underlying metric… While profile measures yield a wealth of information,

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higher-order summary measures [such as PROMIS GH 29 and PROMIS GH 10] are also useful." (p1885-6) [2].

The goals of PHO are to 'provide reliable, valid, and cost-effective measurement of relevant health outcomes to the greater scientific and clinical research community and to other health care organisations', and to increase their 'clinical adoption by organizing and presenting PRO data that are relevant and useful to clinicians, patients, and researchers'. Its aspirations include 'developing PROMIS into a gold-standard outcome metric' and making it 'part of routine clinical practice across multiple specialties'.

The subsequent adoption of PROMIS® global measures by the International Consortium for Health Outcomes Measurement (http://www.ichom.org), can be seen as a response to calls by ICHOM founder Michael Porter [3], to end the definition of quality in healthcare as compliance with evidence-based practice guidelines; re-defining it as improvement in patient-relevant outcomes and thereby ending the 'outcome-measurement paralysis' that has been the provider-based obstacle to 'value-based care':

"... to unlock the potential of value-based health care for driving improvement, outcomes measurement must accelerate. That means committing to measuring a minimum sufficient set of outcomes for every major medical condition - with well-defined methods for their collection and risk adjustment - and then standardizing those sets nationally and globally." (p504-5) [3].

The aim of this paper is to alert those contemplating such development and/or use of a universal PROM (e.g. the adoption of a PROMIS® global measure) to its incompatibility with the acceptance of international (and intra-national) difference in preferences.

2. Method

Unfortunately the development of PROMs, has been, and still is, occurring without acknowledging that many of the latent (unobservable) constructs such as 'global mental health' and 'global physical health' in PROMIS® (and adopted in several ICHOM standard outcome sets) are *formative* not *reflective*. Apart from their validation as if they are reflective being improper methodologically, their preference-insensitivity potentially undermines decision making aimed at optimal person-centred care [4].

An inflamed appendix, e.g. appendicitis, is a reflective construct. It is 'reflected' in its various signs and symptoms - indicators, criteria, cues - such as rebound tenderness. Crucially the inflamed appendix can be operated on directly and this will, if successful, cause the signs and symptoms to disappear, along with construct (in this patient).

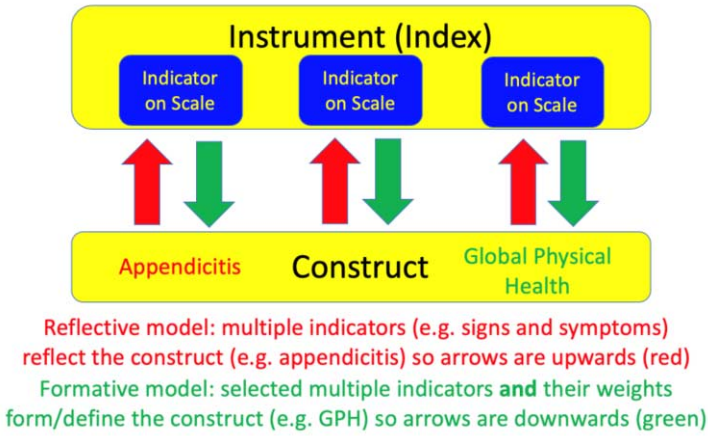

Figure 1. Comparison of formative and reflective constructs

'Global physical health', like most index measures in healthcare, including all multi-criterial PROMs, is a formative construct. It is 'formed' by the set of indicators selected to define it, such as 'everyday physical activity ability', 'pain' and 'fatigue' in the case of PROMIS GH 10. These three indicators need not be highly, or at all, inter-correlated, 'internal consistency' being a necessary condition only for a reflective construct. Moreover, removing/replacing one of them will change the construct, whereas removing/replacing any indicator of a reflective construct does not change it, any indicator being a reflection of the construct, not part of its definition. Crucially 'global physical health' cannot be affected directly, only by changing its indicators. (An online interactive version of PROMIS GH 10 is available at http://orthotoolkit.com/promis-10.)

So PROMIS GH 10 and 29 define and measure the multi-dimensional formative constructs of 'global physical health' that Promis GH 10 and 29 measure. Neither measures a thing called global physical health, which does not exist until it is constructed. They are measures of two different constructs, not two different measures of the same construct. If many agree to use them, given the embedded preferences, the source of any validity is dependent on that intersubjective agreement.

Generic instruments developed by economists for use in economic evaluation are the most prominent examples of acceptance that multi-dimensional indexes, such as Health-Related Quality of Life (HRQOL), are formative constructs. This is acknowledged in accepting that any HRQOL measure is preference-sensitive, so that a population-based 'tariff' is needed for policy use. Crucially *Danish HRQOLas measured by EQ-5D-5L using the Danish tariff* is a different construct from *French HRQOLas measured by EQ-5D-L using the French tariff*. They are *not* two measures of the same construct, i.e. HRQOL as defined by EQ-5D-5L. While one can compare the two measures, applying the very different French tariff in Denmark - or vice versa – doing so would only confirm the irrelevance of the comparison for any decision in either.

3. Result

One example is sufficient to confirm the issue with preference-insensitive 'global' PROMs. Using PROMIS GH 10 in their study of stroke patients, Katzan et al. noted that 'measures that make up the physical component score are less highly correlated with each other than the measures that make up the mental component score' [5] (p150). While 'the results of our study support the recommendation from ICHOM to use PROMIS GH as part of the standard set of outcome measures in stroke… [because] of the moderate internal reliability and poor model fit of summarizing items into physical and mental health component scores, greater focus should be placed on individual PROMIS GH items than on the component scores in patients with stroke.' [5] (p153). Given that formative indexes are weighted scales, their main problem lies in the lack of a credible, or any, preference basis, not such statistical considerations.

The case-mix origins of the 'internationalisation' problem is well-recognised, but not the preference-mix one. 'The mean and standard deviation of all PROMIS scales are anchored on the US population… An open question for the future therefore remains: should we anchor scales based on the US general population, the respective country's population, or even on a global level?' [6] (p1010). Given these three options, only the country-specific one respects international heterogeneity in preferences.

4. Conclusion

PROMIS® and ICHOM fail to recognise that a 'gold standard' measure of any preference-sensitive formative construct is impossible. As with established generic measures of health-related quality of life, PROM researchers need to develop country-specific tariffs to ensure their measures reflect international differences in preferences.

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PROMs Need PRIMs: Standardised Outcome Measures Lack the Preference-Sensitivity Needed in Person-Centred Care

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Abstract. A growing number of condition-specific standard outcome sets have been developed by the International Consortium for Health Outcomes Measurement in pursuit of 'value-based care'. These sets embrace many Patient-Reported Outcome Measures (PROMs), reflecting a simultaneous commitment to 'patient-centred care'. However, none of these sets embody recognition of the preference-sensitive nature of the decisions that eventually generate the outcome database. 'Patient-Reported Importance Measures' (PRIMs) are the valid source of the required preferences. The ICHOM Stroke standard set is input into a hypothetical Multi-Criteria Decision Analysis-based decision support tool to provide simple confirmation that PROMs should be preference-mix adjusted as well as case-mix adjusted. PROMs need PRIMs if value-based care is to be personalised values-based care.

Keywords. Patient Reported Outcome Measures, value-based care, preference-sensitive decisions, Multi-Criteria Decision Analysis

1. Introduction

Most of the development and use of Patient-Reported Outcome Measures (PROMs), has been, and still is, occurring without adequate debate about the conceptualisation of the latent (unobservable) constructs being measured. Efforts to improve patient-centred care by the systematic collection and dissemination of standardised data on the multiple outcomes that matter to patients are to be applauded. However, it is qualified applause, because the failure to acknowledge and highlight the preference-sensitivity of most decisions in healthcare will severely limit the benefits from all this activity, for two main reasons. First, the ambition to develop 'benchmarking' and 'gold standard metrics', even global/international ones, denies the existence of inter-cultural, intra-national and inter-national heterogeneity in outcome preferences . While case-mix is addressed as a serious concern, preference-mix is ignored. Second, there is no recognition that the vast and increased amount of 'standardised' data being collected as a result of these initiatives, imposes - absent decision support - an almost impossible information-processing burden on the clinician and patient, attempting to engage in person-centred shared decision making in the presence of heterogeneity in the preferences of patients regarding the multiple considerations involved in many healthcare decisions.

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The mission of the International Consortium for Health Outcomes Measurement (http://www.ichom.org) is 'to unlock the potential of value-based healthcare by defining global Standard Sets of outcome measures that matter most to patients, and driving adoption and reporting of these measures worldwide to create better value for all stakeholders.' ICHOM founder Michael Porter sees it as the vehicle to end the definition of 'quality' in healthcare as compliance with evidence-based practice guidelines, re-defining it as improvement in patient-relevant outcomes. 'That means committing to measuring a minimum sufficient set of outcomes for every major medical condition - with well-defined methods for their collection and risk adjustment - and then standardizing those sets nationally and globally.' [1] (p504-5).

ICHOM draws on the US National Institutes of Health (NIH) Patient-Reported Outcomes Measurement Information System (PROMIS®) initiative, which has used state of the art psychometric and statistical techniques to create a universal PROMs language, with potential application across the whole spectrum of health conditions, languages, and geographic location. The scores of each health domain or a standardized profile of multiple domains are all scored on a common metric scale [2]. PROMIS operates under the aegis of the PROMIS Health Organisation (PHO), with an associated user community (http://www.promishealth.com). Its announced long-term aspirations include 'developing PROMIS into a gold-standard outcome metric' and making it 'part of routine clinical practice across multiple specialties'.

Twenty-seven Standard Sets are now available from ICHOM, with nine in production. To avoid misrepresentation it is important to quote the specific aim of ICHOM as being to

> … ensure collection of comparable data for global benchmarking and learning. Each Standard Set focuses on patient-centered results, and provides an internationally-agreed upon method for measuring each of these outcomes. We do this because we believe that standardized outcomes measurement will open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care we provide our patients. Our Standard Sets include initial conditions and risk factors to enable *meaningful case-mix adjustment globally*, ensuring that comparisons of outcomes will take into account the differences in patient populations across not just providers, but also countries and regions … Our aim is to make Standard Sets freely accessible to healthcare institutions worldwide to begin measuring, and ultimately benchmark the outcomes they achieve. [https://www.ichom.org/standard-sets/#standard-sets]. (italics supplied)

The aim here is to establish that PROMs need to be preference-mix adjusted as well as case-mix adjusted if they are to facilitate more person-centred care.

2. Method

To establish why the current efforts of ICHOM (and PROMIS) can only be given qualified applause, we take the case of Stroke and input the components into a largely blank Multi-Criteria Decision Analysis (MCDA)-based decision support tool. In this way we can (i) establish the methodological problem of developing 'benchmarks' relevant to the *values/preference*-based care that is a condition of *value*-based care; (ii) demonstrate the magnitude of the decision burden placed on the clinical dyad by an expanded database containing a wide range of diverse and often overlapping outcome measures;

but nevertheless (iii) provide both clinician and patient with an indication of the type of support needed to move towards a preference-sensitive decision.

In the Salinas paper [3] and the diagrammatic wheel presentation on the ICHOM website [https://www.ichom.org/portfolio/stroke] the Standard Set for Stroke has 3 domains and 10 sub-domains. [** indicates exclusively or * partly drawn from PROMIS GH 10]. SURVIVAL AND DISEASE CONTROL: Overall Survival; Stroke Recurrence; Smoking Cessation. ACUTE COMPLICATIONS: Symptomatic Intracranial Hemorrhage. PATIENT REPORTED HEALTH STATUS: Cognitive and Psychiatric Functioning**; Non-motor Functioning**; Motor Functioning*; Social Functioning*; General Health Status**; Health-Related Quality of Life**.

Patient-reported importance measures (PRIMs) are required *ex ante* a healthcare decision to establish optimal management for the individual and obtain their informed consent. Varying PRIMs within a heterogeneous patient group will impact on any PROMs collected *ex post*. Go to https://ale.rsyd.dk and enter survey ID 1510 for a simple hypothetical example to confirm this. Ratings and Weightings of one's choice can then be entered, but no data security is offered.

3. Results

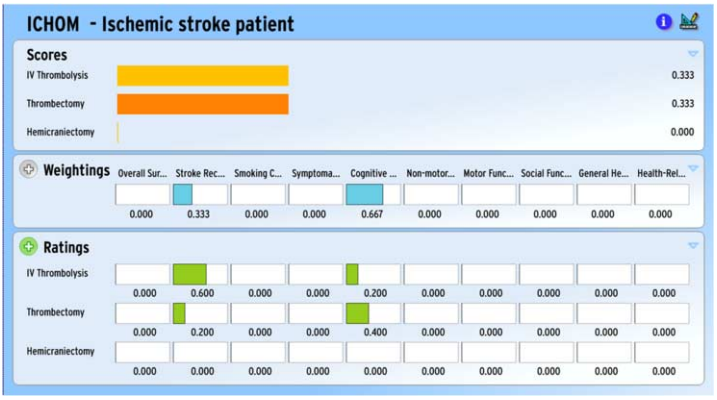

Figure 1. Hypothetical example using ICHOM standard stroke set with only two criteria rated and weighted. They are set at values that produce equipoise ('toss-up').

Two *clinically identical* patients assign different weights to avoiding Stroke Recurrence and impeded Cognitive and Psychiatric Functioning. Given the different hypothetical performance rates of Thrombolysis and Thrombectomy on these two criteria, one will favour the former, one the latter. The conventionally-measured PROMs for both interventions will be affected, as will any consequent PROM-based evaluations. Patient preference-mix therefore needs to be adjusted for in PROMs, as well as clinical case-mix, most likely by sub-group clustering.

4. Discussion

ICHOM standard sets are valuable *profile* measures. However, profile measures, comprising numerous individual *scales*, do not supply the aggregate outcome *index* required to decide the direction and extent of overall change. The production of a Stroke index requires weighting of the component scales. To have this aggregation based solely on the implicit preferences (weightings) of developers of the Standard Set, means the ICHOM ones are questionable facilitators of preference-sensitive values-based care. Apart from the double-counting most of them involve, the Standard Sets lack the empirically-derived group and sub-group average preferences ('tariffs') necessary to give them credible preference-sensitivity. A final irony arises in the efforts to map measures of formative constructs that have been validated as if reflective [4], on to explicitly formative and tariff-based generic constructs, for use in QALYs [5].

5. Conclusion

Value-based care requires *values*-based, i.e. preference-sensitive, decision making. PROMs need to be preference-mix as well as case-mix adjusted and research on the development of PRIM-adjusted PROMs is needed.

6. Funding

The software at https:// ale.rsyd.dk was funded in a project to develop decision support tools (Danish National Board of Health/SATS J.nr. 1-1010/116/27).

7. Conflict of Interest

Jack Dowie has a financial interest in commercial use of Annalisa.

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Experiences and Quality of Life in Critically Ill Patients: Can Technology Lead to Improvements?

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Abstract. Experiences and outcomes of critically ill patients reflect quality of intensive care. The aim of this study was twofold: a) to investigate factors affecting patients' experiences to Intensive Care Units (ICUs) and b) to measure patients' post discharge Health-Related Quality of Life (HRQOL). **Methods:** A cross-sectional study with retrospective data collection was carried out. The participants (n=108) were discharged patients from four ICUs of three military hospitals in Athens. Telephone interviews were conducted using the "Patient Empowerment Questionnaire" and "Quality of life Questionnaire". **Results:** Patients suffering from pain ($p<0.001$), polytraumatized or patients underwent a "non-scheduled surgery" ($p=0.001$) reported worse sleep at night. Mechanical ventilation was associated positively with pain relief ($p=0.021$). Extended length of stay ($p<0.001$), bad health status prior ICU admission ($p=0.005$), "polytrauma" and "non-scheduled surgery" patients ($p=0.032$), mechanical ventilation ($p=0.005$) and pain during ICU stay ($p=0.04$) were correlated with worse HRQOL after discharge. **Conclusions:** ICU staff must consider the factors that affected patients' experiences during their ICU stay and worsened HRQOL after discharge. Adoption of new technological innovations could help them to improve the quality of intensive care provided.

Keywords. Experiences, HRQOL, Intensive Care Unit, technology

1. Introduction

Critically ill patients usually deal with many stressful experiences in ICUs and face problems in post-discharge HRQOL. Evaluating patients' experiences of intensive care would reveal some factors affecting them and strengthen interpersonal relationships with the staff [1]. In addition, consistent measurements of post discharge HRQOL, would provide valuable feedback to health care stakeholders to apply preventive or corrective

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actions to improve quality of care and consequently HRQOL [1]. Thus, the aim of this study was twofold: a) to investigate factors affecting patients' experiences in Intensive Care Units (ICUs) and b) to measure patients' post discharge HRQOL.

2. Methods

A cross-sectional study with retrospective data collection was carried out with patients who have been discharged from ICUs for six to twelve months in order to ensure the best possible HRQOL [2]. Telephone interviews were conducted with adult patients (n=108) discharged from four ICUs of three military hospitals in Athens. Patients hospitalized for at least two days in an ICU and able to communicate were included. Patients who died, did not understand Greek, could not remember anything or denied to participate were excluded from the study. The response rate was 69%.

"Patient Empowerment Questionnaire" (PEQ) [3] was used to evaluate patients' experiences related to staff's behavior, physical comfort etc. A five-point Likert scale was used for the possible answers (never, rarely, sometimes, usually and always). Always represented the best experience (5 points) and never the worst (1 point). "Quality of life Questionnaire" [4] was used to assess HRQOL and had three dimensions: "Basic physiological activities" (0-9 points), "Normal daily activities" (0-15 points) and "Emotional state" (0-5 points). The higher the score the worse was the HRQOL. Both questionnaires were designed specifically for critically ill patients.

Phone calls to eligible patients were conducted, initially informing them for the purpose and methodology of the study. Given patient verbal informed consent, four sets of questions in regards to demographics, clinical characteristics, experiences and HRQOL were asked.

Statistical analysis was carried out using the SPSS v. 25.0. Descriptive statistics were used to present mean, median, standard deviation, minimum and maximum values. Bivariate correlations were conducted using Student's t-test, Pearson's and Spearman's correlation coefficients and Analysis of variance. The HRQOL scores, "pain relief" and "be able to sleep" (items derived from PEQ which had the highest variability) defined as dependent variables, while patients' demographics and clinical characteristics consisted the independent variables. [2,3,4,5] Multivariate linear regression was used when more than two independent variables were statistically significant at the level of 0.2 ($p<0.2$). [6] The two-sided significance level was set equal to 0.05.

Dr. Wahlin, Dr. Vazquez-Mata and Dr. Fernandez provided their permission to use the aforementioned questionnaires. The study protocol was approved by the Ethics Committee of National and Kapodistrian University of Athens, by the Scientific Committees of each hospital and by the ICUs' directors. All patients were informed that the participation was voluntary, their decision to participate or not could not affect their care and asked for verbal informed consent. The study design was based on the European General Data Protection Regulation (GDPR) and aligned with the Declaration of Helsinki.

3. Results

Most of the participants were men (74.1%) and healthy prior admission (75%). The majority of the patients reported very positive experiences from ICU, as the percentages

of those who rated always to each PEQ topic were more than 80%. The least positive experiences were "night's sleep" and 'pain relief'. Improved pain relief claimed patients who were mechanically ventilated. Patients suffering from pain ($p<0.001$), and those who were "polytraumatized" or underwent a "non-scheduled surgery" ($p=0.001$) reported worse sleep at night. In regards to HRQOL, 83% of the participants reported low scores. Disability and extended hospitalization in an ICU were associated with worse emotional state ($p<0.001$ & $p=0.002$) and HRQOL in general ($p=0.005$ & $p<0.001$). "Polytraumatized" and patients underwent a "non-scheduled surgery" had worse 'normal daily activities' ($p<0.032$). Mechanically ventilated patients had worse "basic physiological activities" ($p<0.07$) and worse "normal daily activities" ($p<0.005$). Inadequate pain relief in ICU was associated negatively with HRQOL ($p=0.04$).

4. Discussion

Pain and sleep difficulties were the least positive experiences in this study, which are two of the most common problems of critically ill patients in ICU [5]. When pain relief was inadequate, patients reported worse quality of sleep, as pain causes sleep deprivations and lack of sleep increases pain sensitivity [7]. Improved pain relief claimed the mechanically ventilated patients, maybe because they can't express the real levels of pain, so it was possibly "overtreated". Polytrauma and non-scheduled surgery patients reported the worst quality of sleep. They usually have high levels of pain and stress, which can cause sleep disturbances.

Patients with extended ICU stay reported worse emotional state and HRQOL in general. Extended ICU stay is associated with prolonged immobility, increases the likelihood for weakness and muscle atrophy [8] and exposes the patients to more stressful experiences which can cause negative feelings. Patients suffering from chronic disabling diseases, also reported worse emotional state and HRQOL. Possibly these patients had bad HRQOL prior to ICU admission. "Polytrauma" and "non-scheduled surgery" patients reported worse 'normal daily activities'. It is widely recognized that polytrauma patients face the worst problems in functional status than other ICU patients [9] and need much more time to improve HRQOL. In the current study, mechanically ventilated patients reported worse "basic physiological and normal daily activities". Mechanical ventilation increases the necessity of staying in ICU and exposes patients to nosocomial infections, which could possibly increase the necessity of intensive care. Patients who suffered from pain in the ICU, also had worse HRQOL after discharge. Possibly, they continued to suffer from pain which restricted them from carrying out their daily activities.

5. Conclusions- Recommendations

ICU staff must consider the factors that affected patients' experiences during their ICU stay and worsened HRQOL after discharge. In an era of rapid advancement in information technology (IT), exploitation of its modern applications is necessary to improve quality of intensive care. Systematic assessment of patient reported indicators, both experiences and outcomes (e.g. HRQOL), should be established by developing appropriate mobile applications or using electronic questionnaires sent automatically via email or mobile phone. The collected data could be used to develop a national electronic

database in order to help health care stakeholders to evaluate the quality of the provided care, facilitate hospitals' performance benchmarking and finally suggest measures for improvements. [10].

Furthermore, adopting mobile applications in intensive care like ICU diaries would improve patients' experiences by reminding ICU facts, providing information and explanations for their stay and maintaining connection with the staff after discharge [11]. Wearable devices could be worn for post- ICU discharge patient monitoring, as they generate useful data related to HRQOL, such as quality of sleep [12]. Increasing attention is paid to Machine Learning (ML), a branch of Artificial Intelligence which constructs algorithms to accurately predict future outcomes. ML in ICU can learn from past cases, use the available data to early recognize clinical deterioration and submit evidence-based suggestions for the best treatment. [13] This approach would improve quality of care and consequent HRQOL.

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Developing a Gamified First Aid Training Application for Children

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Abstract. This paper presents a high-fidelity prototype of a mobile game for teaching children fundamental skills in first aid. The study utilizes expert interviews to define learning scope and evaluate design. The game introduces two situations based on realistic scenarios; a boy who fell on a skateboard, and an elderly man with chest pains. Interactive elements introduce a way for the user to explore and assess a given situation. Gamification keeps motivation for learning high, and choice of graphical elements keeps situations feel familiar but non-frightening. There is a quiz to help children learn how to communicate with emergency services. Experts believe that children can learn essential steps for providing basic first aid, except physically fatiguing techniques, so they found the prototype to be a viable option for learning basic first aid at a young age.

Keywords. First aid, children, e-learning, high-fidelity prototype.

1. Introduction

Every year approximately half a million people in Norway are injured as a result of an accident, violence or self-inflicted injury, and approximately 3000 people suffer from cardiac arrest outside of hospitals [1]. A study of response times of the emergency services in Norway by the department of health showed that their goals of having under 12 minutes response times in cities and towns in 90 percent of acute situations is not realistic, and the 12-minute goals is only reached in 67.5 percent of the time [2]. For sparsely populated areas where the goal is within 25 minutes in 90 percent of acute events, this response time was achieved in 80.3 percent of the cases [2]. The time it takes from a serious acute event occurs to having received necessary health care is often crucial to avoid unnecessary death, loss of function, or disorder [2]. These studies illustrate the importance of proper first aid training in Norway, and a group that is not being prioritized in first aid training is children. Starting training at an early age can increase both the overall knowledge and skill level, and continuous repetition can help with retaining the information better over time. Generally, there are few solutions for e-learning, one good example is "A Breathtaking Picnic App" developed by the Italian Resuscitation Council. This app teaches children simple first aid steps in the case of an emergency [3].

This project aims to develop a mobile application to give children a fundamental introduction to first aid early in life. We are following guidelines for administering first aid developed by the Norwegian Association for Heart and Lung Diseases [4].

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2. Method

A literature review was conducted to acquire knowledge as a basis for creating an e-learning application for children, finding ways to effectively use gamification for motivation, and to get an understanding of the cognitive and physical limitations and abilities that can impact teaching first aid to children. In the next step, semi-structured interviews were conducted with experts in the field of first aid training and teaching. Results were used to define requirements for the content and development of the prototype. Four experts participated in the project, two of whom are from the Norwegian Red Cross, while one is a principle with responsibility for children in primary school ages. In addition, one project manager from the Norwegian Association for Heart and Lung Diseases (LHL) was involved due to her role in improving first aid training in Norwegian schools. The experts were all engaged to ensure that criteria for effective and safe educational use is met. We have implemented two learning situations suggested by LHL. A high-fidelity prototype was designed and implemented for iOS, and thereafter evaluated by having walkthroughs with the experts. Feedback included a System Usability Scale for the second design iteration.

3. Results

3.1 Requirements

When creating a digital learning application aimed at teaching children first aid, their cognitive and physical abilities must be taken into account. The target audience of this project are children of ages 6 to 7. For them learning through playing is essential, and the aim of most first aid training is to build some basic fundamental understanding and skills through simple exercises that foster curiosity and safety [4]. It takes time to build this foundation, and studies show that training in small doses with multiple repetitions give the best results [4]. Using visual presentations can create a closeness to situations when first aid is needed [4]. The life-saving chain can be described in three steps, where first step is to identify the situation, assess risks both with regards to one's own and the patient safety, and to properly notify the emergency services when necessary. The second step can be summarized as assessing vital life functions, like checking the patient's consciousness, whether airways are open and if they are able to breathe properly. The third step is to provide necessary first aid techniques, for instance Cardiopulmonary Resuscitation(CPR) or putting the patient in a recovery position [4]. Findings from the expert interviews suggest that children are capable of learning most elements in this chain. They are somewhat limited by their physical ability to, for instance, perform CPR. This limits the scope of teaching children to the first two steps. So, the focus will be identifying and assessing situations, notifying emergency services, and providing help within children's individual physical and cognitive capabilities. To facilitate a safe and good learning environment it is important that the language and graphics are age adjusted, to not be frightening for the children.

3.2 Prototype

The high-fidelity prototype is implemented for iOS devices with the Swift[5] programming language and using SpriteKit[6] as a framework for game elements and mechanics. The prototype presents different situations where fundamental first aid

principles can be practiced in an interactive way. Each situation consists of interactive elements like a patient, background elements indicating what has happened, and a first aid toolkit. After assessing the situation, a first aid toolkit is available to help. The situations introduce interactive elements to stimulate curiosity and exploration when looking for solutions. The prototype has three characters, Ane, Tom, and Herman (Figure 1). Ane is an 8-year-old girl that helps guide the player throughout the different cases and gives feedback on interactions. Tom and Herman are patients. Firstly, Tom presents himself as an 8-year-old boy who fell on his skateboard and hurt his knee. Tom explains what happened and what help he believes he needs. The background elements in this case are related to skateboarding, and through interaction the user gets clues of what has happened. Based on the given information the user can solve the case by using various tools from the first aid toolkit. For Tom, the user can simply give him a band-aid. In the second case the user is introduced to Herman, a 79-year-old man with chest pains. When interacting with Herman he explains that he was walking in the park and got short breathed and started feeling chest pains. Herman thinks he needs water, and thankfully accepts it, but he still feels pain. Based on this information the user can solve the case by calling the ambulance in Norway with an interactive phone that is part of the toolkit. After dialling the correct number, the user is tested on what information should be given to the emergency services. A three-question quiz appears, each with two alternatives. A correct resolution of the case gives a positive feedback both visual, in a textual form, and auditive, through dialogue and sound effects. The dialogue in the game is textual and combined with a text-to-speech synthesiser to help the target audience whose reading skills are still limited. To distinguish the characters and to easier relate to them, the voices used by the speech synthesiser change.

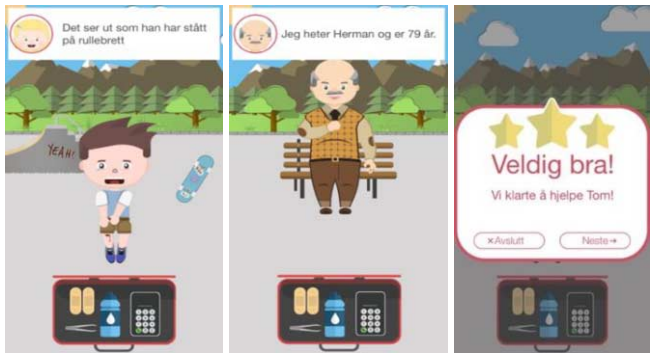

Figure 1.a Case with Tom. **1.b** Case with Herman. **1.c** Feedback for a solved case.

4. Discussion

When creating an application for children it is important to achieve a balance between the level of detail in the information and visualisation of the content. The design, pace and content of the solution has to be configured with the target audience in mind.

Different ages need different approaches, and the main takeaway from the expert interviews and literature review was that the early age group should be able to learn basic first-aid principles and techniques, however physical and cognitive limitations means CPR, and other fatiguing techniques can prove troublesome. There was a consensus in the expert group that children should learn first-aid as early as possible, at least to identifying acute situations and to call the emergency services.

The character and general design of the porotype were made with flat and simplistic illustrations to make them less intimidating and frightening, but at the same time design should show enough detail to make them prepared for a potential real case where they need to administer first aid. The choice of character design and cases to solve for Ane, Tom, and Herman, was to introduce a realistic representation of people and situations the users might come across in daily live. The interactive elements are meant to stimulate curiosity and exploration to figure out what has happened, and to make the user assess what is needed to help. The scenarios are presented in familiar environments, like a park.

The quiz for completing the phone call to the emergency services is meant to help the user communicate with the emergency services, as this knowledge can make the user more confident when having to call the emergency services in a given situation. The use of gamification as a learning tool can make the learning experience less frightening and keep the motivation for repetitive learning high [7]. The motivation is further strengthened by giving encouragement and instant feedback for interactions, and thus making the user able to experiment and solve the situation on their own. The user can dictate the pace of the game, making room for individual progression based on problem solving skills. These are all game elements children are familiar with through other games they play. Experts see the potential of using such tools.

5. Conclusion

Findings from the interviews with experts in first aid training led to a high-fidelity prototype of a mobile game aimed at giving children a fundamental understanding of first aid. The design solutions encourage exploration and present a serious topic in a non-frightening way. Testing with experts and users gave useful feedback on actual usage and usability. The attitude towards such learning was positive, and there is a place and a future for this kind of interactive first aid learning tools for children.

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Defining an Architecture for a Coaching Module to Support Self-Monitoring of Chronic Obstructive Respiratory Diseases

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Abstract. Over time there has been an increase of the number of people affected by chronic obstructive respiratory diseases, burdening healthcare providers. Following the growth of information technologies, it has been sought the development of innovative solutions that help monitoring and treating patients. In this work is proposed the architecture for a coaching module to be integrated in the system developed by the PHE project. With the goal to improve patients' health condition by providing innovative and intelligent measuring and monitoring tools for preventive healthcare and allow affordable solutions with increased patient involvement. With this work, we define the architecture for a module that can generate recommendations adapted to each patient. By doing so, we believe to be possible to motivate the adoption of behaviors that benefit the health condition of the patient and decrease the risk of complications associated to the disease.

Keywords. CORD, mHealth, Personal Healthcare, Self-Monitoring

1. Introduction

Chronic obstructive respiratory diseases (CORD) affect people all over the world, being reported that, by 2017, more than one billion people suffer from these diseases [1]. Due to the high prevalence of CORD and the constant monitoring of the patients' condition there has been a burden on the healthcare providers [2], making the development of cost-effective solutions for monitoring and treatment of patients necessary [3]. The continuous growth of information technologies in recent years has been aiming towards the automatization and customization of processes, resulting in the development of innovative solutions to existing problems in healthcare [4]. As a result, concepts such as mobile health (mHealth) have emerged. mHealth aims towards the self-management of the patient's disease, by providing mobile systems that are capable of monitoring their health status and giving customized feedback about activities and behaviors patients can do to improve their health [5,6]. Mobile devices now offer a wide set of features and embedded sensors that can be used to measure and monitor patients' current health condition and support them in the management of their diseases [7]. Solutions for monitoring and treating patients with CORD are already available. AioCare [8] is a mobile app that helps the self-monitoring of the patient's

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health status by allowing the self-reporting of the symptoms and also measures the parameters associated with the disease. SmartOne [9] monitors the patient's health status by tracking the disease's parameters and detects if the patient is having an exacerbation. SpiroSmart, presented in [10], is a mobile app that monitors the patient's health status by performing the spirometry using only the smartphone's microphone. BKSpiro, presented in [11], is similar to SpiroSmart, performing the spirometry using only the smartphone's microphone to monitor the patient's health condition. These systems are heavily focused on monitoring patient's health condition and require the use of external sensors for the acquisition of data, except for SpiroSmart and BKSpiro. Currently, most smartphone solutions for CORD management lack of customized interactions with personalized recommendations and cannot accurately measure clinical data, such as the expiratory flow rate and then detect exacerbations.

The main goal of PHE2 is to empower people to monitor and improve their health using personal data and technology assisted coaching. To achieve this goal, PHE will apply innovative and intelligent measuring and monitoring tools for preventive healthcare and allow cost-saving and self and home-care solutions with increased patient involvement. Furthermore, PHE project will exclusively use the smartphone and its embedded sensors to acquire all the necessary data to provide personalized support to the CORD patient. The technologies developed for PHE can be licensed as project components that can be independently used and integrated in companies (mHealth, pharmaceutical, etc.) and to provide innovative health services for other healthcare systems. In this sense, the Inspirers project [12] is highlighted as an ongoing European initiatives which could benefit from the innovations offered by PHE.

This paper proposes an architecture for the individualized support module (coaching) which will be integrated in the system developed by PHE project. This module is responsible for the data processing in order to generate both customized recommendations regarding behaviors that benefit the patient's health and reports about the patient's monitoring and health state. Furthermore, the coaching module should be able to detect and predict exacerbations during the processing of the patient's data.

2. Proposed Architecture

Figure 1 presents the proposed architecture for the coaching module. The main user will be the CORD patient which provides clinical and demographic data, preferences and feedback, besides the information automatically acquired by the smartphone.

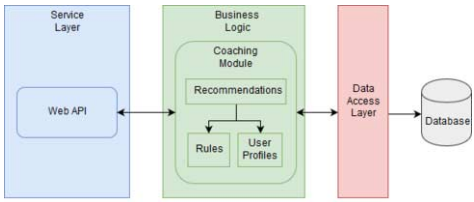

Figure 1. Proposed architecture.

[2] https://itea3.org/project/personal-health-empowerment.html

The Service Layer serves as a gateway between the coaching module and external services. This layer contains the Web API, which provides a set of services to acquire patient's information and provide personalized recommendations.

The Business Logic Layer is responsible for the data processing and business logic operations, such as the generation of customized recommendations. This layer contains the Coaching Module, that processes the information received by the Web API and includes three components: Rules, User Profiles and Recommendations. Rules specifies the set of conditions associated to the patient's clinical data which are necessary to identify possible recommendations to send to the patient. User Profiles specifies all the characteristics that can identify a certain profile which is assigned to the patient. So far two main groups have already been identified, which are Asthma and Rhinitis groups. Furthermore, the remaining groups will be defined using clustering techniques to identify users sharing characteristics related to patient's demographic data, context, etc. Recommendations verifies and processes the received data according to the defined Rules and User Profiles. This component sends the identified recommendations to the Web API.

The Coaching Module will be developed using JBoss Drools, which is the most used open-source rule engine framework for Java programming language. Besides that, this framework offers many advantages which can be beneficial for the Coaching Module here proposed [13,14] such as: intuitive rule language for non-developers, supports flexible and adaptive process, enhances intelligent process automation and complex event processing and is easy to integrate with web services. Figure 2 shows an example of a rule that was defined for a recommendation to send to the patient.

```
rule "Asthma"
when
    variable0:Variable(Name=="Asthma",Value=="yes")
    variable1:Variable(Name=="Pregnancy",Value=="yes")
    variable2:Variable(Name=="Sex",Value=="female")
then
    recommendation.setRecommendation("Counsel women with asthma regarding the
    importance and safety of continuing their asthma medications during
    pregnancy to ensure good asthma control.");
end
```

Figure 2. Rule example in Drools

The Data Access Layer will serve as a middle layer between the Business Logic Layer and the different data sources. This service receives requests from the Business Logic Layer about whether to read, insert, update or delete information available in the database. The database contains information regarding the patient's clinical data, variables associated with recommendations and the history of provided recommendations. It also contains knowledge provided by health professionals, rules used for the generation of recommendations and the defined user profiles and respective characteristics.

3. Conclusions and future work

The high prevalence of CORD has led to an overload of healthcare providers, being imperative the development of technological solutions that provide the remote monitoring of patients. Mobile health systems have emerged in order to ease the burden of healthcare providers, being able to remotely monitor the patient, by regularly tracking the patient's health condition.

In this paper it is presented an architecture for an intelligent individualized support module for the PHE project, which will be responsible for the customization of the system by generating customized recommendations about behaviors that benefit the

patient's health. The knowledge presented in the database regarding the Rules component is currently being integrated in the Drools framework and afterwards tests will be carried out to validate which type of recommendations will be generated and which will be relevant to the patients.

As future work we intend to study intelligent strategies to improve the Recommendations component such as Case-Based Reasoning that can be used to verify if there are cases where recommendations can be generated even though there isn't full knowledge about the patient, for example: missing data related to a specific variable used in the generation of a certain recommendation.

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Gathering Real World Evidence Through the Evaluation of Decision History

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Abstract. Clinical Practice Guidelines (CPGs) gather latest evidence-based results to guide and support clinicians over the decision-making process to provide best care. Nevertheless, clinical cases may be subject to some biases (understood as non-compliance with CPGs) that can lead to adapt care delivery. In this work an experience-based decision support leaning on the structuration of the Decisional Event concept for tracking and storing each clinical decision is presented. Moreover, a visual analytics tool is provided in order to facilitate the visualization of biases from guideline-based decision support and the identification and inclusion of real-world evidence into the reasoning process by augmenting the knowledge formalized in the implemented guidelines.

Keywords. Decision support system, Clinical practice guidelines, Experience formalization, Decisional event

1. Introduction

Clinical Practice Guidelines (CPGs) gather latest evidence-based results to guide and support clinicians over the decision-making process. Clinicians, policy makers, and payers expect guidelines would standardize clinical practice while making it as personalized as possible. Hence, the objective is to establish some standards in healthcare considering not only what clinicians do but also what scientific evidence supports [1]. Nevertheless, some clinical cases are subject to some biases (understood as non-compliance with CPGs) that can affect care delivery. These variations can come from different sources affecting clinical practice, such as restrictions coming from the patient him/herself, restrictions related to the proposed therapy, or restrictions related to the analyzed clinical parameters (e.g. a patient is not covered by CPGs due to his/her specificity or complexity and hence, there is no optimal clinical recommendation that would promote its clinical success). Clinician-related effects can also produce clinical

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errors, e.g., overconfidence judgement. This effect occurs when clinicians biased their decisions by overestimating the accuracy of their own clinical judgment [2].

In this work we present an experience-based decision support system that allows not only to report non-compliant cases and generate new knowledge from these non-compliant decisions, but also allows to generate "real-world evidence" for future similar clinical cases. For that, a methodology based on the formalization, storage, and reuse of all the decisions made over time is presented. The objective is to be able to measure and evaluate all biases from guideline-based decision support by reporting (i) the compliance rates with CPGs of the decisions made, (ii) the generation of new knowledge from cases that did not comply with guideline specifications and the evaluation of this new knowledge on new cases, and (iii) the evaluation of the clinical performance of the whole process on the basis of patient-reported clinical outcomes. Finally, a visual analytics dashboard is presented to show up at a glance all the generated real-world evidence to be validated and analyzed by the clinician.

2. Measuring biases from the decision-making process

When identifying the different causes of clinical care biases from the recommendations provided in guidelines, we could differentiate several causes such as (i) the difficulty or complexity of the studied clinical case, (ii) some healthcare or patient-related restrictions, and (iii) the reasoning process of clinicians. In the next chapters, we will analyze the main reasons of guideline non-compliance (understood as a bias on the treatment recommended by CPGs) and how to measure and evaluate the clinical performance when using the information gathered from the decisions made over time.

2.1. Causes of guideline non-compliance

Most of the time, clinicians tend to follow the recommendations provided by CPGs as they expose latest and most reliable evidence-based medicine. Nevertheless, implementing guidelines is not always feasible and not all clinicians do know how to proceed in certain clinical situations [3]. The complexity of clinical cases, the severity of the illness, or the health care system inefficiency have been identified as the main causes for clinicians not to comply with CPGs [4]. On the other hand, patient preferences have been shown to influence the decision-making process, even if this is not yet reflected as evidence [5]. Several works have discussed strategies to include this criteria within the guidelines, re-rating the strength of recommendations and the quality of evidence of the already defined criteria or including this knowledge as new criteria to formalize [6].

2.2. Overconfidence

As every effective problem solving, the clinical reasoning process is governed by an intuitive approach together with an analytic approach [7]. Both approaches work together for the optimal decision-making process in every context. Nevertheless, human behavior can break the balance and introduce a bias in the reasoning process due to some reasons generating overconfidence, among others [8]. This effect can change clinicians' attitude towards a more confident one, making cognitive aspects the most valuable (i.e. their own criteria are considered to be the best ones with no critical analysis or comparison) and tending to underestimate errors, assuming that they may not occur [9]. Sometimes the

clinician is not even conscious of this bias and this remains untracked, as it happens in a low percentage of the studied clinical cases. Hence, tracking and evaluating clinical practice should better identify and prevent misdiagnoses.

2.3. Generating real-world evidence from the decisional history evaluation

In [10] we proposed a Decisional Event (DE) structure to gather all the information related to the decision making process in a processable way, generating an history of all the decisions made over time. This approach concedes two kinds of information evaluation. First, guideline compliance rates can be measured. As we not only gather the recommendations provided by the guidelines but also the final decision made and even the real executed treatment, compliance can be computed, and non-compliant cases tracked to evaluate their performance based on reported outcomes [11]. On the other hand, having all this data over time permits generating real-world evidence by the use of machine learning techniques. These algorithms allow predicting the variables that most influence patients' outcomes and relationships among them for a given treatment in a particular scenario. The results from these analyses should estimate the expected clinical outcomes for new upcoming cases similar to previous treated patients and even more, see if clinicians are self-consistent with the previously made decisions that were biased from the actual evidence.

2.4. Visualization of the Decisional History

To provide all the information stored within the DE in a visual and intuitive way, we designed a visual analytics dashboard (Fig.1). This dashboard allows exploring all the decisions made over time and the compliance rates slanting the information by the most relevant clinical variables or the treatment of interest. Moreover, details about the specific treatment given (e.g. lumpectomy) within a group (e.g. surgery) can be analyzed along with the toxicities or relapses suffered by the patients concerned.

Figure 1. Visualization of decisions made for a sample of 568 patients with breast cancer, filtered by their tumor size and age. Patients are at the diagnosis stage, which explains why surgery and chemotherapy are the treatments mostly proposed.

This visualization gives at a glance all the results of the computation coming from the DE analysis. The scope of this visualization is to easily identify real-world evidence and give insights to clinicians when diagnosing and treating patients. Moreover, using

the experience-based decision support they can include this new evidence as new rules that will augment the knowledge contained in the implemented guidelines.

3. Discussion and conclusion

In this work, we have analyzed the main causes of CPG non-compliance and we have proposed experience-based decision support leaning on the structuration of the DE concept for tracking and storing each clinical decision. Moreover, a visual analytics tool was provided in order to facilitate the real-world evidence identification and inclusion into the actual reasoning process by augmenting the knowledge formalized in the implemented guidelines. Our approach is expected to promote a more reliable and compliant care by a continuous gathering and evaluation of information and clinical performance in every clinical decision-making process.

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Improving Antimicrobial Prescriptions with Computerized Decision Support Systems: Where Are We?

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Abstract. Antimicrobial computerized decision support systems (CDSS) have been developed to improve decision-making at the point of prescribing. Uptake of CDSS for antibiotic prescribing remains low, and evidence to suggest that CDSS provides a clear benefit for antimicrobial outcomes is scarce. We reviewed existing evidence on the impact of CDSS on antimicrobial prescribing. Based on the results of our literature search, we discuss the use of CDSS for antimicrobial management in hospitals and antibiotic prescribing practices in ambulatory primary care settings. We identify some of the issues surrounding selecting and defining appropriate outcome measures for assessing the impact of CDSS on antimicrobial prescribing in the hospital setting. In the primary care setting, we observed that CDSS has a modest impact in changing antibiotic prescribing practice, which could be related to the underutilization of antimicrobial CDSS.

Keywords. Antibiotic, antimicrobial, computerized decision support system

1. Introduction

Antimicrobial resistance is one of the greatest global healthcare challenges. Inappropriate use of antimicrobials has led to widespread resistance to antimicrobial drugs. Antibiotics generally provide no benefit for patients with upper respiratory tract infections and acute bronchitis. Yet, despite the ineffectiveness of antibiotics, their prescription in the primary care setting remains common practice, leading to concerns that levels of antimicrobial-resistant microorganisms will increase. One of the most important goals of antimicrobial stewardship programs (ASPs) is to minimize and overcome resistance to antimicrobials. Use of computerized decision support systems (CDSS) is one strategy for improving antimicrobial prescribing and deployment of ASPs to contain this problem.

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2. Material and Method

Using PubMed and MEDLINE, a literature search was conducted to identify studies including "computerized decision support system" and "antimicrobials" or "antibiotics" in the title. The search was limited to full-text studies published in English within the last 5 years. Abstracts of potentially eligible articles were retrieved for review. Studies conducted in settings not relevant to our review subject were excluded. Abstracts and full articles were reviewed by the investigators, and seven eligible articles, including four systematic reviews and meta-analyses and three quasi-experiments, were identified.

3. Results

3.1. CDSS for Antimicrobial Management in the Hospital Setting

We reviewed three systematic reviews and a quasi-experiment. A systematic review of 58 original articles on the use of CDSS in antimicrobial prescription showed that most CDSS targeted antimicrobial prescribing (76%). The most common CDSS platforms were integrated with electronic medical records (EMR) (74%). Most of the infrastructures used had rules-based decision support (76%). Outcomes were focused on the appropriateness of prescriptions based on guidelines or expert opinion, or on microorganism sensitivities. Other outcomes included cost, appropriateness of antibiotic choice, and mortality. Use of CDSS was found to have no effect on appropriateness or survival [1].

In a quasi-experiment of 40,605 hospitalized patients who received antimicrobial drugs, the aim was to examine the effects of a novel CDSS (the Antimicrobial Prescription Surveillance System; APSS) on an ASP. Implementation of the APSS with CDSS was associated with a positive effect on several outcomes that persisted over 3 years. These outcomes included decreased average length of stay (LOS) in hospital by 11.4 days; reduced antimicrobial consumption with defined daily doses (DDD) per 1000 inpatient days (–12.2%); reduced antimicrobial spending by at least 28.3%; and reduced non-concordance with local guidelines for prescribing [2].

In a meta-analysis of 21 studies, the appropriate use of antimicrobials improved by 50%, and mortality reduced by 10%. These effects disappeared when the analysis included only higher quality trials. Appropriateness was defined as whether antimicrobial drugs were compliant with guidelines or microbial culture. In studies assessing the susceptibility of microbial cultures to antimicrobial drugs, a significant effect of CDSS on the appropriate use of antimicrobials was indicated. All but one of these studies showed no effect on mortality. Two studies reported a significant reduction in LOS with the introduction of decision support in pre-order sets for bacteremia, or alerts notifying physicians of serious bloodstream infections. In the intensive care unit (ICU) setting, there was a trend towards reducing mortality [3].

Another systematic review of 81 studies reported seven outcome measures. Meta-analysis showed that CDSS significantly improved the adequacy of antimicrobial coverage, adherence to guidelines and antimicrobial consumption, and there was a marginal effect on mortality. Of the four studies that reported on antimicrobial resistance, only one found a 10% reduction in the rate of multidrug-resistant organisms. Another study showed a trend towards increased susceptibility to antimicrobial resistance after

implementation. Conflicting effects of CDSS on LOS, antimicrobial costs and CDSS acceptance and use were reported [4].

3.2. CDSS for Antimicrobial Management in the Primary Care Setting

Three included papers examined the effects of CDSS on antibiotics prescriptions in primary care. First, a quasi-experiment was conducted with nine CDSS intervention practices and 61 control practices. The aim of this study was to assess the effect of a CDSS on antibiotic prescriptions for acute respiratory infections (ARIs) in primary care. The primary outcome measure was the rate of inappropriate prescription of antibiotics in ARI episodes, with prescription of broad-spectrum antibiotics being a secondary measure. This study showed that the inappropriate prescription of antibiotics in ARI episodes declined significantly (–0.6%) among CDSS intervention practices compared with control practices (+4.2%), but not for pediatric patients (+1.4% versus +4.2%). However, among adults, the CDSS intervention improved the prescription of broad-spectrum antibiotics, with a decline of 16.6% among intervention practices versus an increase of 1.1% in control practices. A similar effect on broad-spectrum antibiotic prescription was found in pediatric patients, with a decline of 19.7% among intervention practices versus an increase of 0.9% in control practices [5].

A three-arm cluster randomized trial of 33 primary care practices in an integrated health care system examined three different implementation strategies to reduce antibiotic use for uncomplicated acute bronchitis. The three arms were a printed decision support (PDS) strategy intervention (11 practices), CDSS strategy intervention impeded into EMR (11 practices), and a control arm (11 practices). Compared with the baseline period, the percentage of antibiotic use for uncomplicated acute bronchitis during the intervention period decreased at the PDS intervention sites (from 80.0% to 68.3%), and at CDSS intervention sites (from 74.0% to 60.7%), but it increased at the control sites (from 72.5% to 74.3%). After controlling for confounding factors, the differences for the intervention sites were statistically significant from the control, but not between CDSS and PDS [6].

A systematic review including three randomized controlled trials (RCTs) and four cluster randomized trials found a marginal benefit of CDSS in improving antibiotic prescribing behavior. CDSS that automatically provided decision support were more likely to improve prescribing practice outcomes compared with systems that had to be actively initiated by providers [7].

4. Discussion

Many of the CDSS interventions in the reviewed studies were based on decision pathways or guidelines; very few used pre-deployment analysis or prescriber decision-mapping to justify the intervention design. These CDSS studies fail to show consideration of non-expert decision-making, engagement of clinicians, and end-users' workflow. They reported a high physician override rate (50%), which might be explained by practitioners' lack of engagement.

Outcomes measures varied widely across the studies conducted in the hospital setting. They mainly focused on antimicrobial selection, antimicrobial use, and indirect health-related outcome measures, such as mortality and LOS. There were no consistent definitions for some of these outcomes, such as antimicrobial use. Individual patients'

outcomes, such as adverse drug events, were not sufficiently addressed. Addressing the cost of antimicrobials lacked in-depth evaluation of indirect savings, such as savings made by decreased hospital LOS. Most studies did not address the incidence rate of bacterial-resistance as a very important outcome measure for the effect of CDSS.

In the primary care setting, CDSS has no or only a modest effect on the practice of prescribing antibiotics for URI and acute bronchitis. However, the CDSS approach may not be heavily used by physicians in ambulatory care; this may have contributed to the fact that it did not lead to significant levels of improvement in antibiotic practice and reduce prescriptions of broad-spectrum antibiotics. Another limitation of the studies was that many of the trials failed to control for other confounders. This makes it hard to conclude whether this modest improvement in antimicrobial prescription is related to the intervention.

In conclusion, we believe that outcome measurement of the effect of CDSS as an intervention on antimicrobial prescriptions should focus on adherence to and compliance with prescribing guidelines, the utilization rate of broad-spectrum antibiotics, and the incidence rate of antimicrobial resistance as direct outcome measures.

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Discovery of Hidden Patterns in Breast Cancer Patients, Using Data Mining on a Real Data Set

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Abstract. The aim is to recognize the unknown atterns in a real breast cancer dataset using data mining algorithms as a new method in medicine. Due to excessive missing data in the collection only data on 665 of 809 patients were available. The other missing values were estimated using the EM algorithm in SPSS21 software. Fields have been converted into discrete fields and finally the APRIORI algorithm has been used to analyze and explore the unknown patterns. After the rule extraction, experts in the field of breast cancer eliminated redundant and meaningless relations. 100 association rules with a confidence value of more than 0.9 explored by the APRIORI algorithm and after the clinical expert feedback, 10 clinically meaningful relations have been detected and reported. Due to the high number of risk factors, the use of data mining is effective for cancer data. These patterns provide the future study hypotheses of specific clinical studies.

Keywords. Breast Cancer, Data Mining, Association Rule Mining, Pattern Recognition, Knowledge Discovery, Iran.

1. Introduction

Breast cancer is one of the most common cancers in women that affect almost 10% of women [1]. In recent years, the prevalence of the disease is growing, but the early detection of this type of cancer has increased chances of successful treatment [2]. New approaches such as knowledge discovery in databases (KDD), including data mining techniques are now popular and become a good research tool for medical researchers by reducing the number of false-positive results and false-negative decision [3]. With these techniques, researchers can identify patterns and relationships among many variables and predict the outcome using the available data or information in databases [4].

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Few studies exist on pattern recognition on cancer [5], but there are several studies in medical sciences using data mining predictive approach in which different techniques are use and compared and the final conclusion is on accuracy of such models [3, 6]. On the other hand, in Iranian studies, approaches of data mining are done in the field of breast cancer with the same approach [7, 8].

Unfortunately, most of such studies are done by computer or control engineers using informatics methods to examine the algorithms, not to help physicians in prevention, diagnosis or treatment. Also, most of these studies study on unreal or non-native data which their results may not be used in Iran or other developing countries. So, due to the double advantage of data mining methods, the aim of this study is to use the methods of data mining on real data in one database of breast cancer in our country, to discover unknown association rules in the data set.

2. Methods

For this retrospective study, data were obtained from Motamed Cancer Institute, a referral center for cancerous patients in the Tehran, capital of Iran. The dataset included the data of 809 adult women breast cancer of the stage one to five and were recorded eighteen parameters for each patient. These parameters and their kind can be seen in Table 1. Data collection had been done from 1-1-2009 until the end of September 2012. All patients being treated or have finished their treatment process (death or health).

Table 1. The variables (Parameters) for each patient collected and analyzed their types and their missing rate.

Characteristic	Type	Probable Values /Unit	Missing (%)
Age	Continuous	years	3
Tumor Size	Continuous	CM	7
Breast Cancer Stage	Categorical	1/2/3/4/5	9
Estrogen Receptor	Categorical	+/-	8
Progesterone Receptor	Categorical	+/-	11
P53	Categorical	+/-	12
HER2	Categorical	+/-	20
Lymph Node Involvement	Categorical	+/-	23
Recurrence	Categorical	+/-	32
Marital Status	Categorical	+/-	2
Smoking	Categorical	+/-	12
Weight	Continuous	Kg	23
Height	Continuous	CM	23
Menopausal Status	Categorical	+/-	7
Pregnancy	Categorical	NO.	4
Family History of Breast Cancer	Categorical	+/-	18
History of Previous Cancer	Categorical	+/-	19
Tumor Grade	Categorical	1/2/3/4	34

First, the data matrices were reviewed by two physicians in order to check the validity of data and extract the whole patient set characteristics. Due to missing data in 144 record, only information of 665 patients were available. In fact, all records with more than 15% missing of patients parameters were excluded to avoid inaccurate data mining results. Therefore, in this study, a total of 665 records of people who had been diagnosed as breast cancer patients were included. Since some fields in the records were left with some empty values which were imputed applying EM algorithm using SPSS version 21. The whole data have been analyzed through WEKA data mining

software using APRIORI algorithm. After running the algorithm, the association rules with higher confidence rate (more than 0.9) were considered as the best results. The first 100 rules were selected from these rules and presented to medical experts in the field of breast cancer (two cancer surgeons and one experienced general physician) to determine the clinically significant relationships. For this reason, these relationships were defined in everyday language for physicians in some relationships or mathematical changes (for example, contradictory statements; $p \rightarrow q$ to $\neg q \rightarrow \neg p$) were made to have better understand of the statements. Finally, the statements which were clinically significant were confirmed by the physician and reported as the result.

3. Results

According to patient's available data, all patients were adult women, most of them (79%) were in the age range 30 to 50 years and the remaining (21%) have more than fifty years. The age mean was 43.5. All patients being treated or have finished their treatment process (death or health). After running the algorithm the software presented more than 13100 rules. We chose the rules which had gotten a confidence value more than 0.9 of 1. The number of them was 1206 association rules. We selected and presented the first 100 statements for more clinical survey. Finally, clinical experts confirmed 10 rules which were acceptable in real clinical field. After examination, the following rules were considered clinically significant which were as follows translated into everyday language (Table 2).

Table 2. The result rules translated to natural language with the confidence values and patient numbers.

Rules	Confidence value	Evidence
High tumor size patients had no recurrence.	1	426
Non married premenopausal patients have larger tumors.	1	273
In relapse, ER and PR negative Patients, have smaller tumors.	1	256
Non-smokers have not cancer recurrence.	1	251
Non-smokers have smaller tumors.	1	242
P53 positive Patients in recurrence have smaller tumors.	1	238
ER and PR negative Patients, has smaller tumors.	1	252
ER and PR positive patients with large tumors have more lymph nodes involved.	1	239
Married patients had smaller tumor size	0.99	393
Patients with negative HER2, have had a large tumors	0.99	533

4. Discussion

The aim of this study for the physicians' community and clinical experts was to get familiar with one of new ways of knowledge extraction from medical data even in a small scale. So, a number of lesser-known and interesting patterns have been derived from a set of real breast cancer patients' data using association rule mining. The significance of these rules has been confirmed by specialists in the field of breast cancer. However, each of these rules should be translated into everyday language and rather physicians' and finally be the base hypotheses of further more clinical studies

(like clinical trials). The ten final statements are not the only clinically true statements, but the most statistically reliable ones. Most of them are really new in medical, especially the facts about non-smokers (the 4th and the 5th) and some of them may be experienced by physicians but has not been mentioned in scientific texts.

Similar studies are seen in different parts of the world, but not in our country. This fact should be noted that such studies (that examined the association rules) are very different and varied so, actually the results are not statistically comparable [8]. But in terms of confidence, confidence value of at least 0.9 is acceptable and above many other articles in the field of cancers including all studies we mentioned in the introduction part. In comparison with the results of Land, Kiani, Diz and Aalaei in the application of data mining algorithms on data from breast cancer despite more data (both for the number of records and for the number of properties) the results of the present study is more confident. Of course, in our study because of choosing the more confident rules first and the clinical expert confirmation, the results are more trusted to use in clinical field [3,8,9].

One of the limitations of the present study was large amounts of missing data. Estimating these values may be affected the results to some extent. Another limitation was the small number of patients for developing a model. The authors suggest further works to have larger databases. Another interesting point in this study is the small number of results. It is obvious that if this method was run to all the rules provided by the software, of course, the result was much larger and more considerable.

The use of data mining concepts, especially in medical data is very useful with considering the large volume of data and unknown relationships between causes of disease and the demographic characteristics. Due to the high number of risk factors, the use of these techniques is effective for cancer data. After pattern recognition these patterns or models provide the future study hypotheses and the next studies, for example RCTs will confirm or reject the hypotheses.

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Roots of Interdisciplinarity in European Medical Informatics

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Abstract. The roots of interdisciplinary of medical informatics are sought through the analysis of the themes approached by the pioneers of this field. The data included in the study comes mostly from "personal stories" of European these scientists collected by IMIA WG History as well as from some biographical notes. Most researchers came from the technical-scientific field, but the double specialization was very common. The proportions of the main topic approaches are discussed. The roots of medical informatics interdisciplinary were formed during the pioneering period, when most major concepts and chapters of medical informatics took contour.

Keywords. Interdisciplinarity, history of medical informatics

1. Introduction

The very name of the field – medical informatics – reflects its nature as an interdisciplinary field, or, as van Bemmel stated: "medical informatics is interdisciplinary *avant-la lettre*" [1]. The gradual development of medical informatics - and health informatics more generally - arose from the overlapping and intermixing of diverse streams of scientific, technological and clinical practice, resulting in a highly heterogeneous group of academic sub-disciplines involving biomedical scientific inquiry, systems engineering, and technology-driven healthcare practices. It is interesting to trace back the roots of these interdisciplinary endeavors, since each subfield has developed differently, and blossomed more or less, depending not only on the degree of success of symbiotic technological and scientific fields, but also on location- and time-specific economic and socio-political factors. The IMIA WG History[2] therefore decided to collect personal stories reflecting how each contributor answered the question: "*How did I start in the field of medical informatics?*" rather than *Who's Who* style biographies. All pioneers in medical informatics had to come from other disciplines while the field coalesced, so the IMIA History becomes interlaced stories reflecting the interactions between people, and their ideas from different scientific schools of thought and diverse technological specialties - and most importantly the clinical practices.

This paper is a qualitative study, partially based on these stories, tracing the most frequent paths by which practitioners of medical informatics entered and developed the field – including which topics proved most challenging in the early days of the field.

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2. Methods

To trace evolutionary changes, we use the eras proposed by Mihalas [2] and limit our survey to the first two periods. From the personal stories collected by the IMIA WG History [3], we have selected those with sufficient detail for grouping them, focusing on those European contributors whose work started in the first two periods, that is, began their careers before 1980. We have also added data from those who started in this period as listed in a number of original sources, and summarized in the set of collected biographies by Masic [4]. All these pioneers came from fields which contributed later to topics in medical informatics, representing the roots of medical informatics, demonstrating the diversity of its origins the interdisciplinary character of the field.

Fifty four biographies were analyzed, of which 43 were 'Personal Stories' written for the IMIA History, and 11 were biographies from [4] with a variety of sources.

The characteristics of the analyzed group are presented in table 1, drawing from:

Table 1. Characteristics of the analyzed group.

Year of graduation							Gender		
before 1955	1956 - 1960	1961 - 1965	1966 - 1970	1971 - 1975	1976 - 1980	Total	Male	Female	Deceased
7	7	8	12	12	8	54	48	6	9

- basic initial background field of the pioneering investigator, including complementary studies,
- professional affiliation, type of occupation or millieu of work within which the first medical informatics topics were approached (academic/university, healthcare unit, industry, other institution)
- medical informatics topics or approaches, both initial and subsequent.

3. Results

3.1. Professional background

Professional backgrounds vary, covering both medical disciplines as well as scientific or technical disciplines. Several people have a double specialization (table 2).

Table 2. Professional background

Scientific / technical (SC)	Medical / life sciences (MD)	Double specialization
44 (81% of Total)	27 (50 of Total)	17 (31% of Total, 39% of SC, 63% of MD)

There is an asymmetry between medicine as the subject of study while informatics/computer science is primarily concerned with the methods and informatics tools. One can conjecture that the informatics researchers and scientists foresaw the great potential of computing technologies for various applications before the domain beneficiaries came to realize it. Fortunately, the mysteries of living matter and the desire to improve human health led to biomedical science research. A high percentage of combined formal specializations is reported: medical practitioners involved in informatics or mathematics/statistics, as well as engineers and mathematicians focusing on biomedicine. More are likely to come from self-study of informatics. In greater detail

from the scientific and technical profiles, the most common were mathematics-statistics (19) and physics (13), with 10 having both, followed by engineering (14), of which 7 specified informatics/computer science. Other profiles included chemistry/biochemistry (4) and biophysics (4). The biomedical stream comprised classical medical studies (20), nursing (2), public health/epidemiology (2), dentistry (1) and psychology (1).

3.2. Professional/Occupational

Early medical informatics practitioners are mainly academic: 41 people started their jobs within various departments of universities, with 9 from university hospitals; 4 from industry with others from regular hospitals or public health or research units. Fourteen were involved in governmental activities or European institutions. The most frequent activities involved coordinating or participating in projects - both national and European, acting as experts or consultants. Education is predominant, leading to important contributions and further development of the field.

3.3. Subfield or Topics

We have used four research challenge areas proposed by Kuhn et al. [5]: bioinformatics and systems biology, biomedical engineering and informatics, health informatics and individual healthcare, and public health informatics – see table 3.

Table 3. Topics approached

Bioinformatics and systems biology	Biomedical engineering and informatics	Health informatics and individual healthcare	Management and public health informatics	Total
8	37	65	39	149

However, these areas interconnect at several levels [6], so a finer granularity offers better detail. Some applications are found in different categories; such as databases, data processing or statistical analyses - both in information systems and public health. Other subtopics, such as standards, protection and security, quality management can apply to several of the general topic categories listed above. To avoid potential duplications we chose mixed topics: databases, data processing and statistical analyses (23), healthcare management and organizational impact (9) and, ethical issues and qualitative assessment studies (5) which were included in public health informatics, in contrast to security and protection, standards and technological assessment (13) which were included in biomedical engineering and informatics. Most people contributed to several directions of research and practice, not unusual or even typical for pioneering periods of all fields. Bioinformatics was minimally represented since the term did not then exist, though molecular biology and genetics did. Systems biology, based on modeling and simulation of biophysical or pharmacological processes were well represented (8). Modeling biological processes preceded computers; now new technology enabled simulation of more complex models. Biomedical engineering was one of the most active subfields as involving parallel progress in processing methodologies - 11 for biological signals, 6 for medical imaging and 3 for telemedicine applications. Table 3 shows most applications are in health informatics, for which a more refined classification is shown in table 4.

Table 4. Topics in the area of health informatics.

Health information systems	Decision support	Electronic health record	Other topics (nursing, guidelines, homecare)	Total
28	16	15	6	65

Health information systems involved 28 while half of them (14) worked on hospital information systems; with others being clinical/laboratory systems or large (national) health information systems. Decision support (16), including expert systems, ontologies or artificial intelligence and EHRs (15) were also most impactful. The complexity of EHR was reported with the need for standards. Applications in the field of healthcare management and public health informatics, the first fostered by healthcare authorities at various levels, interested in more accurate data and reports of indicators for developing strategies and allocation of resources.

4. Discussions and Conclusions

The "personal stories" represent a primary source of information and have been written in a free style, quite easy to read, but, difficult for extracting precise information. The same holds true for the biographies from [4]. For this reason the numbers used in the Methods and Results section should be considered as approximate estimates, though they do provide a qualitative assessment of the main research topics covered by contributors in the early period of medical informatics in Europe. We have not included persons who started their career after 1980, since by then medical informatics had reached the status of a stand-alone discipline and could be an academic choice for advanced studies.

Our study shows that during the pioneering period we find the true roots of medical informatics. Multidisciplinary training and an encyclopedic spirit allowed the harmonious fusion of two major domains - medicine and informatics/computer science. From the simple analysis of the themes approached in early times we can see that some subjects, through their complexity, still persist as the focus of researchers', while others have faded, and new themes have emerged. This kind of study is worth pursuing to follow the evolution of these topics [2] over the full five decades of medical informatics.

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Patients' Use of Health Village Portal: The Central Role of Healthcare Professional Support

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Abstract. Healthcare professionals play a key role in supporting self-care among patients and clients. Their attitudes and behaviors may influence a patient's capacity to use electronic services (e-services) and may increase patients' trust toward a technical solution. The technology acceptance model explains information systems use and the important variables that play a role in an individual's acceptance of e-services. This survey was designed to capture the expectations of healthcare personnel. Participants (n = 91) suggested that patients would benefit from this e-service. The e-services enabled participants to find patient health records more easily than before, and they perceived that the care relationship improved as a result.

Keywords. Health services, Portal, Attitude

1. Introduction

The number of electronic health services available has grown and accessing these services involves challenges not only for patients and clients but also for healthcare professionals. Clients have a wide range of health and social services from which to choose. Studies have suggested that more investment is needed to improve computer literacy and ensure that technologies are accessible for those who wish to use them [1]. In Finland, the public, private, and third sectors have chosen to provide publicly funded electronic health and social services [2]. Online services, care consultants, and service coordinators guide and support clients in choosing the services that best meet their needs [3].

Health Village (Terveyskylä.fi) is a digital interactive secured portal delivering health-related information and services. The portal has been developed jointly with five university hospital districts and patient associations in Finland [4]. Health Village delivers three distinct services: 1) public health services for all citizens, 2) digital care

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pathways for patients with specific diagnoses and care relationships, and 3) electronic learning tools for healthcare professionals to improve working practices. It consists of themed virtual hubs, and there are currently 32 virtual hubs and more than 80 diagnoses served by digital care pathways. To support continuity of care, a national database—Kanta—has been created, which is a core service that also supports Health Village. Using the Kanta service, healthcare professionals can find patients' entire clinical histories in one place [3].

In this study, we expected the use of electronic services (e-services) to improve healthcare professionals' subsequent intentions to use such services. Healthcare professionals play a key role in supporting and engaging patients in self-care [5, 6], and their attitudes and behaviors may influence a patient's capacity to use these services [6]. The technology acceptance model (TAM) suggests that the acceptance of a technology by healthcare professionals can be increased if efforts to improve the technology are directed at how the technology is perceived by them [7]. The TAM is a common and useful model for developing strategies to increase the acceptance of an information technology, as it provides a direct relationship between the acceptance of a technology and its perceived usefulness (PU) and perceived ease of use (PEoU) [7].

The Virtual Hospital 2.0 Project coordinated the work of university hospitals to transform health service access and harmonize care processes. Service provision in the Virtual Hospital 2.0 Project was built around the Health Village concept, which aimed to revolutionize health and wellbeing services using digital methods [4]. The purpose of this study was to determine healthcare professionals' acceptance of and intention to use e-services based on their opinion of its PU and PEoU.

2. Methods

A survey was designed to capture healthcare personnel's expectations of a national, interactive patient portal for self-management developed as part of the Virtual Hospital 2.0 Project [4]. The study focused on healthcare professionals, such as nurses, physicians, physiotherapists, and information system designers, who worked as developers on the Virtual Hospital 2.0 Project. For the present study, we sent a link to an electronic questionnaire to 501 developers at five university hospitals. Data was collected over three weeks in August 2018. Our questionnaire consisted of 50 statements, each with one of six overall themes (attitude toward virtual services, intention to use, usability, information quality, service quality and self-assessment of the project). Data on participants' backgrounds was collected by 11 questions, and there was one open-ended question in which developers could expand on issues of patient portal development.

Acceptance of e-services was measured with reference to their PU (nine statements), PEoU (six statements), attitude toward using e-services (three statements), and intention to use (four statements) [7]. We also tested the effect of background variables, such as age, gender, education level, and experience in the project and in healthcare, on the significant associations found between the independent variables. All statements were measured using a 5-point Likert scale (with 5 denoting strong agreement and 1 denoting strong disagreement). Construct validity of the constructed TAM was tested using confirmatory factor analysis [8]. To evaluate the effectiveness of the research model, we employed structural equation modeling [8] to test whether the research model demonstrated healthcare professionals' perceptions of the e-services' impact on intention to use. The final model presented in the paper includes only significant predictors of

participants' intentions to use e-services. All statistical analyses were performed using SPSS 23 and AMOS (IBM, Armonk, NY, US).

3. Results

Participants (n = 91) believed that patients would benefit from e-services. The e-services enabled participants to find patient health records more easily than before, and they assessed the care relationship as having improved as a result. The participants also raised usability issues, such as difficulty navigating a complex system. More than half the participants were working elsewhere while the developing the project, while around a fifth worked part-time and a fifth full-time, on the project.

Healthcare professionals' attitudes (B = 0.486) toward e-services were significantly associated with their intention to use them. Both PU (B = 0.338) and PEoU (B = 0.536) had a statistically significant effect on the attitudes of healthcare professionals toward e-services. The association between the PEoU of e-services and their PU was statistically significant (Figure 1). PEoU had an indirect association (B = 0.463) with intention to use services.

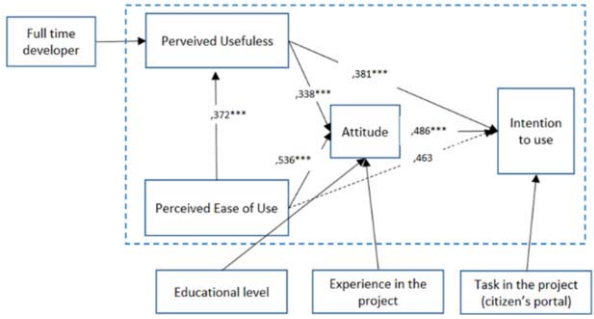

Figure 1. Assessment of the research model ($p < 0.05$).

Participants' roles in the project, especially if this was to do with the public patient portal, were associated with their intention to use e-services. Educational level was significantly associated with health professionals' attitudes, with participants having higher educational attainment being less favorable than those at lower levels.

4. Discussion

This study has demonstrated the acceptance of and intention to use Health Village e-service by healthcare professionals working as developers. The results indicate that the PU and PEoU of e-services influenced professionals' attitudes toward and intention to use such services. The association between participants' attitude toward e-services and their intention to use them was positive. However, participants reported usability issues, such as difficulty logging in and navigating a complex system. Interoperability has been identified as one of the greatest challenges in healthcare IT, and it is seen as one of the key drivers of the success of e-services and healthcare provision [1,5,6]. The results of the present study suggest that more investment is needed to ensure that technologies are accessible for those who sign up for them [1].

Healthcare professionals play a central and critical role in supporting patients; their attitudes and behaviors may influence a patient's capacity to use services [1,6] and increases patients' trust toward a technical solution [1,4]. Our findings provide insights into the implementation phase, which is considered critical to success [1,5]. Healthcare professionals' estimated that patients would benefit from the virtual hubs [5,6]. Ease of use was a key facilitator in this study, which has been cited in other studies [7].

The strongest predictor of acceptance was the usefulness of the e-services. Usefulness for patient care was high and the usefulness measure correlated with healthcare professionals' attitude toward e-services and their intention to use them. This suggests that as healthcare professionals, they were concerned with providing optimal patient care and offering patients' new opportunities to become active participants in self-care. Patient portals hold much promise for bringing together patients and providers, especially outside of traditional office visits. The use of portals can be facilitated by technical assistance and both family and provider advice [1,4,5]. It is essential to conceptualize the patient portal as a dynamic component of the care relationship and to emphasize care coordination between patients and providers. Healthcare administrators should incorporate the impact of portal access into capacity planning and resource allocation, ultimately aligning patients' and providers' needs with the functionality of e-services to enhance care delivery [1,2,5].

The limitations of our findings should be acknowledged. This study sampled developers from university hospitals in the Virtual Hospital Project in Finland. The response rate was relatively small within each organization, but the combined data made it possible to conduct statistical analyses and allowed a preliminary interpretation of the study results.

To conclude, patient portals offer a promising mechanism to support patient engagement by increasing communication between patients and providers. If the services are professional-centered today, then the use of the National Health Village means, that in the future, services will be patient- and client-centered.

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Children's Immunisation in Europe – A Vision of Using the HL7 International Patient Summary to Transform Local Data into Child-Specific Information and Population Health Knowledge

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Abstract. Immunisation is a key preventive health measure for children. E-health applications have been used for over 50 years, yet still there is no harmonization or standardization, while uncoordinated policy initiatives proliferate. Two EU research projects (Trillium II and MOCHA) have come together with experts and stakeholders, and used EU-wide situation analysis research to seek to stimulate development of data and process standards as a harmonizing force in a supporting policy environment, putting the child as the central data collation unit.

Keywords. Child health; immunisation; data standards; summary record

1. Introduction

Immunisation is a key component of preventive health services for children. However, as health systems are a national competence, immunisation is delivered and recorded by different means in each country, and often by different agencies within a country. In this disparate process, information about an individual child can be fragmented and not always linked. Consequently, some children may not be fully protected because of lack of continuity in their receipt of planned protections, while there is also a risk of over-immunisation. Thus, from a child-centric perspective, data at the encounter level may not be aggregated to the crucially important and core purpose child level information.

Secondly, not only is analysis of the overall level of protection for children important to ensure their immunity – witness recent concerns about population vulnerability to measles due to reduced child population immunity levels [1, 2] – but there is also much that can be learned about immunisation related delivery and population behavior if this case-level information is aggregated effectively to a level of population-based knowledge. For instance, in the current climate of concern about the harmful effects of vaccine resistance, there is little understanding of how many children' immunizations are deferred because of a short-term illness (or holiday) but then not completed due to

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follow-up failure, how many times vaccine supply or other organization problems are to blame, and how many parents are genuinely hesitant, but are not identified as such for more personalized explanation and reassurance.

More recently, within the European Union, several well-intentioned proposals have arisen to increase immunisation protection, but these too are uncoordinated. This paper reports a follow-on to a recent initiative instigated by the Trillium II [3] project of the HL7 Foundation, and the Models of Child Health Appraised (MOCHA) [4] project, both funded by the European Commission's Horizon 2020 Research and Innovation programme, through events hosted by CEN and WHO, to seek to instigate some cohesion based on information management and use of data standards and an International Patient Summary dataset as the core [5].

2. Digitization of Immunisation Records and Scheduling

Use of computers to schedule and record immunisation is a very early European digital health application, having started more than a half-century ago [6], and even at that time evaluated as being cost-effective [7]. That led to a series of local and national implementations in many countries, but then also a lack of continuity as policies vacillated between innovation, devolution to localities, and integration with generic and adult focused records and commercial EHR systems [8]. The net result is a lack of European standards or functional specifications, and a fragmentation of immunisation delivery. However, many countries have their own case-based child public health records, with a split between those which actively schedule, monitor uptake with identification of those out of schedule, and passive recording (Table 1).

Table 1. Functionality of Child Public Health Systems in Europe (Source: [8])

System Directly Schedules Appointments	System advises Provider of Children Overdue	Passive Record
Czech Republic	Czech Republic	Croatia (SA)
Denmark	Denmark	Finland
Estonia	Estonia	Malta (SA)
Iceland	Hungary (SA)	UK (Wales)
Spain	Iceland	
UK (Northern Ireland and Scotland) (SA)	Ireland (SA)	
	Italy	
	Norway	
	Romania	
	Spain	
	UK (England) (SA)	

All use a form of automated data exchange unless marked Stand Alone (SA)

At the same time, the European Centre for Disease Control (ECDC) has called for countries to develop Immunisation Information Systems, which record and produce person-centered summaries of immunisation, including travel and other vaccinations, and for all ages [9]. There is strong synergy between the objectives and survey findings between MOCHA and ECDC. One key element of this is the lack of formally agreed data standards, or functional specification for proactive functions. In short, in 50 years little progress has been made on building on validated foundations.

3. A Confusion of Initiatives

Recognizing the importance of immunisation for children, and aware of falling rates and of vaccine hesitancy, several European agencies have recently proposed initiatives.

The World Health Organization Regional Office for Europe, in its European Vaccine Action Plan (EVAP) 2015–2020, stated priority areas for action, so as to ensure that all countries are able to "provide equitable access to high-quality, safe, affordable vaccines and immunisation services throughout the life course" [10]. The Council of Europe has proposed a range of immunisation supportive information projects including a European Vaccination Card [11]. The EU Expert Panel on Effective Ways of Investing in Health (EXPH) has recommended more activity to address vaccine hesitancy but not looking at investing in record or delivery systems [12]. WHO globally issued guidelines on home-based records to include immunisation data without specifying the data items [13]. The WHO-linked organization TechNet-21 advocated home-based records primarily as an immunisation support but again without more detailed content specification [14].

Significantly and of concern, particularly in an era of digital health, none of these initiatives suggests how data may be created, managed, linked, or progressed to child-specific information or system knowledge, though those objectives are implied.

4. The Trillium II and MOCHA Initiative to seek Digital Harmonization

Given this agitation of interest and confusion of concern, the Trillium II and MOCHA initiatives saw a need and also an opportunity to work in tandem, based on the hypothesis that data standards, and the International Patient Summary [15], might provide a way forward. A collaboration protocol was signed.

First, an analytic workshop was held in September 2018 in Brussels [16,17]. This meeting proposed a stakeholder workshop, for which it set an agenda of issues for discussion. This Stakeholder Workshop was then held at the WHO Regional Office for Europe in November 2018. Five immediate short-term actions were agreed as important, and six longer-term actions which should be explored if resources could be identified [5].

Within the context of health informatics, key issues were:

- Boosting the International Patient Summary (IPS) immunisation component with an indicator of reason for non-immunisation.
- Addressing gaps in health data standards for child health; autonomy and consent in patient summaries for adolescents; common interface to immunisation registries; and child patient summaries for children at school.
- Examining the feasibility of supporting the European Vaccination card as part of the roadmap for CEF eHealth DSI, addressing coding issues.
- Exploring the support of patient summaries to children with complex needs, developing further the care plan component for the IPS
- Developing the Application Programming Interface (API) to retrieve patient summary immunisation component with Immunisation Registries to extract up-to-date information.
- Exploring validation of patient summaries in Portuguese community Pharmacies (where immunisations are given in Portugal)

5. Conclusion

Childhood immunisation is an important public health concern. Despite 50 years of experience, digital health is not being used optimally, while in a wide policy context numerous initiatives are being proposed without either cohesion of consideration of Data, Information and Knowledge as the foundation. This two-project initiative seeks to bring some standards-based harmonization, to the potential benefit of Europe's children.

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The Limited Extent of Accreditation Mechanisms for Websites and Mobile Applications in Europe

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Abstract. A potentially useful resource for health promotion and guidance is eHealth. However, this field also presents challenges, and one of the most important obstacles is the lack of regulation, without which citizens including young people may be exposed to misleading or risky information and applications. The aim of this study was to investigate the extent of accreditation processes for mobile applications (apps) and websites in European countries, to determine whether regulation is on the agenda. A survey was conducted in 28 European Member States and 2 European Economic Area countries, between 2017 and 2018. Twenty-seven responses were collected. Six countries have accreditation processes for apps and eight countries have accreditation processes for websites. However, processes are fragmented and there is variety within and amongst countries.

Keywords. mHealth; eHealth; mobile applications; apps; websites; accreditation.

1. Introduction

Health promotion, and citizen access to health information, are fundamental to improve health outcomes within the context of primary healthcare. Major challenges for effective health promotion are the unprecedented global changes in society due to population growth, urbanisation, and technology developments [1]. Resultantly, new approaches to address the changing needs of society and the broader determinants of health are desirable; one such approach is electronic health (eHealth).

The European Commission defines eHealth as the use of information communication technologies to enhance prevention, diagnosis, treatment and other areas of healthcare [2]. It is an umbrella term comprising websites and mobile health (mHealth), amongst other technologies. eHealth could provide benefit to entire communities, reduce social barriers, and increase health sector efficiency. Therefore, support for eHealth in the healthcare field is widespread [3].

Traditionally patients have relied on medical professionals for health information, which has provided clear, personalized, and evidence-based recommendations [4].

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However, since the early 2000's, eHealth website usage has rapidly increased. Websites provide financial benefits, reduce time burden on general practitioners, and increase social support amongst internet users [5]. However, along with these benefits comes the risk of uncensored websites with unverified information. This is because different providers create websites with different agendas, leading to information that varies in terms of credibility and expertise. In response to this, a non-governmental organization accredited to the Economic and Social Council of the United Nations, Health On the Net (HON), was created to enable a provision for websites to provide useful and reliable health information to citizens [6].

Under eHealth, mobile health (mHealth) has emerged as a popular health tool. Mobile applications (apps), games and short messaging service (SMS) [7], allow patient empowerment and promote a participative role rather than a passive role in patient healthcare [8]. However, similar regulatory issues exist with apps as with websites. Moreover, they may capture personal data about users, and use this for undisclosed purposes. Another major criticism is the inadequate testing mechanisms and the weak evidence base.

Assessment of the extent to how effective eHealth and mHealth initiatives are is one supportive objective of the Horizon 2020 funded project Models of Child Health Appraised (MOCHA) [9]. This study, embedded within MOCHA, aimed to create an overview as to whether countries have considered accreditation processes for apps and websites for health promotion.

2. Methods

To assess whether countries had considered/the state of development of accreditation of apps and websites a semi-structured survey design was used to collect data. The analysis was conducted through MOCHA, which retains a local expert in 28 EU and 2 EEA countries to collect country-specific information. The question underwent a strict peer review process to ensure scientific validation before being sent out to these experts, known as Country Agents.

Data collection occurred between 2017 and 2018. MOCHA Country Agents were asked to complete the questions on the basis of their expertise, or in cases where this was not possible, to gather data from other sources or national experts on individual questionnaire items. The replies from all countries were analysed using descriptive statistics.

3. Results

Responses were received from 27 countries. Majority of countries have no accreditation process for apps or websites. A full analysis of the results is available elsewhere [10].

3.1. Health mobile applications (apps)

Six countries mentioned that they accredited apps: Estonia, Germany, Portugal, Slovenia, Spain, and the UK (Table 1); of which the UK describes the most formalised process.

Estonia described a Child Helpline Service app, coordinated by the Medical Consultation Centre, which provides a nation-wide family doctor advice line service. In Germany there are currently small, unofficial bodies, internally regulating health apps. However, the federal government and special interest groups have recognized the need for quality assurance and a regulated national accreditation scheme. Although Portugal reported an accreditation process for apps, no further details were provided. Spain described autonomous regions, such as Andalusia and Catalonia, having accreditation processes for health apps called 'Distintivo AppSaludable' and 'AppSalut', respectively. In Slovenia, the 'Slovenian Institute of Quality and Metrology' (SIQ) is responsible for certifying apps, which are certified in the same way as other medical equipment or medical devices. In the UK, the Medicines and Healthcare products Regulatory Agency (MHRA) accredits apps that meet the definition of a medical device, an *in vitro* diagnostic device, or an active implantable medical device. The National Information Board will accredit apps that do not meet these definitions. Collaborations with the Department of Health, NHS England, Academic Health Science Networks, NHS Digital, and Public Health England aim to provide citizens with access to accredited apps.

Table 1. Countries reporting accreditation processes for mobile applications and websites.

Countries	App accreditation	Website accreditation
Austria		♦
Croatia		♦
Estonia	♦	♦
France		♦
Germany	♦	♦
Portugal	♦	♦
Slovenia	♦	
Spain	♦	♦
United Kingdom	♦	♦

3.2. Health websites

Eight countries mentioned the presence of an accreditation process for websites: Austria, Croatia, Estonia, France, Germany, Portugal, Spain, and the United Kingdom (Table 1).

Austrian health-specific websites use quality seals for accreditation, in order to present transparent health information. The two quality seals are the HON code and the afgis seal. The *Aktionsforum Gesundheitsinformationssystem* (afgis) is an association promoting the quality of health information on the internet by awarding a quality seal to websites that are eligible. In Austria, the Institute for Quality and Transparency of Health Information is obliged to ensure that industry does not influence the content of health websites. In France, information quality is crucial and is monitored by supervisory and public authorities using the 'HON certification'. The HON code is also used in Germany. Alongside this, the Federal Ministry of Family Affairs promotes and endorses certain websites. Additionally, it also regulates and removes websites harmful to children. All existing websites in Portugal are institutional websites and are therefore accredited by the providers. Health websites in Spain are accredited through various bodies, including but not limited to, the HON code, MedCIRCLE (a project funded by the European Union), and the Code of Conduct for Medical Websites Certification Program. In the UK, The Information Standard (run by NHS England) ensures rigorous assessments for health websites to guarantee high quality information. Members of the organization receive the right to display a logo on their website, which acts as a clear, visible quality mark promising users high quality information.

4. Conclusion

A survey into the accreditation processes of apps and websites in the EU and EEA showed that very few countries report having an established validation protocol. Processes mentioned vary widely for apps since they are generally not considered medical devices according to EU regulations. Accreditation mechanisms for health websites are also uncommon, even though they are one of the most popular sources for obtaining health information. A few countries showed similarities in using the HON code to accredit their websites. Results from this study indicate that further efforts through policy decisions and health authorities are needed to regulate apps and websites for health promotion information, to protect citizens from known risks of misleading information [11, 12]. The processes are still at an early stage and further work is needed to harmonise accreditation processes both within and between countries.

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Implementation of USSD Technology to Improve Quality of Routinely Reported Health Data in a Resource-Limited Setting

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Abstract. Health decision-making is heavily premised on routinely reported data from lower levels of healthcare delivery to the national level. The reported data are of best use if their quality is high. Unfortunately, in many resource-limited settings in sub-Saharan Africa, the quality of reported data is often poor. Among the reasons attributed for poor data quality is use of sub-optimal modalities for collecting and transmitting data, such as paper-based and Short Message Service (SMS). Through a user-centered approach, we developed and implemented an Unstructured Supplementary Service Data (USSD)-based health data reporting intervention in a district in Uganda. The impact of the developed system on report accuracy, timeliness and completeness was evaluated against the expected 100% rates by the Ministry of Health (MoH). A total of 224 reports were submitted over the two-month study period. Of the submitted reports, 171 (76.3%) were complete ($p < 0.0001$) compared to MoH's required 100%). 161 (71.9%) were accurate ($P < 0.0001$), and 158 (70.5%) of the reports were submitted on time ($p<0.0001$). The deficiencies were largely attributed to a few facilities, as only 17.9% of facilities had data discrepancies with a mean of -2.11 (P=0.38), 96.4% (0.130) of the facilities had complete reports and 87.4% (0.100) of the facilities reported on time. Poor network coverage was an outstanding challenge to reporting.

Keywords. Data Quality, Unstructured Supplementary Service Data (USSD), Routine Health Information Systems, Low- and Middle-Income Countries.

1. Introduction

Health system performance depends on production and use of quality health [1]. A functional Health Information System (HIS) avails the right information into the right hands at the right time to aid decision-making, and hence the data it holds should be of good quality [2]. Routine health information systems (RHIS) provide information at regular intervals to address predictable health information needs [3] and are a vital component of any efficient, country-owned and integrated HIS.

In low-resource settings, RHIS have long relied on a paper-based mechanism for reporting of health data. Paper-based reporting approaches are fraught with quality control and portability limitations, which escalate with increase in geographical spread

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[1]. Given the mobile phone's ubiquity and affordability, (SMS) has been adopted for health reporting to address challenges of the paper-based modality. However, SMS also has challenges such as need for complex and inflexible syntax to enable fitting as much information into a single SMS, and inability for immediate data validation which negatively affects data quality [4]. Given the aforementioned limitations of the currently used methods of health data reporting from lower levels of healthcare delivery to the national level, we set out to evaluate an alternative, yet affordable, aggregate health data reporting system and evaluated its impact on quality of data reported.

2. Methods

2.1. Study site and Participants

This study was carried out in Mpigi district in Uganda at 28 health facilities which were both private and public offering various levels of care, and using paper or SMS-based reporting systems. Facilities were selected using MEASURE Evaluation's measure of relative variance facility sampling method [5]. Study participants were purposively selected to include: (1) health information assistants, who are charged with data management at the selected facilities, and (2) the district biostatisticians responsible for data management of the reported data at the district level.

2.2. Developing of the USSD-based data reporting intervention

To identify the approach to improve quality of data reported from the lower levels of healthcare delivery to the national level, we first conducted in-depth interviews with the study participants to elicit existing challenges to data reporting and opportunities for improvement of the existing paper-based and SMS-based reporting systems. Based on the interview findings, we determined that an approach based on USSD, a Global System for Mobile (GSM) technology, used to facilitate communication between a mobile phone and an application in a network, [6] would offer improvements because USSD: (a) was available even on lowest-end handsets, (b) was more secure than SMS, (c) was affordable, (d) allowed for reporting in a single session, (e) allowed for menu functionality therefore eliminating complex syntax seen with SMS-based systems, and (f) allowed for data validation prior to report submission. The server-side of the USSD-based reporting system was developed using the java programming language with an open Application Programming Interface that allowed it to integrate with the national data aggregation system, DHIS2.Through a user-centered approach, the following workflow was identified for the mobile side of the reporting system: (1) a user on their phone could dial the USSD code, (2) they would then access the data reporting menu, (3) they would follow the USSD prompts to complete their report, (4) when they were ready to submit report, they would be provided an opportunity to make edits after validation of data, and (5) they could submit the data to the integrated reporting system (Figure 1).

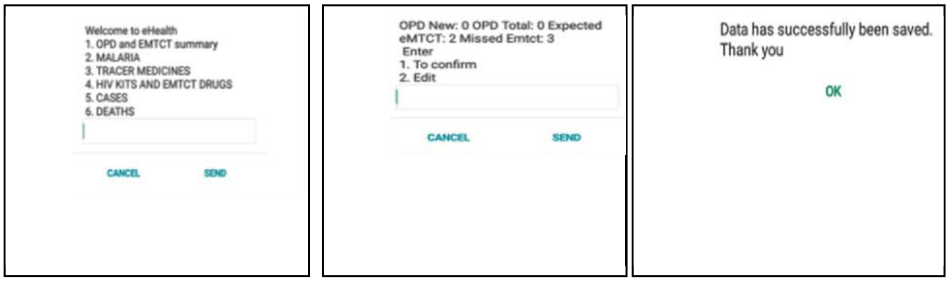

Figure 1. Screenshots for phone USSD-based Reporting Interface

2.3. Implementation of the USSD based intervention

The developed application was availed to users through a USSD code (*270*225#) accessible from different GSM networks in Uganda. Reports for mandated MoH weekly surveillance were submitted from peripheral facilities to a central server using the USSD system on a weekly basis for two months.

2.4. Performance of the USSD based intervention

Data quality of weekly reports submitted through the USSD-based reporting system was evaluated using a quantitative questionnaire adapted from the Performance of Routine Health Information System (PRISM) framework [7]. Dimensions of data quality assessed included data accuracy, timeliness and completeness. Reports were complete if all the data elements required to be reported had values in them, accurate if the mean discrepancy between the values transmitted to the central server and those in the source document was ±5 and timely if the reports were submitted before the nationally-recognized deadline. The performance of the USSD-system was compared using a chi-square test against the Ministry of Health standards for reporting, which required 100% timeliness, 100% completeness, and an accuracy with a mean discrepancy of ±5 per report. P-value used was 0.05.

3. Results

Key informant interviews revealed the following challenges with the existing SMS system: (a) difficulty in learning the syntax required for SMS, b) the vulnerability of SMS format to mistakes, c) the poor feedback loop with SMS-based data transmission, and d) network problems. Paper systems were deemed time-consuming, required higher levels of human resource that were not available, and had high transportation costs.

A total of 224 reports were submitted over the two-month study period. Of these reports 171 (76.3%) were submitted complete ($p < 0.0001$) by 96.4% (0.130)) of the facilities compared to MoH's required 100%). 161 (71.9%) were accurate (with mean discrepancy of -2.11 for all reports which was within the range permitted by MoH) ($P < 0.0001$), and 158 (70.5%) of the reports were submitted on time ($p<0.0001$) by 87.4% (0.100) of the facilities. The deficiencies were largely attributed to a few facilities, as

only 17.9% of facilities had data discrepancies (P=0.38) with a mean discrepancy of -2.11.

4. Discussion

Current paper-based and SMS-based reporting systems within resource-limited settings are suboptimal, and USSD-based reporting systems offer a scalable and affordable approach to provision of accurate, timely and complete reports though their implementation has to be monitored especially for underperforming facilities.

The user-centered approach to developing the intervention ensured that characteristics, needs and challenges of users were addressed [8]. Next steps to this work include comparative assessments of SMS and paper-based reporting systems against the USSD system. Further, there needs to be close monitoring of use the USSD system over time and an assessment of user perceptions of the USSD system.

5. Conclusion

A USSD-based system for reporting resulted in timely, accurate and complete reporting in the resource-limited setting of Uganda. However, to scale USSD systems, good GSM network infrastructure is required.

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Measuring Patient Experiences from Intensive Care Units to Improve Health IT Systems and Nursing Care

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Abstract. The purpose of the study was to investigate the experiences of discharged patients from Intensive Care Units (ICUs). A study with retrospective data collection (n= 112) was conducted via interviews using the Intensive Care Experience Questionnaire. 93% of participants reported positive experiences from the ICU. Frightening experiences were restricted to minimum levels (mean score=9/25), while the feeling of security was prevalent (96.5%) and care satisfaction was high (mean score= 18.2 / 20). Communicating the aforementioned experiences, professionals may better understand patients' needs in order to improve the IT systems and patients' hospitalization.

Keywords. Intensive Care Unit (ICU), patient experiences

1. Introduction

ICUs present challenges that are not encountered in other healthcare facilities to the same extent. Acute and critical illness, mechanical respiration support and suppression are just some of the ICU's particularities, making it a demanding and stressful environment [1]. The aim of study was to investigate the experiences of patients who were hospitalized in an ICU and based on them to examine potential improvements on the provided healthcare services as well as on the Health IT systems.

2. Methods

This is a non-invasive, cross-sectional study with retrospective data collection conducted in 2018. The study sample consisted of 112 adult patients discharged from the ICU of Papageorgiou Hospital and 424 GMTH. The Data collection was conducted by the principal investigator via telephone interviews with patients (response rate was 62.2%) after obtaining their consent. The Intensive Care Experience Questionnaire (ICEQ), was

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used to carry out the survey [2] after conducting a backward translation in Greek. The ICEQ is a valid instrument used [3,4], focused particularly on evaluating patients' experiences [3,4]. A pilot survey (n= 20) was carried out to test the reliability of the questionnaire [5]. Results of the pilot study documented high reliability and acceptable internal consistency. Data analysis was performed using IBM SPSS 21.0.

3. Results

The majority of the participants (93%) reported positive experiences from the ICU. In particular, 85.7% of the participants stated that they were provided with understandable information and 62.5% had the opportunity to choose. Also, 96.5% of the participants claimed that they felt safe, most of the time, 90% agreed that the ICU was not noisy and 68% were able to distinguish day from night. Bad dreams seemed not to be a common condition (4.5%) and only 10.7% experienced pain, at some time. Regarding to the analysis of the open-ended questions (n=78), staff behavior was reported as one of their best experiences at the ICU (40.2%). Correlation analysis showed that patients suffering from pathological diseases and those who underwent a scheduled surgery had a better perception of their disease (p=0.021). More frightening experiences were expressed by patients with unscheduled surgery (p=0.008), women (p=0.025) and patients with mechanical ventilation (p=0.002). Patients with a higher socio-economic status expressed a greater desire to find out more about what happened (p=0.048).

4. Discussion

Patients from both hospitals expressed positive experiences that coincides with other studies [2,3]. Moreover, the increase in the socio-economic level was associated with a greater desire of the patients to find out more about what happened. Considering the aforementioned results, it is important for healthcare professionals to take into account the patients' experiences in order to provide quality services and improve the patient's care. It is also suggested that mechanisms for the assessment of patients' experiences through IT applications (e.g. automated sending of electronic questionnaires via mobile phone) should be implemented. Additionally, an electronic database of patients' experiences and a time-based analysis/interpretation of the results, within the context of implementing measures to improve the quality may contribute to the provided care.

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Moving Towards a Blockchain-Based Healthcare Information System

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Abstract. One of the major problems that a national health system face is the lack of a unified clinical data management. In Greece, the critical and sensitive medical data generated during a patient lifetime are fragmented in one or more hospitals and healthcare services are not characterized by a 'continuity' factor. There is not the appropriate technological and administrative infrastructure for a unified patient medical history, prescriptions, laboratory tests or therapeutic plan. Technological, administrative and economic factors have led to this situation. We propose the integration and implementation of a blockchain network as a complementary technology to the existing information systems, so reliable and effective information management could be provided by a healthcare organization or the national healthcare system. Blockchain technology could be implemented as a bridge that can provide information systems interoperability within a hospital or between different hospitals.

Keywords. health information management, integrity, availability, interoperability, blockchain technology

1. Introduction

A patient may visit various hospitals or clinics along his/her lifetime and should be able to provide the necessary data access authorization to healthcare professionals. Health information must be distributed among the health care providers involved, such as hospitals, pharmacies, laboratories or relatives. At the same time, nowadays challenges require more and more accuracy in storage, management and access of medical data. Also, medical data can be exploited for economic reasons and they often are target of "cyber attacks" [1]. In Greece, the required infrastructure has not been implemented and hospitals are not interconnecting for the exchange of medical records of a patient. This is essentially due to the architecture and design of IT systems installed in hospitals and it is still a difficult task in both the technological and administrative level.

Blockchain networks are an innovative technology that has been grown rapidly in recent years, mainly in financial services with the use of 'cryptocurrencies'. There are

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reviews that address the potential usage of blockchain in healthcare field and, specifically, in the field of data management and data exchange [2].

MedRec is a proposed solution that implements a decentralized record management system to handle EHRs, using blockchain technology. The main participants are the patients but the system uses APIs to integrate with medical stakeholders for interoperability. It supports an Ethereum blockchain, 'smart contracts' technology and a cryptographic hash to ensure authentication, confidentiality and accountability in data sharing. Additionally, Guardtime is a blockchain-based framework in Estonia. Patients have a smartcard that links their medical data with a unique blockchain-based identity and all updates in their health record are specified by a hash and recorded in a blockchain. Its purpose is to guarantee that any modifications to the healthcare patient record are secure and auditable [3].

The lack of communication and interconnection within the hospital itself as well as between different hospitals of the national health system in our country can be met with the advantages of blockchain technology. Such an implementation, in essence, is suggested in this paper.

2. Methods

The structure of the information systems in Greek hospitals is based on a patient-centered logic, where the patient is the benchmark and health services, such as hospitalization, prescribing, costing, laboratories, pharmacy, surgery, administrative and financial management, are developed having him on the centre [4]. Communication between these subsystems is implemented by the development of a HL7-based interoperability interface. The intermediate HL7 subsystem (middleware) works independently and is directly connected to the database. A specific network security plan is implemented (security policy) supporting user roles, password management, access rights, auditing and log files.

A blockchain is a ledger (a database) that stores and verifies data that are typically organized in blocks using cryptographic methods and in such a way as to create a continuous data-chain (scalability). Each block contains a timestamp that links it to the previous block, and each event requires acceptance from the most of the network users while the changes in data are always logged so they can be traced and checked. There is not a central maintenance authority but only 'nodes', that are users who update the ledger, at the same time, for every change to it, and everyone always has the same status of the ledger [5]. All transactions are recorded in the ledger and are publicly accessible at any time, increasing this way the data transparency and security.

3. Results – Proposed system

3.1. Proposed blockchain – based system into a hospital

The blockchain network within a hospital should be a private network and its users must be the professionals who generate and manipulate information through health care procedures [6]. Additionally, it should be taken into account that the blockchain system should essentially operate as a complementary tool and will not replace the current information system entirely. Blockchain technology may handle any kind of information like medical history, prescribing, treatment plan or laboratory results but very big data

files can cause delays to the speed and the performance of the network. There must be criteria and limitations related to the storage and processing requirements of the system [6]. The main concern of our work is to propose a functional blockchain infrastructure within a hospital in order to overcome the communication and integration barriers among the different information subsystems.

The blockchain network should be implemented as a bridge linking the hospital's central information system with the independent subsystems. In each independent subsystem, along with the central one, nodes (users) can participate in the blockchain network, along with participation in the standard health information system. The nodes communicate directly with each other through the blockchain network and faster data processing is ensured. Every node is composed of a function-call APIs, an Ethereum client and a health record manager with access to a database [7].

3.2. Proposed blockchain – based system among hospitals

A patient, during his life, may need to visit more than once different hospitals in the country. The clinical data that concerns him are scattered over time in different information systems. Blockchain technology could help to unify a patient clinical data at hospitals interchange level.

Such an implementation could provide the appropriate infrastructure for continuing patient health care, a goal that our national health system cannot face for decades. The blockchain network will, in this case, be private and specific nodes will be representing the country's hospitals. Cloud technology will also be a key feature of peer-to-peer communication. In order to be achieved higher level of security and scalability, only high-level data will be stored on the blockchain network (on-chain high level data), such as metadata, transactional information and audit records, which will contribute to reliability of the systems communication. Other high volume clinical data will be stored in the current RDBMS (off-chain data) and metadata and links stored into the blockchain will ensure the data integrity [8]. An Ethereum is been used for data access management and APIs for access to the cloud services (Figure 1).

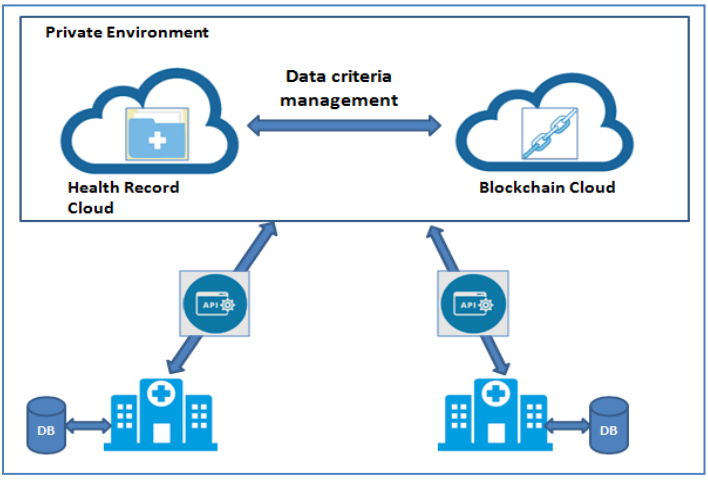

Figure 1. Hospital interoperability through blockchain network.

4. Discussion - Conclusions

This work, initially, highlights the problem of interconnectivity and lack of communication of healthcare information systems that are operating in a hospital environment, but also between different hospitals in the Greek territory. The reasons that have led to this situation are related to technological, administrative and economic factors over the last few decades. The solution proposed is the implementation of a blockchain technology, which has recently been applied in many fields of healthcare. Through this, it is possible to be achieved an integration of clinical and administrative data in terms of reliability, security, extensibility of structures, data integrity and speed processing [9].

There are limitations that have been already arisen in blockchain–based systems. The main concern is that a blockchain platform maintains a large volume of data and all blocks are stored on every node in the system. So, computational power and cost-effectiveness issues must be addressed. The proposed implementation may complement existing infrastructures and technologies rather than replacing the standard health information systems. A blockchain network can ensure more reliable and effective information management to a health network. Many health blockchain implementations have already been evaluated, useful conclusions have been drawn and relative concerns should be taken into account according to the difficulties of a transition process of standard information systems to the blockchain technology [9]. Furthermore, these results could lead to more effective solutions for genomic data sharing as there are many legal and privacy issues that have to be addressed in this field. Decentralized blockchain-based platforms are more proper in managing active participation of patients or medical stakeholders in data sharing [10].

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Blockchain as a Process Control Tool for Healthcare

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Abstract. The blockchain is one of the most popular information technologies and, at the same time, it was discredited by stories about crashes of multiple cryptocurrency projects. Even though this technology has recently found application in many areas not related to cryptocurrencies, mainly for security purposes, the attitude towards it remains wary. Herein we shall try to demonstrate that blockchain is something going far beyond cryptocurrency and security issues, and may become one of the fundamental information technologies in future healthcare.

Keywords. Healthcare, blockchain, smart contracts, distributed processes

1. Introduction

The technology of distributed ledgers (blockchain, BCT) has caused so much noise that it can be compared with .com boom of the early 2000s. In most cases, the word "blockchain" is used in conjunction with the word “cryptocurrency,” and is accompanied by stories of both unprecedented enrichment and deafening crashes. It is not surprising that serious business began to be interested in it somewhat later and still the number of successful projects outside the financial sphere is not so big, though the number of publications grows very fast. Most of them are dedicated to various security and privacy issues. The same picture we observe in attempts to use BCT in healthcare.

Herein we will present our view how BCT can improve the efficiency of certain processes in healthcare. It is necessary to note that one can find many publication concerning applications of BCT in healthcare (see reviews [1],[2]) but practically in all of them the role of blockchain is limited by problems of security and privacy. No doubt these topics are extremely sensitive in healthcare, but it does not exhaust many areas where blockchain may be applied. The aim of this paper is to deliver a sketch of possible applications of blockchain in medical processes, where doctors may appreciate the strength of this technology. Our opinion is based on several projects implemented in industry, mining, and logistics, and many years of work in medical informatics, what allowed elaborating a new approach to BCT: to treat blockchain technologies as a tool for process control.

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2. What is a blockchain?

The technical essence of the BCT is rather complicated, but its deep understanding is not necessary for understanding the idea of this submission. One can find popular but accurate statement of the BCT in [3]. We will only talk about its business and process components.

At a first glance, the blockchain is a heavy, redundant, inefficient technology that solves exactly one task: monitoring compliance with agreements (consensus) in processes with many independent participants. The strengths and weaknesses of the technology complement each other. Transparency is complemented by absolute inflexibility, the inability to cancel/change a transaction by the difficulty of correcting errors, the consistency of the rules by the complexity of their even regulated changes.

Is this technology a breakthrough? Yes and no. Yes, being applied adequately, it can significantly improve the efficiency of processes and even form a new paradigm of interaction between the participants. At the same time, in most cases it is meaningless to implement technology in parallel to existing processes without changing them: this will only complicate the process.

So, what is a blockchain in the context of this paper? It is a technology that allows to set immutable and accepted by all independent participants of information processing rules and to guarantee the absence of workarounds and falsifications.

3. Evolution of technology

- **Blockchain 1.0** The association of the blockchain with cryptocurrencies is quite understandable: the technology itself was developed as a key element of the information security system for Bitcoin - the first cryptocurrency. The technology guaranteed the absolute reliability of transactions among anonymous users. Punctures happened, but in general the place of technology was clear. "Distributed ledger" is a principal concept of this stage ([4]).
- **Blockchain 2.0** appeared with the developing of Ethereum ([5]) - platform and cryptocurrency. Its key feature is the ability to consider business logic by creating so-called “smart contracts.” A smart contract is an instrument of fixing business rules accepted by all participants and unchangeable. That is what led to the ICOs (Initial Coin Offering, the cryptocurrency space's rough equivalent to an IPO in the mainstream investment world) popularity - attracting investments for distributed projects, most of which ended in a crash. But it also allowed the use of block-chain outside the financial sphere.
- **Blockchain 3.0** This is the stage when business became interested in technology. At this stage blockchain is considered as a mechanism of guaranteed compliance with the rules by participants in an atmosphere of total distrust (in the best possible sense of the word). The technology allows creating a trusted space that is not controlled by anyone of the participants, and ensuring compliance with the rules of the game. Roughly speaking, the business process cannot proceed to the next stage until all the lights come on and it is impossible to fake the switching-on of a light bulb. This approach allowed implementing numerous interesting projects, and its main merit is equalization of the rights of

all participants. At this stage "distributed ledger" is transformed to "distributed log" ([6]).

- **Blockchain 4.0** Nowadays the technology is on the verge of another evolutionary leap. While retaining the advantages of the second and third stages, blockchain begins to play two new roles: the integration layer and the regulator of relations in distributed communities.

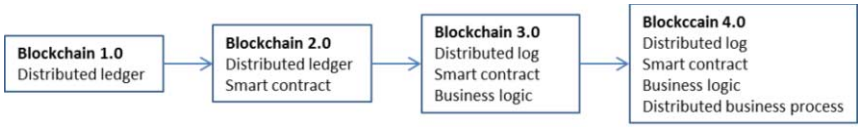

Figure 1. Each stage is characterized by the concepts that distinguish it from the previous one.

4. Blockchain in health care processes

In this section, we will formulate hypotheses about the applicability of the blockchain in various processes in the healthcare sector. The fact is that so far there are no serious projects implemented in healthcare domain. The aim of our presentation is to attract attention to the potential of Blockchain 4.0 in healthcare.

4.1. Managing Queuing Flows in Clinical Studies

When conducting clinical trials of drugs, there raises the question of the exact match between the study rules and patients participating in the research. In fact, there is a process of balancing two counter queues. This process should be strictly formalized and not allow human intervention, except in exceptional cases. The place and role of the blockchain in this case is clear: the mathematical model and compliance rules are laid down in a smart contract, and the parameters of patients and study rules are stored in the registry itself. In case of coincidence, it is proposed to conduct a specific study. Of course, the final decision is made by a specialist, but the process is more controlled and complete.

4.2. Organ Donation

This process is organizationally similar to the previous one. The line of patients to receive donor organs is fixed on the blockchain, and when donor material appears, the smart contract seeks compliance. As before, the person makes the final decision, but what the patients can be exactly sure of is that they were not “pushed” in the queue and that the process is under complete control.

4.3. Managing distributed treatment processes

As the treatment process is improved, increased participants take part in it: doctors from specialized medical institutions and GPs, social workers, patient’s relatives, specialists from diagnostic centers and so on. The process, in fact, becomes multivalent and distributed. Specific actions and procedures will depend on others, and the sequence of treatment steps is usually regulated.

In this case, smart contracts can be assigned to control the fulfillment of prescriptions, and, more importantly, to control the completeness of information to proceed to the next stages of treatment. Especially effective approach may be in the rehabilitation of patients after discharge from the hospital, when there must be performed many actions at the patient's place of residence.

4.4. Maintaining an integrated information space

The number of medical and laboratory information systems, even in one country, can amount to dozens. When a patient is referred to or planned to move to another clinic, and even more so in another country, obtaining patient history data may present both technical and organizational difficulties. In addition, there is a problem with the organization of access to personal data.

How can blockchain help in this situation? First off, it may be the organization of transparent mechanisms for accessing data from various systems. When organizing the correct system of access control of smart contracts, source data may be stored in local systems, and only the required parts may be transmitted, and all facts of access to information are recorded and managed according to the same rules.

And finally: BCT may become a mighty tool for self-organization of healthcare ecosystem. We see two factors pointing to this role of BCT.

Smart contract may follow the consensus of medical and civil communities as well as administrative regulations.

The BCT-based systems may be planted from small local systems to worldwide ones - like many other systems based on self-organization, Internet among them.

5. Conclusion

Blockchain is a new and rapidly changing technology. As any new and reasonable technology, it follows Gartner's hype cycle [7]. It starts at "Innovation trigger" (Blockchain 1.0), technology passes "Peak of inflated expectations" (Blockchain 2.0). Then it falls into the pit of "Trough of disillusionment" and then begin to climb up the "Slope of enlightenment" (Blockchain 3.0) to the "Plateau of productivity" – Blockchain 4.0, we hope. It seems that current days are optimal to start serious implementation of blockchain in healthcare.

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The National Star Model of Medical Informatics Education in Montenegro

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Abstract. Nowadays, medical informatics is unavoidable topic when talking about health innovations and modern practice. Education of professionals in medical informatics is a challenging issue since they need to be capable to respond to challenges of modern health care systems, heterogeneous health information systems with integrated devices and remote access/controls, rapid development of both technology and the character of applications, etc. However, variety of medical informatics educational programs are established all over the world, and there is no general approach that shall be followed and applied. This paper presents key findings and results of comprehensive review and analyses of well-known EU best practices in medical informatics education, on which bases innovative star model is created for educational system in medical informatics at national level.

Keywords. medical informatics, education, star model, national level.

1. Introduction

The healthcare industry is one of the sectors that has significantly revolutionized around the central core of information technology, in the last few decades [1]. In the middle of last century, the healthcare institutions used computers only for administrative and financial purpose, while today almost all healthcare actions are dependent on information technologies to provide efficient clinical treatments and improve the quality of healthcare services. Medical informatics becomes one of the rapidly growing areas in the field of healthcare sector, so special attention should be given to education of healthcare professionals, to be prepared for the new ICT environment [2]. Medical informatics professionals manage and use data for the purpose of improving patient care. They combine their knowledge of healthcare, information systems, cyber security, databases and big data to collect, store, manage and interpret the large amount of data generated through patient medical treatments. Medical informatics professionals are also responsible for ensuring security, integration, accuracy and accessibility of patient health information.

On the other side, even being a small country, Montenegro (ME) developed integral health care system (HIS) at national level in 2000 [3]. Integral HIS of Montenegro is a cornerstone IS that connects primary health care centres, hospitals, pharmacies, public health laboratories and all relevant healthcare institutions to facilitate the secure electronic exchange of clinical information [4]. HIS development started from the early 2000, with development of fundamental databases and codebooks, IS for pharmacies in

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2004, HIS at primary health level in 2009, followed by HIS on secondary level of healthcare in 2010, and many other components developed continually till nowadays. Thus, medical informatics education can be considered as one of core drivers for effective use of data collected from health information system at national level, which can be further used for cost-efficient optimization, enhanced management and improved health care in general [5]. The paper is aimed to present methodological approach applied at educational system in Montenegro as well as key findings and results.

2. Methods

Methodological approach is carefully selected since the following facts characterize educational system and the needs for medical informatics education in Montenegro [6]: (i) due to small population, there are only 4 universities in Montenegro (1 state university- which is the largest one and 3 private universities), (ii) there is no educational program in medical informatics field in Montenegro, (iii) there is only one medical faculty (as a part of state university), while (iv) strategic documentation at national level clearly identifies the needs for modern health professionals capable to manage, use and understand data coming from health care information system. Therefore, proposed methodology consists of the following two major steps:

Step I- Reviewing and learning from highly experienced nations at EU and global level. Firstly, we are aimed to understand the heterogeneity of existing programs in medical informatics (ranging from BSc to PhD level), and identify their key characteristics, reported experience and results. However, even being so heterogeneous, all programs in medical informatics follow learning outcomes from Recommendations of the International Medical Informatics Association[1] (IMIA) on Education in Biomedical and Health Informatics that cover some aspects of the foundations of Big Data, which includes the following key three knowledge/skills domains: (1) Biomedical and Health Informatics Core Knowledge and Skills; (2) Medicine, Health and Biosciences, Health System Organization; (3) Informatics/Computer Science, Mathematics, Biometry.

On the other side, having in mind recent trends about data science applied in a specific subject domain of healthcare, there is a open debate about key skills needed to be gained by future biomedical and health informaticians working in analytics and Big Data. The following forth list of skills is set in [7] with opened question to the informatics community about further modifications and improvements: (1) *Programming* - especially with data-oriented tools; (2) *Statistics* - working knowledge to apply tools and techniques; (3) *Domain knowledg*e - depending on one's area of work, bioscience or health care; (4) *Communication* - being able to understand needs of people and organizations and articulate results back to them.

Step II- Creation of appropriate model at national level. Based on existing experience in developing innovative programs with expected low number of enrolled students at national level, specific approaches are needed to be analysed [8] [9]. Suggested model is expected to use all available resources at national level already existing at 4 universities, and in the same time ensuring high quality of education, modern study programs which implements recent standards and international suggestions in the field.

3. Results

On the bases of conducted research on best EU and global practices and their cross—matching with existing situation at national level in Montenegro with focus on one integral health information system (which integrates primary, secondary and tertiary health care), the national priorities in ICT development and health improvements (defined by relevant national bodies), innovative star model was created, consisting of the following core elements:

i. The core point consists of joint support to (i) innovative methods of teaching and learning in the fields of public health implemented within *National Platform for education and research*, and (ii) support to life-long learning and specialized education/training implemented through *National Centre for Education in Public Health*. The Platform is developed in order to provide access to real data at national level and integrate evidence-based teaching and learning. The Centre is primarily established at University of Donja Gorica focused on the fields of medical informatics and economics, while The School for Public Health education is planned to be established at University of Montenegro, which will together represent national network of centres for education and training.
ii. University of Montenegro as state university improved existing BSc programs in medicine and integrated new Module of Public Health at PhD level.
iii. University of Donja Gorica with clear strategical focuses on the medical informatics and economics established new *Master study program in Health Information Management* and made improvements at existing curricula in the fields of economy and management, informatics and law.
iv. Mediterranean University is oriented towards medical tourism, legal and business perspectives of health, and therefore created new courses which are integrated into existing study programs.
v. Having in mind available human resources at each HEI in Montenegro, the nodes corresponding to each HEI are connected related to different levels in educational system.

The topology of presented model has the minimum number of intersection points, thus proving the effectiveness in using available resources and efficiency in delivery. However, the presented model is planned to be evaluated from different aspects, including teaching and learning methods, the programs' contents, as well as educational resources and graduates' perspectives and career developments.

4. Discussion

Creation of innovative star model was made based on careful analyses of existing situation at national level in Montenegro, as well as best practices and trends in education in different fields of public health. However, several prior steps are created in order to ensure support of key stakeholders at national level as well as to strengthen national posture in public health, through the following actions: (i) *capacity building trainings* for ME HEI staff members in multidisciplinary fields of public health, (ii) carefully selected *raising awareness campaigns* about health prevention and public health promotion for citizens, (iii) *promotional campaigns* of new/improved study programs

and opportunities for life-long education and specialized trainings. However, the preliminary impacts are expected to be measured after implementation of the first year of new Master study program and core elements of the National Platform and the National Centre and their comprehensive evaluations.

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Using Microbiological Data Analysis to Tackle Antibiotic Resistance of Klebsiella Pneumoniae

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Abstract. Optimal antibiotic use for the treatment of nosocomial infections plays a central role in the effort to control the rapidly increasing prevalence of multidrug-resistant bacteria. Antibiotic selection should be based on accurate knowledge of local susceptibility rates. Traditional methods of resistance reporting, which are in routine use by microbiology laboratories could be enhanced by using statistically significant results. We present a method of reporting based on antibiotic susceptibility data analysis which offers an accurate tool that reduces clinician uncertainty and enables optimization of the antibiotic selection process.

Keywords. Antibiotic resistance; K. pneumoniae; Microbiological data analysis; antibiotic susceptibility; Multidrug resistance

1. Introduction and background

The rapidly growing incidence of antibiotic-resistant bacterial infections constitutes a global threat resulting in serious public health and economic consequences [1]. A recently published ECDC study estimates that about 33.000 people are losing their lives each year as a direct result of such infections [2]. Health-care associated infections, especially those caused by Gram-negative bacteria like *P. aeruginosa*, *A. baumannii* and *K. pneumoniae* account for the major burden of these multidrug-resistant (MDR) infections, while last-line treatments, as carbapenems and colistin become increasingly ineffective, limiting the available therapeutic options [3]. Overuse and misuse of antibiotics play an important role in the development of bacterial resistance. This has led to the introduction of antimicrobial stewardship programs aiming to optimize the

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appropriate use of currently available antibiotics to improve therapeutic results for Gram-negative MDR infections, reduce antimicrobial resistance and decrease hospital costs [4].

K. pneumoniae is a frequent culprit in nosocomial infections. According to the annual report of the European Antimicrobial Resistance Surveillance Network for 2017, Greece has the highest percentage of resistance to carbapenems and fluoroquinolones for *K. pneumoniae* among all European countries [5]. Hospital physicians are often called to administer antibiotics empirically in cases of suspected *K. pneumoniae* infection or while the results of antibiotic susceptibility testing of *K. pneumoniae* isolates are pending. It is therefore essential to ensure that antibiotic selection is based on knowledge of accurate local epidemiological data regarding bacterial resistance. Using information technology to improve surveillance of antimicrobial resistance is a promising tool for clinical use [6]. The aim of the present study was to perform antibiotic susceptibility data analysis by using a database management system (DBMS) and a software package used for the analysis of statistical data. These results could enable hospital internists to optimize treatment of *K. pneumoniae* infections.

2. Methods and Materials

This is a longitudinal surveillance study conducted in inpatients of two General Internal Medicine departments of a public tertiary care hospital in Greece.

During a two-year period (1/2017-12/2018) a total of 297 clinical samples from 1.324 inpatients with suspected infections were processed by the Microbiology Laboratory according to established protocols [7,8,9]. Blood cultures were incubated in BacT/Alert system (bioMerieux). Isolation and identification of pathogens were carried out according to classical microbiological procedures [10].

Antimicrobial susceptibility testing was performed by the MicroScan system (Siemens), according to CLSI guidelines [11,12] and the results were confirmed, when necessary, using a gradient minimum inhibitory concentration (MIC) determining method following the manufacturer's guidelines. MIC's of colistin were retested via microtiter plates. Sensitivity and resistance breakpoints for the antibiotics were determined according to CLSI interpretive criteria [11,12]. *Escherichia coli* ATCC 25922 strain and *Pseudomonas aeruginosa* ATCC 27853 were used as quality control strains for susceptibility testing.

The resistance for *K. pneumoniae* was measured based on the following 21 antibiotics: Amikacin, Amoxicillin / clavulanic acid, Ampicillin / sulbactam, Cefepime, Cefotaxime, Cefoxitin, Ceftazidime, Cefuroxime, Ciprofloxacin, Colistin, Ertapenem, Gentamicin, Imipenem, Levofloxacin, Meropenem, Nitrofurantoin, Norfloxacin, Piperacillin / tazobactam, Tetracycline, Tobramycin, Trimethoprim /sulfamethoxazole. The overall two-year and semester resistance rates of *K. pneumoniae* clinical isolates against individual antimicrobial agents were analyzed. Firstly, the raw data of the Microbiology laboratory was processed by a DBMS software (MS Access) in order to apply all the necessary microbiology rules by running multiple queries (e.g., avoid counting duplicates results from the same patient in a certain period). Secondly, a statistical analysis was performed with IBM SPSS Statistics version 24.0 [13]. The differences between means regarding the resistance to individual antibiotics were determined by Univariate Analysis of Variance and Tukey's multiple range tests. A significance level of 0.05 was used.

3. Results

We analyzed antibiotic resistance rates based on 4.811 tests of *K. pneumonia*e against routinely tested individual antimicrobial agents. The relevant data were analyzed by the two years (2017-2018). The mean differences regarding the resistance of *K. pneumoniae* between individual antibiotics were determined by Univariate Analysis of Variance and Tukey's multiple range tests. The test results were summarized in the form of a two-way table for clinician use, a part of which is shown below (Table 1). Since the size of the full two-way table is too large to fit into one page, only seven antibiotics are presented. For example, the resistance rate of *K.pneumoniae* isolates averaged 20,6 percentage units more ($P < 0.05$) in Ceftazidime than in Amikacin. The reader can find the full table on the hospital's website [14].

Table 1. *K.pneumoniae* resistance differences. Partial table of seven representative antibiotics.

	Amikacin	**Amp/sulb**	**Ceft/ime**	**Colistin**	**Gent/cin**	**Mer/nem**	**Tetr/cline**
Amikacin	0,0%	-36,2%*	-20,6%*	20,7%*	-3,2%	-7,5%	-1,7%
Amp/sulb	36,2%*	0,0%	15,6%*	56,8%*	33,0%*	28,7%*	34,5%*
Ceftazidime	20,6%*	-15,6%*	0,0%	41,3%*	17,4%*	13,1%	18,9%*
Colistin	-20,7%*	-56,9%*	-41,3%*	0,0%	-23,9%*	-28,2%*	-22,4%*
Gentamicin	3,2%	-33,0%*	-17,4%*	23,9%*	0,0%	-4,3%	1,5%
Meropenem	7,5%	-28,7%*	-13,1%	28,1%*	4,3%	0,0%	5,8%
Tetracycline	1,7%	-34,5%*	-18,9%*	22,4%*	-1,5%	-5,8%	0,0%

*. The mean difference is significant at the 0,05 level.

4. Discussion

In an era of rapidly increasing microbial resistance, knowledge of local susceptibility patterns is mandatory for antibiotic selection for treatment of *K. pneumoniae* infections. As a general principle, drugs with high intrinsic activity against the bacterium are used in order of decreasing resistance, to prevent the emergence of strains resistant to the more potent antibiotics. Traditionally, to inform clinicians' decisions, hospital microbiology laboratories have issued regular (e.g., six-monthly) tables of mean antibiotic resistance rates for the common nosocomial pathogens, based on the total number of isolates from the entire inpatient population of the hospital. This method of reporting could be improved in the following two directions: Firstly, to account for significant differences in bacterial resistance that exist even between departments of the same hospital (article in review process). Secondly, to inform the clinician whether the reported differences between individual antibiotics are statistically significant. However, one limitation of our approach is that all resistant rates in our study refer to single antibiotics. We examined all the isolates versus all the antibiotics independently and not on an MDR basis which could be the subject of future studies.

In the present work, we have tried to reduce clinician uncertainty regarding optimal antibiotic selection for the treatment of nosocomial infections. We have used *K. pneumoniae* infection as an example, but the method can be applied to all common pathogens. Our data are consistent with the reportedly high rates of antibiotic-resistant

K. pneumoniae strains in Greek hospitals [15]. The results of antibiotic susceptibility data analysis are presented in an easy to understand two-way table format. They are department-specific and statistically significant values are clearly indicated. This method of reporting promotes accuracy medicine and supports antibiotic stewardship programs.

5. Conclusion

Our methodology enables the clinician to select the most appropriate antibiotic, based on statistically significant sensitivity results which are specific for his own department. These results could be embedded in a user-friendly software application where each doctor can be informed directly for each antibiotic's resistance versus all other available antibiotics regarding a certain microbe without the need to study intricate statistical tables. The longer-term goal is to have it operate as a standard data engineering service to accommodate clinicians' requests about antimicrobial resistance (AMR) conditions of their departments.

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Analysis of Usage of Indicators by Leveraging Health Data Warehouses: A Literature Review

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Abstract. The very act of using indicators by converting the raw data collected to information for purposes such as monitoring, evaluation, decision-making and management make indicators essential tools for health care services and health systems. In addition, Health Data Warehouses (HDWs) play an important role in development, and use of indicators in healthcare. Despite the numerous studies revolving around use of indicators in health care, analysis of usage of indicators by various studies in healthcare, which have leveraged HDWs are limited. To bridge this gap, we conducted a literature review to provide an analysis of usage of clinical indicators, and health indicators by various studies, which leverage HDWs in their development or use. We further discuss the benefits, and challenges of indicator use faced in these studies. As a result of the analysis, this paper thus aims to promote leveraging HDWs in development, and use of indicators for decision-making, and monitoring and evaluation efforts in health care.

Keywords. Health indicators, clinical indicators, health data warehouses

1. Introduction

Indicators are salient in healthcare for purposes such as measuring performance of various aspects within healthcare[1]. These aspects can also be measured within a population over a specific geographical region, and period of time. The Joint Commission on Accreditation of Healthcare Organizations define indicators as "a measurement tool used to monitor and evaluate the quality of important governance, management, clinical, and support functions"[2]. As such, the indicator industry in healthcare is increasing rapidly, and so are improvements in their development since the 18th century[1]. Use of indicators implemented within Health Data Warehouses (HDWs), promote improved decision-making, business processes as well as discovery of new treatments, and safety of care and of patients[3]. There exists numerous publications on indicators in healthcare. Nevertheless, analysis of development and usage of indicators in healthcare by various studies, which have leveraged the importance of HDWs are limited. To bridge the gap, we conducted a literature review and present usage of Clinical

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Indicators (CI)[2], and Health Indicators (HI)[3] in contexts where HDWs have been utilized. We further discuss the benefits, and challenges in their use as per the literature. This review is not exhaustive of all existing studies, but only a sub-set of those available, and that fit the inclusion criteria of the literature review that we have conducted. Hence, the aim of this analysis is to explore the importance of indicators in healthcare, and whether utilization of HDWs are essential in their development, and use.

2. Method

The literature review search was conducted in February and March of 2019. It included published work from the year 2014 to 2018, to focus on the latest development. The databases used include PubMed, Google Scholar, and BioMed Central. Search words used were limited to the phrases "clinical indicators", and "health indicators", combined with "data warehouse". The inclusion criteria for selection included empirical studies that explicitly reveal the CI, and HI used, and demonstrated utilizing HDWs in their development, or usage. Studies that did not explicitly reveal indicators used, and neither utilized HDWs were excluded from this study. From the articles, we extracted the CI and HI, their usage, and attempted to identify the main benefits and challenges.

3. Results

A total of 761 articles where retrieved. Using the combination "clinical indicator" and "data warehouse", 157 results were retrieved from Google Scholar, 36 from PubMed and 3 from BioMed Central. Using the combination "health indicator" and "data warehouse", 497 results were retrieved from Google Scholar, 65 from PubMed and 3 from BioMed Central. Articles considered as duplicate were excluded. Irrelevant articles were also excluded based on their titles and abstracts. 20 articles were selected, which fit the inclusion. 14 of the articles are represented in Table 1.

Table 1. Summary of usage of indicators and leveraging HDW in different areas within health care.

Indicators	Area	Usage	Data Source
CI examples: -proportion of caesarian section deliveries [4] -evidence of severe bleeding [5] -length of stay [6]	Head and Neck Cancer [8], Maternity Care[4],Blood Transfusion[5] , Clinical pathway[6], Patient safety and quality of care[7] Lung Cancer[9] Cardiovascular disease(CVD) [10] Breast Cancer[11]	-To determine overall survival for patients[8], -To measure quality of health services and to support decision-making[4,7] -To provide insights on clinically unwarranted blood transfusion[5] -To identify useful trends for improvement of clinical activities[6] -To identify treatment patterns and resource utilization[9] -To determine association between MOVE program and reduction of CVD incidences [10]	Medical University of South Carolina Clinical Data Warehouse (DW)[8],Developed Gynecology, and Obstetrics DW[4], Loma Linda University Health System DW[5] University of Miyazaki Hospital DW[6], Developed DW-based CI monitoring system[7] Vector Oncology DW[9] Veteran Health administrative

[2] A clinical indicator has been defined as " a variable that measures clinical activities or medicine-related activities and describes the performance of a specific health care process and respective results "[4].

[3] Health indicators are used to ensure that overall population health goals are met such as, improving health of a population, and reducing health inequalities[19].

-total referral response time [7]		-To develop an informatics algorithm for detection of breast cancer recurrence and timing[11]	DW[10],Cancer Research Network Virtual DW[11]
HI examples: -Aggregate HI [12] - Chlamydia infection rate, [13]	Data Use[12], Invasive fungal infection (IFI)[14] Occupational Health Safety [15] HIV[16],Maternal and Child Health[17] Chlamydia[13]	-To monitor facility , and program performance, decision-making[12],To describe the epidemiology and clinical characteristics of IFI[14], To investigate differences in health problems between sectors, To measure percentage of recovery and treated patients, To determine the effect of result based financing strategy -To measure association of racial residential segregation with county rates of chlamydia [13]	DW (District Health Information Software) [12], Intermountain Health Enterprise DW)[14] Developed health DW[15] National Health Laboratory Service Corporate DW [16], National Health DW[17], Health Indicator DW[13],

4. Discussion

We have looked at the development, and use of indicators depending on the needs of the end users, who include but not limited to researchers, doctors, and policy makers. Besides the technical staff, these end users are usually involved in the development of the indicators[7]. Technical details such as data structure or integration of data across the different information systems and organizations, which can all influence the design and utilization of the data resources, were not part of this study. Table 1. Illustrates the variety of medical specialties and indicators currently used. The CIs fall under different classifications according to Mainz [18], which explains the diversity in usage. The diversity in usage of HI is explained in [19], thus HI enable statistical comparability within the population and healthcare systems. The benefits of the indicators presented include but are not limited to identifying gaps, and causal factors, improving patient care and treatment, improve decision-making, and improving monitoring, and evaluation (M&E). In addition, studies that leverage HDW in Low-and Middle-Income- Countries (LMICs), seem to use more of HI with DHIS2 as the common HDWs for HI[3,12]. As such, studies in LMICs that leverage HDWs in development and use of CI are limited.

Nevertheless, indicator development process has been depicted as labor intensive especially when indicators are collected and produced manually[4,7]. As such, use of HDWs promotes systematic, and continuous monitoring of care and of patient, access to wide range of automated indicators, efficiency in decision-making, and tools for data analysis[7,12]. Still, robustness in analysis of indicators was hindered in most cases by issues such as insufficient timely flow of data, and absence of needed data[4], [6-7], [10]. Inaccuracy of indicator data collected was also reported[17]. To reap benefits of both indicators, and HDWs, evaluations such as for data quality, data collection requirements, and system quality need to be conducted. Limitations of this review are that studies that implicitly used CI or HI were not included hence not analyzed, so as to avoid making assumptions of use of the mentioned indicators.

5. Conclusion

Utilizing HDWs in developing, and use of indicators enable end users such as health care managers, and researchers to access and analyze the data, and enables efficiency in

monitoring and evaluation of hundreds of indicators[3,7]. Advantages of utilizing HDWs in developing, and use of indicators seem to outweigh the efforts related to creating the indicators.

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Evaluating the Health Status of Injured People due to Road Accidents

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Abstract. Road accidents are one of the major causes of loss of life, injuries and damage of property. The aim of this paper is to assess the overall health status (physical and psychological) of road accident victims and to propose a Health IT system to managing the assessment procedure. A prospective observational study was conducted among 474 people attended to the emergency department, after a road accident. 30% of the participants were 18-28 years old. After the road accident, most patients (67.1%) did not develop depression and 3 and 6 months after the accident, depression levels were higher. In contrast, the patients' QoL showed improvement over time. As road accidents seems to be a high risk incidents that can affect the health status of people, an Health IT system is suggested to contribute on the management of the assessment of the patients' health status.

Keywords. Road Accidents, health status

1. Introduction

One of the major causes of loss of life, injuries and damage of property are the road accidents. Road accidents are one of the most important emerging in our time and have therefore attracted a strong scientific interest according to the causes and for their impact on individuals and the society [1-4]. The aim of this paper is to assess the overall health status (physical and psychological) of road accident victims in Greece in different time periods and to propose a Health IT system to managing the assessment procedure.

2. Methods

A prospective observational study was conducted, comparing results 3 and 6 months after initial measurements (time 0). In this study, 474 people attended to the emergency department of three general hospitals in Attica, Greece, after a road accident from November 2016 to March 2018. For the assessment of depression, the Greek version of the "Beck Depression Inventory II" (BDI-II) was used and the "ADDQoL" questionnaire for the quality of life (QoL) assessment [5-7]. The statistical analysis was performed using the SPSS 22.0 and statistical significance level was set at $p<0.05$.

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3. Results

The majority of the participants in the study were women (57.6%), while 30% of the participants were 18-28 years of age. Immediately after the road accident, most patients (67.1%) did not develop depression and 3 and 6 months after the accident, depression levels were higher. The mean score of BDI-II was higher at 3 and 6 months after the accident (14.51 and 13.82, respectively) versus 11.93 at time 0 ($p<0.002$ and $p=0.005$, respectively). In contrast, the QoL of patients showed improvement over time (3 and 6 months). In particular, for general OoL and for unweighted QoL in the absence of the accident, the mean value of ADDQoL decreased over time ($p<0.05$ in all cases). A decrease was also observed for the weighted QoL, without statistical significance. Additionally, gender, age and family, occupational and economic status of the patients were related to the levels of depression and QoL ($p <0.05$) [7,8].

4. Conclusions

According to the results of this study, most injured individuals after a road accident did not develop depression, while 3 and 6 months after the accident, the levels of depression were clearly higher, indicating a burden on their psycho-emotional status over time. In contrast, QoL of patients have been significantly improved over time as a result of a significant adaption of the injured people to the consequences of the accident. As road accidents seems to be a high risk incidents that can affect the health status of people [9], an Health IT system is suggested to contribute on the management of the assessment of the patients' health status.

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Ontologic Model of Diagnostics and Treatment of Gastrointestinal Bleedings of Unknown Origin

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Abstract. The article presents the semantic model of diagnostics and treatment of patients with gastrointestinal bleedings when the reasons of bleeding cannot be establihed by means of a laboratory tests, endoscopy and colonoscopy.

Keywords. clinical decision support systems, CDSS, ontology, database management system, DBMS, clinical guidelines, gastrointestinal bleeding, GI bleeding, small-bowel bleeding, SBB.

1. Relevance

In the International classification of diseases of the tenth revision K92.2 code («Gastrointestinal hemorrhage, unspecified») used in coding the diagnostics in case when an origin of hemorrhage has not revealed after carrying out an endoscopy and a colonoscopy [1]. According to literature [2] 5% of all unspecified GI hemorrhage, usually localized in the small intestine. In most cases, they have recurrent nature. The complexity of diagnostics and treatment diseases in the small intestine is caused by lacking specific symptomatology, anatomical features of human body, availability of GI hemorrhage diagnostic method in the medical organization [3].

The first development of automated clinical decision support systems (CDSS) was started in 1970s. The need of the development such systems relate to complexity of diagnostics and treatment of diseases of a small bowel, which may be complicated by GI hemorrhage. These systems can support the doctor in the diagnostics and treatment of patients with gastrointestinal hemorrhage. Also, these systems can countervail the absence of narrowly targeted specialists in a medical organization.

There are many possible approaches to creation of CDSS. In particular, the approach based on the use of the formalized knowledge of subject domain is known [4].

In this research was set the following goal. Based on it was formulated the tasks.

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2. The aim

The goal is to structure and formalize of knowledge in diagnostics and treatment of patients with the gastrointestinal (GI) hemorrhage.

3. Main tasks are to

1. Create the nomenclature of concepts of subject domain.
2. Develop architecture of the knowledge base of subject domain.
3. Fill the knowledge base with the allocated concepts according to the developed architecture.

4. Materials and methods

Domestic and foreign clinical recommendations about diagnostics and treatment of patients with gastrointestinal, small-bowel bleeding (SBB) were used as sources of knowledge [5]. The development and the filling of the nomenclature were carried out in the Excel MS program. For forming the knowledge base was used the open source graph database Neo4j with web-editor.

5. Results

From domestic and foreign clinical recommendations and other scientific literature [5] that contains considered subject was extracted domain concepts and their synonyms. They became a basis for creation the knowledge base of diagnostics and treatment of GI hemorrhage with unknown origin. The concept means the set of properties which all together are sufficient, and each is necessary to extract this class of objects from others [6]. In order to maintain the sense of the concepts not only linguistic synonyms (e. g. «small blood» and «anemia»), but also the standard options of writing of concepts, (e. g. «small-bowel bleeding» and «SBB») [7].

The logical data model contains types of links between concepts. It's provided by dividing all concepts into two groups: properties and actions. First group is a patient condition characteristic (symptoms, syndromes, etc.), second – different diagnostics and treatment methods. For example, the concept «laparotomy» is carried to group of actions, and the concept «angioectasia» – to group of property. Besides, the last has two synonyms – «vascular malformation» and «angiodysplasia».

For simplification the decision-making process was created a links between properties and actions and named as «physical link», «logical link», «synonym link» and «information link».

Physical links provide the pathway in ontology for decision support system. Logical links provide main logic of the rules interpreter which form the basis of CDSS on diagnostics and treatment of patients with GI hemorrhage.

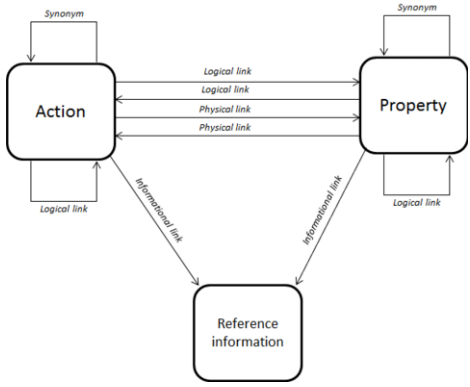

Figure 1. Architecture of ontology.

Figure 1 presents the architecture of the ontology. The main components of architecture are properties, actions and links between them and also the block bearing additional reference information about components.

According to architecture, knowledge base filling was based on the concepts taken from literature [5].

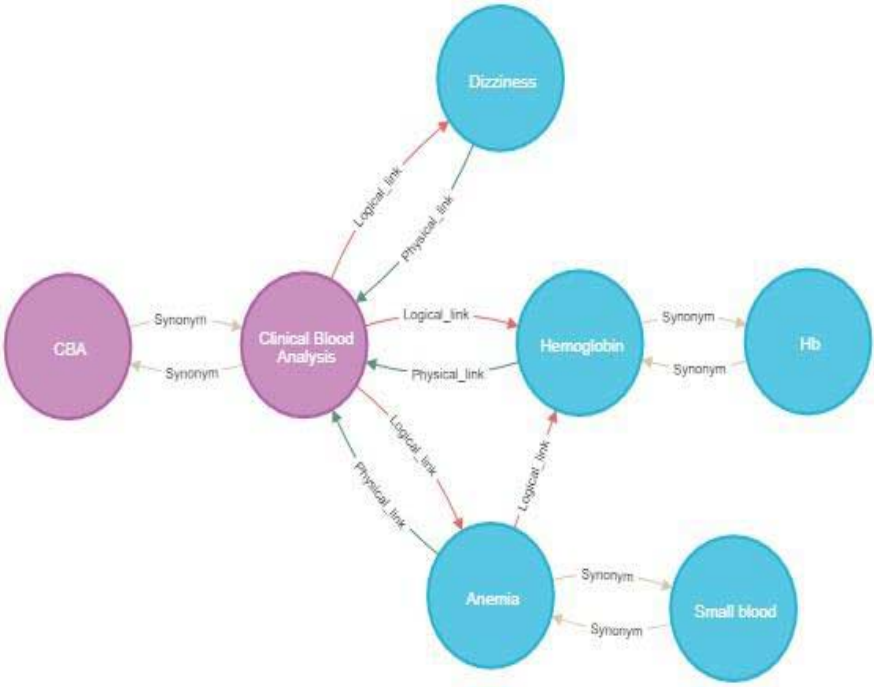

Figure 2. Knowledge base fragment.

On Figure 2 is demonstrated the fragment of the knowledge database, developed in the Neo4j editor. «Clinical Blood Analysis» known as a synonym of «CBA», belongs to the action group. A doctor, suspecting anemia a patient, directs him to CBA in which there is a laboratory test on determination of the level of hemoglobin. Therefore «Clinical Blood Analysis» is connected with concepts from the property group – «Anemia» and «Hemoglobin». The information on possible degrees of anemia is stored in anemias

attributes in the knowledge base. The physical bonds prompting what diagnostic or medical manipulation are in the opposite direction created. It is necessary to carry out to receive the additional information about the patient.

6. Conclusions

1. With the using of literature was created the nomenclature of concepts in diagnostics and treatment of gastrointestinal hemorrhage with unknown origin.
2. Based on the nomenclature of concepts and the selected links between them was developed the architecture of database for ontology.
3. Was created a knowledge base of gastrointestinal hemorrhage with unknown origin for further use in clinical decision support systems (CDSS).

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An Information Extraction Algorithm for Detecting Adverse Events in Neurosurgery Using Documents Written in a Natural Rich-in-Morphology Language

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Abstract. Rich-in-morphology language, such as Russian, present a challenge for extraction of professional medical information. In this paper, we report on our solution to identify adverse events (complications) in neurosurgery based on natural language processing and professional medical judgment. The algorithm we proposed is easily implemented and feasible in a broad spectrum of clinical studies.

Keywords. Electronic Health Records, Neurosurgery, Natural Language Processing, Adverse Events

1. Introduction

Electronic Health Records (EHR) contain a lot of unstructured data significantly challenging for certain information extraction. The processing of medical records may potentially be enhanced using computer automation. However, this task is more difficult when processing rich-in-morphology language, such as Russian. The identification and classification of postoperative complications in neurosurgery is a topical non-resolved issue that may take advantage of text mining[1]–[3]. In this paper, we report on our solution to identify adverse events (complications) in neurosurgery based on natural language processing and professional medical judgment.

2. Methods

N.N. Burdenko National Medical Research Center for Neurosurgery is one of the largest neurosurgical facilities in the world with the electronic database containing data in structured and unstructured formats [4]. In our research the text data from EHRs of N.N. Burdenko Neurosurgery Center related to 77,865 patients underwent 104,489 operations and discharged between 2000 and 2017 were processed [5].

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Below we propose an algorithm for explicit identification of in-hospital adverse events in medical records which implies seven essential steps:

1) Source documents selection to build the general corpus of medical texts
2) Text preprocessing and word tokenization
3) Stratification of tokens by concepts (entities)
4) Selecting the concepts (entities) potentially related to adverse events
5) Mapping the tokens of adverse events concepts to n-grams containing them
6) Labeling n-grams containing the tokens related to adverse events concepts
7) Mapping the labeled n-grams into documents containing them to conclude on adverse events identification

The idea of this method is to preselect a lexicon which could be potentially utilized in reporting of a specific adverse event in EHRs and explore short word sequences (n-grams) containing the lexicon items. This straightforward technique also enables the identification of all spectrum of adverse events that were specified by doctors.

All the data were initially extracted from the relational database of EHRs. The data processing and analysis was done with R programming environment (version 3.5.0) in RStudio IDE for MacOS (version 1.1.453) using *tidyr, dplyr, tidytext, tm, readr, stringr, stringdist, SnowballC, shiny, ggplot2* packages. We briefly describe each step of the proposed algorithm and our experience with it below.

2.1. Shaping the corpus from source documents

Each table in the relational database is queried and screened by the data manager to select the text data fields. This process is augmented with the R script iteratively.

2.2. Text preprocessing and word tokenization

The next step is done to preprocess the text before constructing a comprehensive dictionary with the following:

- Transformation to lower case
- Removing all the characters and symbols from the texts except for letters and single spaces
- Tokenization with a space separator
- Removing “stop-words” and meaningless words (single letters, artifacts, etc.)
- Excluding words found less than N times (seldom) in all texts
- This step could be tuned depending on the task specifications not to lose valuable information in a final lexicon, simultaneously not inflating it.

2.3. Stratification of tokens by concepts (entities)

In this step the tokens are normalized, so that different forms of a word are mapped to the “initial” form based on a common root. The step consists of several following items:

- Lemmatization
- Clustering (matching) the lemmas beginning with the same letters and/or sharing the same root using Damerau-Levenshtein distance
- Naming each cluster by its most frequent lemma and labeling the corresponding initial tokens with the cluster name

- Checking if the lemmas and the corresponding class labels have the same root using stemming
- Manually checking and correcting the labels if they have different root with initial tokens
- Manually checking and modifying the unique labels to name certain concepts (entities) properly

At the end of this step we have a dictionary with each word from the raw text mapped to a unique class by the common root (**Table 1**). The lemmatization appears to be more feasible than stemming to create interpretable normalized forms in morphologically complex Russian language. We found "mystem" lemmatizer by Yandex company (Russian Federation) most effective for this purpose. The Porter stemmer was applied for stemming.

Table 1. The example of morphological forms and typos for the word "status" in Russian. The English translation is given in brackets.

	Tokens in Russian (translation into English)	Counts	Class label
1	состояние (status)	596,807	status
2	состоянии (in status)	54,199	status
3	состояния (of status)	9,930	status
4	состояний (statuses)	2,655	status
5	состояние (statuc)	2,305	status
6	состоянию (to status)	1,310	status
7	состяние (staus)	1,249	status
8	состоянеи (statsu)	1,020	status
9	состяоние (stauts)	973	status
10	состоянием (by status)	874	status
…	…	…	…

2.4. Selecting the concepts (entities) potentially related to adverse events

This step is accomplished by browsing through the list of unique classes (now we call them "concepts") to identify all or searching for specific related to adverse events. This procedure is done and agreed by several experts (doctors) independently and is supported by a user-friendly Shiny application.

2.5. Mapping the tokens of a concept to n-grams containing them

When all the single-word concepts related to the adverse event(s) are selected and agreed, the tokens belonging to these concepts are found in short word sequences (n-grams). So, the text is tokenized into n-grams with n typically set to 3,4 or 5.

2.6. Labeling n-grams containing the tokens from a concept

N-grams, selected at the previous step and indicating the presence of complications, are labeled accordingly. This step should be worked out and agreed by several doctors independently facilitated with a special Shiny application.

2.7. Mapping the labeled n-grams into documents containing them

That is the final automatic procedure to judge whether medical cases are presented with adverse events if the previously selected n-grams are reflected in related documents.

3. Preliminary results of algorithm implementation

The initial corpus of ~13 million texts retrieved from EHR was split into 167,955 unique tokens occurred more than five times. The algorithm (with edit distance set to 3) produced a list of 29,743 unique concepts matching the tokens. The validation of the classification was suggested for 95,364 (57%) tokens with the roots not precisely equal to the roots of the corresponding concepts proposed by the algorithm. The typos in tokens less than seven characters in length, as well as the application of the fixed edit distance for matching words independent of their lengths, were the main reasons. Based on preliminary results we expect the necessity of classification result correction with a special Shiny application in ~20-30% of all tokens. The corrected list of concepts will be mapped into SNOMED CT (research license) and processed by doctors. The evaluation and fine-tuning of the algorithm are ongoing.

4. Discussion (on further improvement)

This algorithm can be modified in step 2.3, e.g., substituting lemmas sharing a common root by most frequent lemma and then grouping the substituted lemmas with edit distance. The edit distance may be applied dependent on word lengths. The concepts appeared in similar contexts may be arranged in larger classes using word embeddings (e.g., word2vec) [6]. The labeled texts will be used for machine learning to identify complications in neurosurgery as a part of our project in artificial intelligence [3].

5. Conclusions

The algorithm we proposed to extract entities from unstructured medical records explicitly, could be easily implemented and is feasible in a broad spectrum of clinical studies. *This project was supported by the Russian Foundation for Basic Research (grant 18-29-22085).*

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Usability Inspection of Multipurpose Scalable Informed Consent Platform

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Abstract. We developed a multipurpose scalable electronic informed consent platform (E-Consent) which is reusable for any informed consent in a multitude of settings. The platform allows research staff to easily upload multimedia information about a research protocol with an approved informed consent into the system, which delivers this content interactively for prospective study candidates in a user-friendly way. Consistent with user-centered design, E-Consent underwent usability inspection via cognitive walkthroughs accompanied by surveys that captured task complexity on a 5-point Likert-type scale. The System Usability Scale (SUS) provided a standardized reference for usability and satisfaction. Overall, the E-Consent framework was considered by participants to be easy-to-use, satisfying, and timely, while delivering complex information such as that on a consent form. E-Consent ranked in the top 10th percentile for usability as measured by SUS. This extensible framework successfully delivered complex information and recorded user consents, all in an easy-to-understand and highly usable fashion.

Keywords. electronic consent, usability inspection, cognitive walkthrough

1. Introduction

Electronic consent is increasingly being used as means to facilitate patient engagement in clinical research. However current electronic consent platforms usually support a single research protocol or a particular clinical trial. We developed a multipurpose scalable electronic informed consent platform which can be reused for any informed consent in a multitude of settings. This has been achieved by introduction of an abstract representation of patient engagement information and informed consent content in a generalizable relational database format. The platform allows research staff to easily upload multimedia information about a particular research protocol together with an approved informed consent into the system which will execute this content interactively for prospective study candidates in a user-friendly way. However, utility of the proposed system will be defined in large part by availability of user-friendly self-explanatory interface. Following principles of user-centered design we employed iterative development of user interface guided by feedback from various stakeholders. In this study, results of the usability inspection performed on the initial prototype are reported. The overall goal of this project is to prospectively assess usability and acceptance of this system and identify potential barriers for using such a system in hospital wards, ambulatory clinics and at patient homes in a prospective observational study.

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2. Methods

2.1. System Design

The system design has been guided by the Cognitive Theory of Multimedia Learning which posits that information should be structured on learning principles accounting for working memory and cognitive load [1]. The user interface was informed by our previous work on implementing successful interactive tools aimed at improving health literacy [2], facilitate patient engagement [3] and provide user-friendly decision aids for patients with potentially limited literacy or numeracy [4]. Accordingly, the long and complex information in a consent form was divided into smaller 'chapters', accessible through a central menu (Figure 1). This interactive menu acts as a table-of-contents, with each chapter linking to a video explanation featuring a person that explains the relevant section in plain English. Following the brief video, a short paragraph of text reiterates the content of that chapter. Each chapter concludes with a quick one-question quiz designed to reinforce the salient points of that section. The complete text of the consent form is available at all times and on all pages of the website via the 'Consent Now' link. Upon completing all chapters, the user is presented with this form and the option to digitally sign it.

Figure 1. Participant education menu.

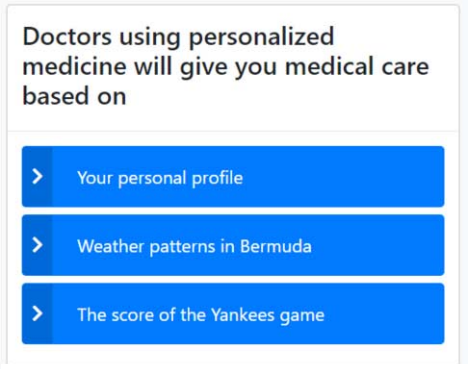

Figure 2. Participant quiz example.

2.2. Study Design

Participants were given a packet of instructions and surveys upon sitting down at a workstation. Surveys consisted of standardized questions with answers arranged as Likert-type scales and additional written responses. A baseline questionnaire was collected immediately, and the starting website was already displayed on the web browser. Participants were instructed to perform three representative tasks while being timed. If participants needed additional help to complete a task, these requests were also noted.

Task 1 prompted the user to select Chapter 5 from the menu (the starting screen), then to watch a 38-second video that would play automatically. This task was relatively simple and could be completed in a single mouse click. Task 2 was progressively more complex: the participant would need to navigate through multiple pages by clicking the 'Next' button on each page, and then read a few sentences of text. The participant would

eventually reach two multiple-choice quiz questions related to the content they just read. Correct answers were required to advance; incorrect answers prompt the user to try again and select another answer. Task 3 expanded on this same format, culminating with a review of the full consent and a digital signature.

After completing each task, the participant was asked to grade that task on a scale of 1 (very difficult) to 5 (very easy) using a 3-item survey that included the following questions: 1) How difficult or easy was it to complete this task? 2) How satisfied are you with using this application/system to complete this task? 3) How would you rate the amount of time it took to complete this task? Once all tasks were completed, the participants were given an exit survey including the System Usability Scale (SUS).

3. Results

Overall, twelve healthy adults at our institution completed usability inspection at end of Q1 2019. Average age of the participants was 36.3±10.2 years old ranging from 26 to 57 years; half of the participants were female. The prior familiarity of the participants with informed research consent varied from being absolutely naive individuals never consenting for research study to experienced principal investigators well familiar with clinical research and patient recruitment.

Table 1. Task Self-Assessment	Mean (SD)
Task 1: Select Chapter 5 and watch video	
Difficulty	4.9 (0.3)
Satisfaction	4.4 (1.0)
Amount of Time	4.5 (0.8)
Task 2: Complete Chapter 5 and return to menu	
Difficulty	4.9 (0.3)
Satisfaction	4.4 (1.0)
Amount of Time	4.6 (0.7)
Task 3: Select 'Consent Now' and complete the consent process	
Difficulty	4.6 (0.5)
Satisfaction	4.1 (1.2)
Amount of Time	4.2 (0.8)

Table 2. Task Performance

	Task Accomplished (%)	**Help Needed (%)**	**Accomplished Time (sec) Mean ± SD**
Task 1	100	0	54.2 ± 15.2
Task 2	100	0	64.3 ± 35.7
Task 3	100	0	181.1 ± 65.0

The resulting usability inspection metrics are presented in Table 1 as average self-assessment scores of three representative tasks with score 5 indicating the highest satisfaction. The task difficulty ranged between 4.6 and 4.9; the task satisfaction varied from 4.1 to 4.4; and the task timing demands were scored between 4.2 and 4.6 (Table 1). The participant task performance is presented in Table 2. All tasks were successfully performed with no external assistance required. The average time required to complete each task varied from about 1 minute to three minutes reflecting increasing complexity of the tasks. System Usability Scores (SUS) were normalized in the usual fashion, and the average of these values was 90.3 ± 9.6 (Figure 3).

Open-ended comments provided by the participants demonstrated that they perceived electronic consenting to be easy-to-use, satisfying, and timely, while delivering complex information such as that on a consent form.

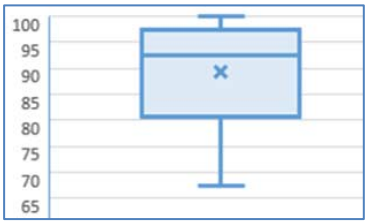

Figure. 3. SUS score distribution

4. Discussion

The usability inspection of the electronic consent platform demonstrated overall high acceptance of the E-Consent interface even by naive users. Our results corroborated previous reports that described positive feedback of prospective research study participants regarding various tools supporting informed consent via interactive media.

Previous studies clearly documented high potential of electronic consent tools for patient enrollment into clinical trials. Blake K et al. [5] reported successful process of enrollment in an asthma clinical trial using mobile devices and internet for multimedia informed consent delivery. A video-assisted informed consent process was shown to be helpful in providing participants with information about study procedures in a way that is easy to understand [6]. Use of electronic consent at Partners HealthCare Biobank has been described as "potentially game-changing strategy" especially for large research studies that depend on patient recruitment [7].

Our next steps in developing a user-centered interface should include usability evaluation in different subgroups of patients with varying socio-economic background, different age groups, computer skills, literacy and numeracy. A larger sample size would also complement a more diverse patient base (and mitigate the limitations of our current study). Testing should be carried out in various settings including hospital wards, waiting rooms in outpatient clinics, and patient homes. The resulting tool will provide support for (1) interactive patient-centered engagement in clinical research via a tailored app that is based on patient profile; (2) in-person and remote consent that can be used in a variety of settings including hospital, outpatient care and community; (3) administration of patient surveys that are linked to institutional clinical trial management systems.

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IPS Governance Framework: Current Practices in Specification Use and Updates

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Abstract. The eStandards methodology stressed the importance of trust and flow for health data as a key characteristic of well-functioning health systems. A digital health compass, leveraging perspectives of health systems, digital health markets, citizens, and workforce, drives a process of co-creation, governance and alignment in eStandards. A repository of best practices and common components further advances interoperability, as new projects add their experience. This paper proposes a governance framework for requirements management, intelligence gathering, specification use, and updates to promote sustainable governance for International Patient Summaries. It is based on interviews of 14 patient summary projects and initiatives in Europe and the United States.

Keywords. Standards Interoperability, Cross-border eHealth Services, Governance

1. Introduction

The International Patient Summary (IPS) was initially developed for unplanned cross-border care. However, soon it became clear that health care providers were not keen to invest in such an exchange of health information, if it was limited to this purpose. Thus, they extended the core notion of a patient summary (PS) to fit their business needs. In fulfilling a broader purpose, a governance framework for the standards used and the specifications developed to serve their local business case(s) is needed.

The Health Informatics Standards Life Cycle is intended to be generic for all eHealth Standards and not just specific to the IPS [1]. Viewed from a different perspective, the explicit standardisation activities are just one particular aspect of the real-world concept of a PS. A PS has its own life cycle and activities, much of which are not explicitly related to, or directly impacted by the formal standardisation processes. It is important to note that PS standardisation and implementation can take place at various levels.

At a global level, we have the Patient Summary Standards Set (PSSS) [2], a guidance document, published by the Joint Initiative Council on Global Health Informatics Standardisation, which catalogues several base standards from the participating standards developing organisations (SDOs). Meanwhile, CEN/HL7 collaboration led to the aligned CEN International Patient Summary Standards and the HL7 International Patient Summary, with implementation guides for HL7 CDA and FHIR standard format. Together, the CEN and HL7 IPS standards take the notion of the informative guidance

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provided by the PSSS to a whole new level, providing a coordinated and fully specified set of standards and implementation guides for the PS. They build upon the C-CDA patient summary (US Meaningful Use Summary of Care) program in the US and a CDA patient summary using the eHealth Digital Service Infrastructure (eHDSI CDA Implementation Guide) building on the eHN guidelines in Europe [3]. Recently, SNOMED International made available a free set of SNOMED CT terms to use in the IPS leading to four linked standards (Fig. 1). If EU member states adopt PS in a way compatible/interoperable with global standards, that will drive sustainable cross-border exchange of PS data, giving rise to feedback and activities that influence standards and advance interoperability. Substantiated recommendations for governance of specifications in PS initiatives, connected to global standards, need consideration of PS governance at various levels of implementation.

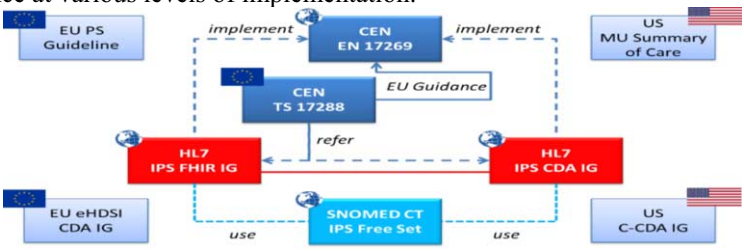

Figure 1. Four closely linked global IPS standards with EU Implementation Guidance

2. Methodology

In the context of this study, a PS initiative is defined as **any specification, implementation, or operational effort that uses the exchange of patient summary data as the basis for adding value to the identified care setting**. This includes the original focus on cross-border unplanned care for the international PS, as well as part of a targeted effort for specific patient groups (chronic diseases, rare diseases) or for general patient empowerment initiatives using personal health record exchange. The need for governance and the interlinked life cycle models of both generic standards and the IPS specifically guided the construction of an interview guide on the topic of IPS governance. An inventory of patient summary governance practices was taken using the following five steps:

1. Identify key Patient Summary initiatives;
2. Assess goals, objectives, and activities related to governance within the initiative;
3. Assess the initiative's current linkage with standards governance;
4. Make an inventory of the initiative's needs for standards updates and version management of the specifications in use;
5. Compare results, identify best practices and provide a summary.

We identified and conducted interviews with 14 PS initiatives in Europe and the United States. Twelve initiatives are PS at national or regional levels and two are standards developing initiatives. The questionnaire used in these structured interviews is available upon request. After processing the information collected, the findings were summarized in a report focusing on best practices and encountered problems [4].

3. Results: The IPS Governance Framework

Governance of PS specifications is focused on the Information layer of the Refined eHealth European Interoperability Framework [5] and is frequently isolated from the way PS is implemented in the Care Process and Application layers. The CEN/TS 17288 PS Guideline for European Implementation includes a section on governance that covers process and product aspects of governance, pointing to guidance on GDPR compliance considerations. The interviews confirmed the five main topics to be addressed by PS governance:

1. **Initiative:** aim of PS initiative and stakeholders directly involved in the exchange
   All interviews acknowledged a clear definition of scope and how stakeholders contribute to the stated objectives of the patient summary initiative.
2. **Specifications and Standards**: overview of specifications and standards;
   All initiatives confirmed the importance of standards. However, not all initiatives develop their own specifications; six of the twelve implementation and operation initiatives rely on specifications developed on a national scale or are conformant to the European Patient Summary specifications.
3. **Governance Scope and Objectives:** future scope, objectives, and sustainability considerations embedding the PS initiative in the broader governance structure;
   The majority of initiatives rely on governance by an independent party set up for health information exchange in general. This puts severe limitations on the influence key stakeholders in the use of the patient summary have.
4. **Stakeholder Involvement**: stakeholders not involved in actual PS exchange;
   It is striking that only a few of the initiatives explicitly mention the engagement of users and expert groups from different stakeholder communities.
5. **Update and Version Management**: provisions for updates to PS specification and alignment with maintenance of underlying standards;
   Only one of the fourteen initiatives employs a fixed cycle for publishing updates, most mention a dynamic process based on the needs expressed by the stakeholders.

4. Discussion

Interlinked governance processes of PS are complex and it is hard to establish an overarching governance for all aspects of the IPS. The governance framework developed can be employed by PS initiatives connecting related initiatives and SDOs. It provides pointers and functions for governance of individual PS initiatives:

1. Identifying change management processes for PS standards and specifications in the initiative engaging the user and stakeholder community;
2. Gathering experience and feedback for the governance processes focussing on best practices, sustainability and continuity of effort;
3. Refining governance structures over time in long and short-term, with flexible structures that facilitate alignment and feedback to standards organisations.

From the perspective of SDOs, it is recommended to establish a joint governance on IPS standards, as a single community or open governance framework for PS initiatives to turn to. SDOs should ensure a balance of interest and provide opportunities for broad participation. Simplicity is key. Community collaboration is favoured over rigid formal bodies to safeguard the relevance of IPS standards and specifications. Collaboration is also necessary at a national level, coordinated by National eHealth Competence Centres (NCCs). Via coordination with relevant sections and experts of the SDOs, NCCs ensure that standards and specifications are coordinated and that required changes are incorporated in the standards, the EU guidelines, and the eHDSI. The connection between local and global governance is crucial for sustainable standards-based innovation.

5. Conclusions

Promoting sustainable IPS governance takes the global collaboration of SDOs in the JIC on Global Health Informatics Standardization as a starting point. Interviewed initiatives provided best practices on engaging SDOs and initiatives in governance of specifications. Identification of shortcomings and coordination of change requests among initiatives, are crucial for effective governance. We recommend a community of experts from SDOs as the point of contact for questions about and suggested changes to the IPS standards. Similar communities can provide guidance at a national/regional scale, with an important role for NCCs. They drive adoption of IPS standards from the global community down to the local implementation in EHR systems. Consistent local implementation is crucial for the effective exchange of data, whether on a local level or a national or cross-border scenario, for improved data quality and ultimately patient safety and better care.

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Mobile VR-Application for Neck Exercises

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Abstract. A VR-based application was developed to explore the potential of mobile technology and the use of mobile-VR to assist in treatment, rehabilitation, and prevention of neck injuries. A prototype was developed through user-centered design and Google Sprint. The application simulated a typical set of exercises that a patient would get from a physiotherapist in the case of neck pain. A semi-structured interview was conducted with a physiotherapist, and an open-ended interview followed to asses usability. Expert and user evaluation indicated that the aim should be to keep patients motivated and working through the pain. The usability was judged as very good. However, clinical evaluation with a patient group would be recommended in the future.

Keywords. Neck pain, Neck exercise, VR, Gamification.

1. Introduction

Everyone owns a smartphone; they are changing our everyday lives [1]. A smartphone is equipped with an array of different built-in sensors that consist of gyroscope, accelerometer and more. We can utilize smartphones with a recurring activity or solving a problem in a person's life. That is the main reasons for the rise of medical applications. mHealth applications deliver or collect healthcare data [2], some of the applications are intended for healthcare workers [1], but more and more are intended for patients. Some mHealth applications have incorporated gamification features and concepts that are typically seen in video games. This can include scoreboards, trophies, and achievements compelling the user to use the application more [3]. mHealth application using VR is on the rise. Using the pre-existing sensors of smartphones, with a cheap VR headset, could make an excellent addition for treatment and prevention. The VR headset is mounted on the head, and as such could be a tool for neck exercises [4]. This study is aimed to explore the potential of VR and mobile technology for the treatment of neck pain using expert evaluation and usability testing.

2. Method

The User-Centred Design (UCD)[5] approach was applied to this study, meaning that design was based upon a clear understanding of users, tasks, and environments. It was driven and refined by user-centred evaluation, addressing the whole user experience [5]. In this case and context users are people who have neck problems that can be

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rehabilitated by neck stretching and neck exercises. The context of use would be a crucial point, due to the mobility of the application. The user could exercise at home, or work whenever convenient. To specify requirements, Google sprint was used [6]. During the sprint phase, the initial idea was developed and use cases outlined. Following the steps in the sprint methodology the use case with the most potential was selected, and a storyboard was made. The storyboard represented what the visuality and functionality of the prototype would be. After the sprint, a low fidelity prototype was created. With feedback from a medical professional and through another iteration, a high-fidelity prototype was developed, using Unity3D. Resulting was an application for a smartphone that could be used with a VR headset. Elements of gamification were applied. The evaluation was done in two parts. The expert evaluation included a physiotherapist with whom a semi-structured interview was conducted. The second part was a usability test with users who tried the application.

3. Results

3.1. The application

The application consists of three-game scenes. The first scene is a start menu where the player initiates the game. Once the game has started, the player gets instructed to move their head to the right and hold over a capsule that turns green when the timer of five seconds is up (Figure 1). When this is done, the same procedure is repeated on the left. The player must do the same looking up to the capsule and, in the last step, looking down and holding for five seconds before getting to the next scene. In this scene, the player is instructed to tilt the head to the right side and hold for five seconds, and then to tilt to the left and hold for five seconds (Figure 2.). This simulates and gamifies a set of simple exercises that a person would usually get from a physiotherapist but can now do at home.

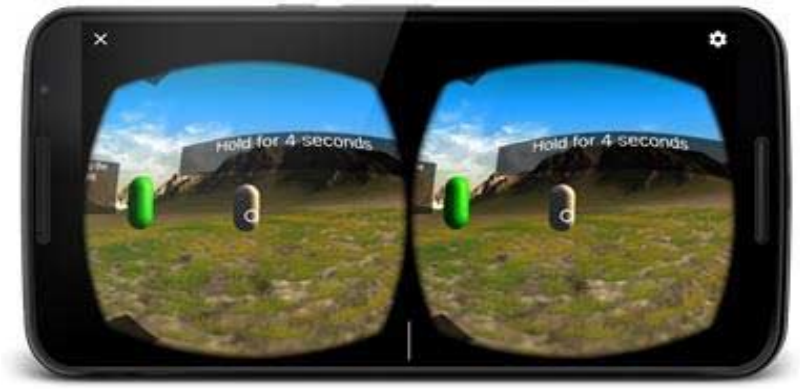

Figure 1. Neck exercises when the application suggest looking to the right.

Figure 2. Neck exercises when the application suggest tilting the head to the side

3.2. Evaluation

The application was first used by the physiotherapist and an interview was conducted thereafter. The physiotherapist was positive about the prototype. He felt that the need for a tool like this could make the exercises more fun and with potential for further development that would tune into patients' needs. The potential concerns are home exercises and rehabilitation, as well as prevention. The physiotherapist stated that the rehabilitation processes sometimes gets hindered by the lack of participation form the patient. Motivation, or lack of it, is probably the main reason treatment takes longer and is not as effective as it should be. Another reason for avoiding exercises is pain. Pain can make patients refrain from exercise. Any tool that could help a patient exercise through pain without being harmful would be an asset. This is where VR can be beneficial and aid the patients. It is also documented that VR has a distracting effect; the perception of pain when using VR is decreased [7].

Cost was an initial concern for the physiotherapist, but when told the actual price of smartphone VR-glasses combined with the patient's own phone, it became clear that the cost is not an issue. Regular VR-headset that usually need additional hardware are costly. The patient can get treatment-option on their own smartphones at the fraction of the cost.

The application was also tested on six users. Two with experience of neck pain, and four without were recruited for usability testing. Four of the test subjects had good IT skills and the remaining two had average IT skills. They were given the same instructions as a physiotherapist would give a patient when trying the application for the first time. They tested the application for an average of two minutes which is the average time for one session with the application. All the test subjects managed to finish all the given tasks. A scale from one (low) to five (high), was used to collect the feedback. The easiness of use was given the highest scores. When asked if the test-subjects found the application useful, the response was more divided, because of the relevance of use for them. There was also some concern about nausea, sometimes occurring with VR. The overall experience of using the application was however was positive and exciting.

4. Discussion

The applications allow frequent and convenient use, so it could simulate patients to exercise more often than during visits to physiotherapists. The therapeutic effect could

be significant given that exercise is well designed. One essential requirement to consider is patient safety. Therefore, a physiotherapist was consulted during the application development. He was fond of the idea to use VR and to implement it within the prototype. However, more work needs to be done to address the patient's medical condition and develop guidelines for continuous training. Keeping patients safe and interested in training ought to be one of the goals of using the application. To that end, a few more clinical experts are being consulted in the future design upgrade. Several design variations of the interface and elements of gamification could be introduced, to keep patients interested in repeating and exercising.

The current solution is built in a way that can be implemented using other tools that can introduce elements of the game and provide feedback to patients over a time period.

The application could also be used to prevent neck pain and injuries, not only to treat it.

5. Conclusion

There is no doubt that there is a need for a VR-application that assist in the treatment, exercises, and prevention of neck problems and injuries. This study has shown one efficient way of implementing exercises in an application which is indicated by the expert and user evaluation. The main aim of future development should be motivating and working through the pain. A clinical study is needed for a complete evaluation.

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Usefulness, Ease of Use, Ease of Learning and Users' Satisfaction of E-Prescription and E-Appointment Systems for Primary Health Care

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Abstract. The purpose of this study is to investigate views of physicians, nurses and administrative personnel working in Primary Health Care (PHC) structures in the Greek regions of Achaia and Attica, on the usefulness, ease of use, ease of learning and users' satisfaction of e-prescription and e-appointment systems. The e-prescription and e-appointment systems we evaluated are developed and hosted by the Greek e-Government Center for Social Security Services (IDIKA S.A.). Data were collected by using Likert-scale questionnaires. Overall, users are satisfied, and they find the studied systems useful, easy to use and learn. Ease of learning of both systems scores the highest score, while users' satisfaction the lowest. Ease of learning of both e-systems is not affected by age, gender, computer skills, and personnel category.

Keywords. Electronic Prescription, Electronic Appointment, Evaluation, Usability

1. Introduction

The introduction of Information Technology (IT) in Primary Health Care (PHC) has led to a number of changes. In particular, the effective IT is able to reduce medical errors, support clinicians, improve information management, and make patient access to health services easier, to support remote care and continued provision of services.

Greek e-Government Center for Social Security Services (IDIKA S.A.) is a non-profit public owned company specialized in IT products for Social Security and Health Service public organizations established by Law [1]. The pilot application of the Electronic Health Record (EHR), e-prescription and e-appointment are the modern electronic systems that are developed and hosted by IDIKA S.A. in the health sector.

Our research aims to evaluate the views of physicians, nurses and administrative personnel working in Primary Health Care (PHC) structures in the Greek regions of Achaia and Attica, on the usefulness, ease of use, ease of learning and users' satisfaction of e-prescription and e-appointment systems hosted by IDIKA S.A.

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2. Methods

We studied a sample of 77 persons in order to evaluate the e-prescription and e-appointment system of IDIKA S.A. The sample consisted of medical, nursing and administrative personnel working in PHC of the regions of Achaia and Attica. Questionnaires were sent to PHC structures and completed by our sample. The duration of the survey was from July to August 2018.

We used a weighted and validated version of the "USE Questionnaire: Usefulness, Satisfaction and Ease of Use" [2], translated in Greek language. The questionnaire evaluated the views on the usefulness, ease of use, ease of learning and users' satisfaction of PHC personnel using the electronic systems (e-prescription and e-appointment) hosted by IDIKA S.A. in their daily clinical routine. We also recorded other data, such as gender, age, level of education, computer skills, personnel's category, e-system used in daily work, etc. For each of the four categories of the questionnaire (usefulness, ease of use, ease of learning and user-satisfaction) we estimated a single score (mean value) averaging across the category answers of all respondents. Data were processed with SPSS v. 25.0.

3. Results

The sample of the survey was 55 physicians, 13 nurses and 9 administrative personnel of the PHC structures in the Greek regions of Achaia and Attica. 43 persons of our sample were women (55.8%), and 34 were men (44.2%). The average age was 41.9 years. 27 persons (35.1%) were between 18-35 years old, 26 (33.8%) between 36-50, and 19 (24.7%) 51 years old and over. The e-prescription system is used by 55 participants (71.4%), all of whom are physicians. The e-appointment system is used by 22 participants (28.6%), 13 of whom are nurses and 9 are administrative personnel. 45 of the participants (58.4%) own a computer driving license, 27 of whom are physicians and 18 are nurses and administrative personnel.

The score (mean) of the respondents per questionnaire category (usefulness, ease of use, ease of learning and user-satisfaction), and the total score (overall mean value) was calculated. The overall mean value of the questionnaire (all four questionnaire categories) is 4.2. 3 out of the 4 questionnaire categories were evaluated above the midpoint of the scale (3.5) of USE questionnaire. Figure 1 presents the profile analysis of the four USE questionnaire categories, where its mean value with its std. deviation is depicted for each category. The profile reveals the deviations of the means above and below the overall mean of the answers. The profile identifies that the category with the highest mean score, is "ease of learning" (mean: 5.5) while the category with the lowest (just below the scale's midpoint) is "user-satisfaction" (mean: 3.4). The rest two categories of "usefulness" (mean: 3.8), "ease of use" (mean: 3.9) are considered above the questionnaire's midpoint.

Based on the survey data, when comparing the mean values of the questionnaire categories, there were some statistically significant differences. Specifically, women more than men find both e-systems useful ($p=0.0013$), easy to use ($p=0.006$), and satisfactory for the user ($p=0.023$); e-appointment more than e-prescription is useful, easy to use and satisfactory for the user ($p=0.000$); nurses and administrative personnel more than physicians find both e-systems useful, easy to use and satisfactory for the user ($p=0.000$); participants who own a computer driving license more than those who

do not own find both e-systems easy to use (p=0.011); participants in the age group above 51 years old more than those in the younger age groups find both e-systems satisfactory for the user (p=0.029). Ease of learning of both e-systems is not affected by age, gender, computer skills, and personnel category.

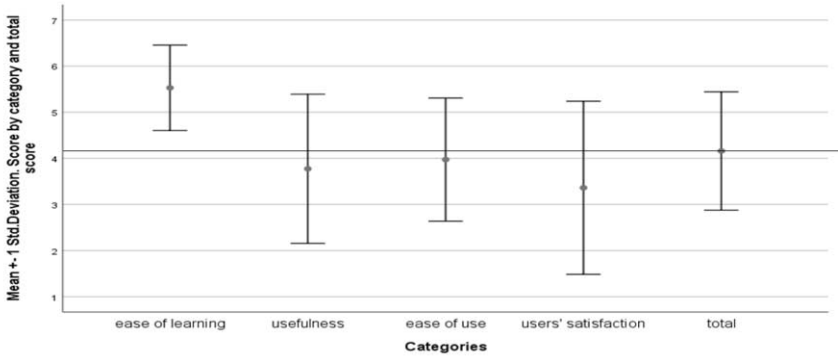

Figure 1. Scores by category and total questionnaire score.

4. Discussion

All respondents believe that IDIKA's electronic systems are easy to learn while opinions differ on usability, usefulness and satisfaction. The relatively high level of computer literacy of the participants may explain their belief that e-systems are easy to learn.

Nursing and administrative personnel seem to be more receptive to new technology. Similarly, the results of Anderson [3] show that doctors tend to be more reluctant to change their traditional practice and use new IT technologies while other staff tend to accept and use them more easily. Administrative and nursing personnel have a more favorable attitude towards new technology than medical staff because they are likely to perceive it as an effective tool to facilitate co-ordination with other healthcare teams. Some studies consider that physicians, unlike nurses and administrative personnel, can perceive new computing as a threat because it leads to a loss of power [4], provocative professions and a "new professionalism" [5].

E-prescription system is used by physicians because in Greece they are the only health professionals who have the right to prescribe. E-appointment system is used by nurses and administrative personnel and not by physicians due to their increased workload.

The users' satisfaction has a lower score compared to other categories, which may be linked to the fact that the e-systems are not user-friendly and simple to use [6]. User groups under the age of 50 are less satisfied with the use of electronic applications than those over the age of 50. Women are more satisfied than men with the e-systems studies. A low user satisfaction may affect the acceptance and adoption of e-systems by the user. Thus, the reasons why user satisfaction is relatively low compared to other categories need further investigation.

Most of the administrative and nursing personnel are computer literate (they hold a computer driving license), while some of the physicians hold a computer driving

license. Users who own a computer driving license more than those who do not own, believe that the e-systems studied are useful and time-saving.

Apart from the studied e-prescription and e-appointment systems, we had also planned to evaluate the third e-system (EHR) launched for PHR by IDIKA S.A. Unfortunately, the users did not evaluate the EHR system. According to PHC professionals, the EHR is a pilot application and unless proper and targeted guidelines are provided by the Ministry of Health, they refuse to use it.

A limitation of the research is that the sample of participants collected is small; moreover, the responses from nurses and administrative personnel were proportionally small compared with those of physicians. This is probably due to the fact that physicians are the most experienced professionals in IDIKA's e-system, and they were more willing to participate in the survey than nurses and administrative personnel who had much less experience in e-systems and probably wanted more time to get acquainted with them and to have a complete view. Another limitation of our survey is that the sample comes from specific administrative regions. Thus, results cannot be generalized for the PHC in Greece.

5. Conclusion

We tried to evaluate the e-prescription and e-appointment systems used by PHC personnel. Overall, users are satisfied by these systems and they consider that they are useful, usable and especially easy to learn.

Further research is required to confirm the results of this survey with a larger sample from different user groups and health districts. Specific elements of both e-prescription and e-appointment systems that influence user response should be investigated. Additionally, research is required for the evaluation of the EHR system which is used by healthcare professionals in PHC in Greece.

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A Smart Infotainment System Equiped with Emotional Intelligence

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Abstract. Bedside infotainment technology has been gaining popularity, helping providers to address patient needs and improve hospitalization experience. Such systems have the potential to become valuable tools for medical and nursing personnel, with the integration of patient monitoring features, bolstering efficiency and coordination. Extending their utility beyond conventional monitoring, the incorporation of affective computing capabilities would allow for early detection of potentially dangerous situations, as an individual's emotional state has a direct effect on their health, cognitive status, behaviour and quality of life. Furthermore, the addition of a serious games module would provide additional value for patients with cognitive decline or mobility issues. This work presents a novel bedside infotainment system, equipped with the aforementioned capabilities and designed to address the needs of patients in long-term care facilities, such as recreation and rehabilitation centres.

Keywords. Bedside infotainment, patient monitoring, affective computing, serious games

1. Introduction

The value-based healthcare system becomes more competitive than ever, and hospitals need to focus on the patient experience as one of the main contributing factors to how patients evaluate their stay. Bedside infotainment and engagement systems have been gaining popularity, as they have proven to be effective in increasing patient satisfaction, helping address patient needs and improving hospitalization experience [1]. Such systems may become valuable tools for medical and nursing personnel, with the integration of patient management and monitoring features, such as automated collection of biosignals, bolstering productivity, efficiency and coordination.

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To extend the system's utility beyond conventional monitoring, the incorporation of affective computing capabilities would allow for early detection of potentially dangerous situations, as an individual's emotional state has a direct effect on their health, cognitive status, behaviour and quality of life [2]. The added value of the system may be further increased with the addition of serious games, which have gained prominence in the field of digital healthcare services, providing a multitude of benefits, including comprehensive assessment of a patient's physiological status and improved self-management [3].

This work presents an innovative infotainment system, named SISEI (Smart Infotainment System Equiped with Emotional Intelligence), which aspires to modernise the infrastructure and services of long-term care facilities. The SISEI solution is equipped with the aforementioned capabilities and designed to effectively address the needs of patients in recreation and rehabilitation centres. The foreseen prototype will be built upon the "HeartAround" assisted independent living platform [4], ensuring optimum levels of user-friendliness with appropriate interfaces for all types of users and exploiting the platform's communication and patient monitoring features.

2. Background

Patient infotainment terminals provide patients with access to information, communication and entertainment services, such as TV, radio and video-on-demand, Internet-based services such as Skype, news feeds, etc. Lately, considering the need for improved usability, especially when providing services to patients with cognitive decline, bedside systems have started to replace conventional displays with touch screens [5]. Therefore, a tablet PC, supported by appropriate mechanical arm, can provide an elegant solution for a bedside terminal that satisfies the need for user-friendliness, but also provides the flexibility of modern mobile app design. Based on this idea, the SISEI solution has been developed upon the mobile app of "HeartAround", which offers many of the required features.

"HeartAround" is an integrated platform for assisted independent living, incorporating communication, health monitoring and emergency response features [6]. The system, which is offered as a mobile application for Android devices, connects end-users with healthcare professionals, relatives, friends, and other caregivers, creating a social and support network. It is also capable of communicating with a wide range of Bluetooth-enabled medical and wearable devices (e.g., blood pressure monitor, blood glucose meter, oximeter, activity tracker, etc.) which allow for continuous monitoring of the user's biosignals and physical activity [7]. Furthermore, affective computing aims to equip systems with the ability to identify, deduce and interpret human emotions [8]. Emotion detection is usually based on the analysis of various parameters, such as facial expression and speech, using advanced pattern recognition techniques. To that end, analysis of video (visual and speech data) with appropriate algorithms allows us to assess an individual's emotional state. The SISEI system is able to analyse video captured during patient-physician videoconferencing and provide to the physician information about the patient's emotional status. In addition, combined analysis with the patient's biosignals, such as heartrate, will allow for more reliable results [9].

3. System Architecture and Implementation

The proposed system consists of the following sub-systems: a tablet application as the users' infotainment endpoint, a web application for doctors, carers and helpdesk users and a cloud back-end platform that coordinates the system functionalities. The system follows a service-oriented architectural design, exploiting the evolution and flexibility of cloud computing, and implements modern interfaces for all types of users.

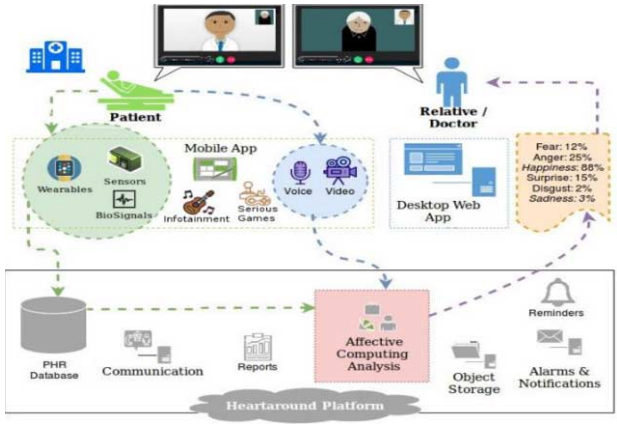

Figure 1. SISEI Architecture.

For the implementation of the system, several cutting-edge technologies and tools have been used, on top of the technologies used for "HeartAround" such as BLE and WebRTC [10]. In order to exploit the latest advancements in the field of computer vision, the OpenCV framework [11] was used for the serious games functionality, to track the user's posture, gestures and body, as well as objects related to the game. In parallel, machine learning techniques are applied to facilitate the transformation of the tracking information to knowledge in the context of each game. For the later, the TensorFlow [12] and Keras [13] frameworks have been integrated, which are also used to implement models for emotion detection based on facial features and speech. In future implementations, we expect to further improve the user experience, and also implement more complex games with 3D graphics and animations, by utilizing the capabilities of Unity platform.

Considering the needs of patients undergoing rehabilitation, two types of serious games are incorporated in the system - serious games for cognitive assessment/rehabilitation and exergames. The first type includes problem-solving games, such as puzzles, while the second involves appropriate physical exercises. Game scores will also be stored in the patient's records to be assessed by their physicians.

The user's doctor is able to access their patients' PHR (Personal Health Records) in compliance with GDPR and privacy policies, which may include medical history, laboratory test results, medication and allergies, and utilize the available tools to assess their health condition. The doctor may also define a monitoring schedule, comprising of a timeline for specific measurements with respective thresholds for each type of measurement. The system processes the data related to the schedule on the cloud and whenever a measurement exceeds the respective threshold, the doctor is automatically notified. The platform also facilitates a helpdesk service, which can provide emergency support when anomalies or potential situations are detected, or at the user's request.

4. Conclusions and Future Work

This paper has presented the SISEI solution, an innovative bedside infotainment system, equipped with affective computing features and functionalities that are able to provide valuable services to patients in long-term care. Moving further than conventional patient monitoring practice, the system is able to provide a high-level assessment the patient's emotional status, as well as cognitive abilities, which can provide valuable information to care personnel and enable them to undertake appropriate measures to mitigate cognitive decline or affective disorders. Furthermore, the system's exergames functionality can be a valuable tool to address the needs of patients in rehabilitation, encouraging appropriate physical exercise in an enjoyable manner.

Future work involves piloting the prototype within an operational scenario, in order to assess the feasibility of the concept and the actual impact on the services provided, as well as user acceptance. Pilots in two recreation and rehabilitation centers have been planned, with the installation of at least 50 terminals. The medical experts will actively participate in the piloting activities to provide feedback, assess the quality of the results and the effectiveness of the overall system, and identify its limitations.

Acknowledgement

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An Epidemiological Analysis for H1N1 Infection

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Abstract. During the last years the dependence of inflections have been increased, especially the infection H1N1, in Europe as well as in Greece. Especially the last 2 years (2017-2018) the percentage of spreading is still significant. For the analysis of the impact's diseases in population during these periods, epidemiological indexes have been introduced.

Keywords. Infection H1N1, epidemiological indexes, virus

1. Introduction

On winter time an upsurge in influenza virus activity is monitoring. The mortality caused by seasonal flu can be varied each year. The characteristics of the virus circulating and the degree of immunity that the different groups have, are some factors that affect the mortality. The influenza virus is constantly mutating genetically and antigenically from year to year. If these changes are large, and there is no immunity in the population, this influenza virus may lead to a pandemic [1-3]. In case of pandemic, the spreading of the disease is intense and fast into the population. This means that a large number of people get sick at the same time, many of them seriously. A situation like this creates serious problems in the healthcare system and implications in social and health activity [1,4]. This is the reason that leading us to inspect the degree of development of the spreading using epidemiological indexes. It must be always kept in mind that the flu is unpredictable, and therefore both the onset, as well the duration of seasonal outbreak may vary from season to season. It should also be noted that the activity of influenza is never nil; beyond the epidemic wave in the winter, sporadic cases of influenza there are all year round [2-4].

2. Epidemiological Analysis for H1N1 Infection for Greece

During the 40th week of 2017 to 20th week of 2018, 111 cases have been recorded in laboratory and 107 of them hospitalized in Intensive Care Units (ICU) in Greece [5,6]. During the same period in Greece, 48 deaths have been recorded, 38 of them were

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hospitalized in Intensive Care Units (ICU) and 4 of them not hospitalized in Intensive Care Units (ICU) [5].

The prevalence (P) for the infected patients is 96.3%. The corresponding percentage (probability) for the patients whom hospitalized in ICU under death and survive is 32.8% (42/107) and 60.7% (65/107). During the period week 40/2018 to week 6/2019, in Greece, 226 cases have been recorded in laboratory, 219 of them were hospitalized in Intensive Care Units (ICU) [6]. During the same period in Greece, 56 deaths have been recorded, 49 of them whom hospitalized in Intensive Care Units (ICU) and 7 of them not hospitalized in Intensive Care Units (ICU) [6].

During the previous period, the prevalence (P) for the infected patients is 96.9% (219/226). The corresponding percentage (probability) for the patients whom hospitalized in ICU under death and survive is 25.5% (56/219) and 74.4% (163/219). Map of geographic spreading of Greece, for 2018 and 2019 (expectation) is given in Figure 1.

Figure 1. H1N1 geographic spread maps of Greece for 2018 and 2019 (expectation) (source: WHO, 2019; European Centre for Disease Prevention and Control, 2019)

3. Conclusion

In this work, an introduction of a spreading disease analysis for the influence H1N1 is described based on epidemiological indexes. Based on the results, an increase of the H1N1 cases were recorded in the general population as well as in the cases that hospitalized in ICU.

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Phenotyping UK Electronic Health Records from 15 Million Individuals for Precision Medicine: The CALIBER Resource

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Abstract. Electronic health records (EHR) are increasingly being used for observational research at scale. In the UK, we have established the CALIBER research resource which utilizes national primary and hospital EHR data sources and enables researchers to create and validate longitudinal disease phenotypes at scale. In this work, we will describe the core components of the resource and provide results from three exemplar research studies on high-resolution epidemiology, disease risk prediction and subtype discovery which demonstrate both the opportunities and challenges of using EHR for research.

Keywords. electronic health records, phenotyping, data linkage, prognosis, biomedical informatics

1. Introduction

Electronic Health Records (EHR) are a rich source of information on human diseases [1]. EHR are generated during routine patient interactions in primary or secondary healthcare. EHR can contain information on diagnoses, symptoms. surgical procedures and interventions, prescriptions, laboratory biomarkers (e.g. high-density lipoprotein cholesterol) and physiological measurements (e.g. blood pressure (BP), body mass index). Linking EHR which span primary care and hospital healthcare settings in the United Kingdom (UK) can enable researchers to create longitudinal phenotypes that accurately capture disease onset, severity, and progression [2]. The process of defining disease phenotypes in EHR data however is challenging and time-consuming since EHR are variably structured, fragmented, curated using different clinical terminologies and collected for purposes other than medical research [3].

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2. Objective

Here we present and describe a state-of-the-art phenomics resource, CALIBER, for developing, validating and sharing reproducible phenotypes in national structured EHR in the UK. We additionally briefly describe contemporary research exemplars using CALIBER data for translational research: a) disaggregating disease endpoints through high resolution clinical epidemiology, b) disease risk prediction using supervised machine learning approaches, and c) subtype discovery using unsupervised learning.

3. Methods

3.1. CALIBER phenomics resource

We implemented and applied a rule-based phenotyping framework [4] for extracting information on diseases (status, severity, onset), lifestyle risk factors and biomarkers and applied it to a sample of 15 million individuals. CALIBER utilizes data from three national EHR sources: a) primary care EHR from the Clinical Practice Research Datalink (CPRD), b) administrative data on diagnoses and procedures during admission to hospital from Hospital Episode Statistics (HES), and c) cause-specific mortality information from the Office for National Statistics (ONS) death register. Data were recorded using five controlled clinical terminologies: a) Read (primary care), b) ICD-10 (hospital diagnoses, causes of death), c) ICD-9 (causes of death <1999), d) OPCS-4 (surgical procedures), and d) DM+D (prescriptions in primary care).

3.2. Contemporary research exemplars

We present three contemporary research exemplars utilizing the CALIBER resource and phenotyping framework: a) high resolution epidemiology: we calculated Hazard Ratios (HRs) based on disease-specific Cox models with time since study entry as the timescale, adjusted for baseline age and stratified by sex and primary care practice and report the associations of systolic and diastolic BP with 12 different cardiovascular diseases (CVD), b) disease risk prediction: using a global vectors model [5], we trained clinical concept embeddings from hospitalization diagnosis and procedure information recorded in HES and evaluated them for predicting for the risk of admission to hospital in heart failure (HF) patients, and c) subtype discovery: we applied dimensionality reduction using multiple correspondence analysis and data clustering using k-means to a cohort of Chronic Obstructive Pulmonary Disease (COPD) patients in order to identify and characterize novel and clinically-meaningful disease subtypes.

4. Results

4.1. CALIBER phenomics resource

We created an iterative, rule-based EHR phenotyping approach which combined domain expert input with data exploration. We curated >90,000 ontology terms from five clinical terminologies and created 51 phenotyping algorithms (35 diseases/syndromes, ten

biomarkers, six lifestyle risk factors). Phenotype validation is a critical step in the process, and we provided up to six approaches for validating phenotypes: a) the ability to replicate aetiological and prognostic associations reported from non-EHR studies, b) case note review for Positive Predictive Value (PPV) reporting, c) the ability to replicate associations with genetic variants from non-EHR Genome-Wide Association Studies, d) algorithm performance in external populations, and e) cross-EHR-source concordance and stratification of populations.

For each phenotype, we created a textual description with details on the implementation logic, the pre-processing steps and implementation steps. For some algorithms, we generated flowchart descriptions to describe how different components are combined to form the finalized phenotype and for facilitating the translation to machine-code (e.g. SQL) for execution and data extraction. Algorithms are curated on an open-access resource, the CALIBER Portal (https://www.caliberresearch.org/portal), [6,7] and have been used in >60 publications from national and international research groups. Each phenotype page on the Portal[2] contains sufficient implementation and validation information for external researchers to re-use the algorithm.

4.2. Contemporary research exemplars

High-resolution epidemiology: In a cohort of 1.25 million patients, we reported [8] highly-heterogeneous associations between BP and CVD disease endpoints: high systolic BP was more strongly associated with stable angina, Hazard Ratio (HR) 0.41 [95% CI 1.36-1.46] than diastolic whereas diastolic BP had the strongest association with abdominal aortic aneurysm (HR 1.45 [95% CI 1.34–1.56]). We have undertaken similar analyses in other conventional CVD risk factors e.g. smoking [9], type-II diabetes [10], alcohol [11], social deprivation [12], heart rate [13], sex [14].

Disease risk prediction: We trained clinical concept embeddings [15] from 2,447 ICD-9, 10,527 ICD-10 and 6,887 OPCS-4 terms across 2,779,598 hospitalizations in the UK Biobank. In the UK Biobank, we identified 4,581 HF cases (using the CALIBER HF phenotype [16,17])(30.52% female) and matched them to 13,740 controls. Clinical concept embeddings performed marginally better (AUROC 0.6965) than one-hot encoding of hospitalization data for predicting admission to hospital due to HF.

Disease subtype discovery: In the CPRD [18], we identified 30,961 current and former smokers diagnosed with COPD and extracted 15 clinical features including risk factors and comorbidities. Using clustering, we identified five clinically-meaningful COPD clusters with distinct dominant clinical profiles (e.g. anxiety/depression, frailty, CVD, obesity and atopy) and different healthcare utilization and exacerbation profiles.

5. Conclusions

In this manuscript, we described the CALIBER resource as a framework for using national EHR from primary and secondary health care, disease and national mortality registries. Challenges remain with regards to scaling the phenotyping efforts to thousands of diseases and for recreating the life course of disease [19] .

[2] For example, www.caliberresearch.org/portal/phenotypes/heartfailure.

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Inappropriate Use of Public Hospitals Emergency Departments in Greece: Magnitude and Associated Factors

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Abstract. The aim of this study was to evaluate the appropriateness of use of the Emergency Departments (EDs) and to identify the reasons for inappropriate use. A study with 805 patients visiting the EDs of four large-scale public hospitals in Athens was conducted using the Hospital Urgencies Appropriateness Protocol (HUAP). 38.1% of the visits (n=307) were estimated as inappropriate, due to several reasons such as increased confidence in hospital rather than primary care services/ patients' expectation for improved care in EDs (46.6%), convenience/proximity to patient's residence (44.6%) etc. Ageing, Greek nationality and insurance coverage were related with the appropriate use of EDs ($p<0.001$, $p=0.04$ and $p=0.005$, respectively). The identified distortions must be tackled so as to mitigate ED crowding, waste of resources and increase quality and responsiveness of care.

Keywords. emergency department, public hospital, inappropriate use of EDs, HUAP

1. Introduction

According to the American College of Emergency Medicine and the Emergency Nurses Association [1,2], ED crowding constitutes one of the major obstacles for EDs

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to achieve their multiple roles. In fact, this problem has been occurring with alarming frequency worldwide. Indeed, in many countries ED visit rates appear to have dramatically increased [3]. The need to identify reasons and potential solutions has led scientists in different countries and in Greece as well, to use specific criteria [4]. In many cases, these increasing rates have been correlated with patients' inappropriate visits in EDs, due to various factors according to patient's self-related responses.

In Greece, EDs constitute the most overused units in terms of exceeding demand. Based on data derived from the ESYnet information system of the Ministry of Health attendances to public hospitals EDs fluctuated from 4.7 to 4.9 mil./annually (equals to 0.43-0.45 visits/inhabitant/annually) over the past seven years (2012-2018). Waiting times in many cases range from 5 to 8 hours, while real emergency cases wait for hours to be considered. The biggest problem is met in the Attica Region, where on a daily basis, around 4,450 individuals visit the EDs (data from three largest hospitals in Attica) [5], a number which often increases during the general on-call days [6]. Nevertheless, these cases are not all urgent, as a great proportion (at least 25%) constitutes inappropriate visits [7,8] due to lack of an integrated Primary Health Care and referral, organizational, psychological, self- related, and/or other reasons [9-13].

The aim of this study was to evaluate the appropriateness of use of the EDs and to identify the respective reasons of inappropriate use.

2. Methods

A non-invasive cross-sectional study was conducted in 2015. The study sample consisted of 805 individuals visiting the EDs of four large-scale public hospitals in Athens (convenience sampling). Data collection was conducted by the investigators via face to face interviews with patients after obtaining their verbal informed consent.

The Hospital Urgencies Appropriateness Protocol (HUAP), an open licensed tool, was used to identify inappropriate visits [10]. The study was carried out following the acquisition of all necessary permissions from the hospitals included in the study. Data were collected and analyzed in a way that ensured anonymity and confidentiality, aligned with the European General Data Protection Regulation (GDPR).

Pearson's x^2 test was used to determine associations between categorical variables and student's t-test was applied for the analysis of group differences within age. Regarding the appropriate use of EDs, we performed backward stepwise multivariate logistic regression analysis in order to eliminate confounding and we estimated adjusted odds ratios (OR) with 95% confidence intervals (CI) for the independent variables included in the model. Data analysis was performed using IBM SPSS 21.0 and a two-sided significance level was set at 0.05.

3. Results

According to HUAP explicit criteria, 38.1% (n=307) used the EDs inappropriately. The main reasons for inappropriate use of hospital EDs are shown in Table 1.

Bivariate analyses showed that age, nationality and insurance coverage status were related with the appropriate use of EDs. In particular, mean age of participants that chose to use EDs appropriately was 57.9 years (19.6), while mean age of those that chose to use EDs inappropriately was 50.4 years (19.8) ($p<0.001$). Greek participants

chose to use EDs appropriately in a greater percentage than the non-Greek participants (63.3% vs. 53.2%, p=0.04). Also, participants with health insurance coverage chose appropriately to use EDs in a greater percentage than participants without health insurance coverage (46.8% vs. 31.6%, p=0.005). Finally, logistic regression analysis identified that increased age (OR=1.02, 95% CI=1.01 to 1.03, p<0.001) was associated with increased probability of appropriate use of EDs.

Table 1. The main reasons for inappropriate use of hospital EDs (n=307).

Reason	N (%)
Patients had more confidence in hospital rather than primary care services/patients expected better care in EDs	46.6%
Patients' residence was closer to the hospital	44.6%
Patients needed diagnostic tests (X-rays, laboratory tests, etc)	31.6%
Patients were not aware whether an out-of-hospital emergency health service was at their disposal or its contact details (telephone number or address)	27%
Long waiting lists for hospital outpatient consultation	20.8%
Long waiting lists for appointments with non-hospital specialists	19.2%
Long waiting lists for primary care consultation (with contracted physicians or in health centers)	16.9%
Patients' family prompted them to the EDs	16.9%
No primary care physician had been assigned to the patient (e.g. family doctor)	16.3%
Lack of a (primary care) physician in the public health system	14.3%
Inability to contact primary care services	13%
Patient did not trust their primary care physician	10.1%

4. Discussion

Study results showed that a significant percentage of the participants (38.1%) used the EDs inappropriately, a consistent finding with many studies conducted on an international level, ranging from 10% to 90% [3,14]. Our study revealed several reasons for inappropriate use of EDs such as increased confidence in hospital rather than primary care services/patient expected better care in EDs, convenience/proximity to patient's residence, need of diagnostic tests, lack of knowledge and information regarding the available PHC services, long waiting times for hospital outpatient consultation and/or long waiting lists for appointments with non-hospital specialists and/or primary care consultation (with contracted physicians or in health centers), etc.

Literature shows that non-emergency visits constitute an important factor for ED crowding. Indeed, in case of Greece this finding is related to the way emergency care is organized. In the two Metropolitan Areas of Athens and Thessaloniki, emergency care is provided on a rotating basis by a few selected hospitals on a given day, resulting to overcrowding every 3-4 days and also problem with patient admissions. Since patients can only be admitted into a hospital when it is on emergency duty, hospital doctors arrange for "their essentially private patients" to come to the emergency department, and the patient is admitted on bogus emergency admission orders by the "attending" physician. Thus, an actual emergency case may find needed hospital beds already occupied. The end result is patient dissatisfaction, on rare occasions, adverse effects on a patient's health and of course a waste of resources and money [15]. Extrapolating the current study results to national level, more than 1.5 mil. visits/year to EDs are estimated as inappropriately conducted, resulting to an extravagance of €120 mil

annually, an amount of money that could be exploited for employing about 5,500 nurses[2].

Our proposal to deal with this situation is the creation of independent Emergency Care Units in selected large public hospitals (staffed with permanent healthcare personnel specialized in emergency care), operating on a 24 h/7 days basis [15].

Additionally, there is need to implement interventions and corrective measures such as an integrated patient screening system based on criteria of emergency or non-emergency of the incident, grading measures, (directed to patients, primary health doctors and private doctors) so as to control the "adverse selection" which drives the exceeding demand for the EDs. Moreover, Primary Health Care sector should act as a gatekeeper of the system and not as a mediator or referral agent. Finally, political willingness to maintain the continuity of the corrective measures and strict regulations accompanied by robust auditing mechanisms constitute essential prerequisites in order to improve the emergency care system in Greece.

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[2] Cost per ED visit was considered to €80 (Governmental Gazette 1702, 01/08/2011). Moreover, based on data derived from accounting offices of public hospitals the average gross annual remuneration cost of a nurse was estimated to about €22,000.

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An Evolutionary Bootstrapping Development Approach for a Mental Health Conversational Agent

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Abstract. Conversational agents are being used to help in the screening, assessment, diagnosis, and treatment of common mental health disorders. In this paper, we propose a bootstrapping approach for the development of a digital mental health conversational agent (i.e., chatbot). We start from a basic rule-based expert system and iteratively move towards a more sophisticated platform composed of specialized chatbots each aiming to assess and pre-diagnose a specific mental health disorder using machine learning and natural language processing techniques. During each iteration, user feedback from psychiatrists and patients are incorporated into the iterative design process. A survival of the fittest approach is also used to assess the continuation or removal of a specialized mental health chatbot in each generational design. We anticipate that our unique and novel approach can be used for the development of conversational mental health agents with the ultimate goal of designing a smart chatbot that delivers evidence-based care and contributes to scaling up services while decreasing the pressure on mental health care providers.

Keywords. Mental health, Arab world, conversational agent, depression, anxiety, Qatar

1. Introduction

The use of conversational chatbot agents has reemerged as a relatively new phenomenon within the healthcare sphere. Conversational chatbots are computer programs that use auditory, textual and visual methods to interact with human users [1]. The first conversational agent was developed in 1966, called ELIZA, to stimulate text based psychotherapy interaction via text messages [2]. With the increase of online data and

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recent advancements in machine learning and natural language processing (NLP), conversational agents developed by companies such as Google (Google Home), Microsoft (Cortana) and Amazon (Amazon Alexa) are now household names used by the mass consumers to shop, search for music, ask general questions, and for general health [2]. Only recently has the phenomenon of using healthcare based conversational chatbots, especially with free flowing conversations, within health have started to emerge [3]. Systematic reviews on the use of conversational chatbot agents acknowledge their limited use but also report promising results for general health and well-being [2].

There can be a variety of approaches to build chatbots/conversational agents, such as agile, incremental or prototyping methods. One method that may be utilized for developing a conversational mental health agent is a bootstrapping approach. Originally referring to an absurdly impossible action ("pull oneself over a fence by one's bootstraps") [4], ***bootstrapping*** has become a term to refer to powerful bottom-up approaches in ab-initio system design [4]. In this context, bootstrapping refers to the approach of first solving smaller, realistically achievable sub-problems of the original task at hand, followed by using these smaller solutions as tools to address and solve the original challenge. Akin to watchmakers first building their tools before designing the movement of a watch, every subcomponent of the solution is carefully instrumented in order to finally solve the original task. The purpose of this paper is to present a bootstrapping approach for the development of a mental health conversational agent/chatbot. In this paper, we use the term ***bootstrapping*** to refer to a design process of a digital mental health platform based on an authored expert system; namely, a rule-based chatbot, with the ultimate goal to design a smart chatbot offloading medical practitioners of all but the most pressing cases.

2. Bootstrapping Development Approach

We suggest that the chatbot/conversational agent be developed in a set of generations or evolutions as shown in Figure 1. For ***Generation 1,*** we start with an initial rule-based chatbot that performs basic screening and assessment of patients according to a number of common mental health disorders such as depression, anxiety, stress, social phobias, and obsessive compulsive disorders and provides relevant recommendations based on the assessment and screening results. All interactions and steps will be recorded and anonymized. At the end of each session, medical professionals and patients rank the performance of the chatbot with respect to its screening, assessment, and recommendations using a Likert-style scale of performance (e.g., Level 1: Unsatisfactory to Level 5: Exceptional). If improvements are flagged by patients and medical professionals, qualitative feedback on how to improve the chatbot will be sought. The feedback gained from this process will be used to build the next generation of the Chatbot.

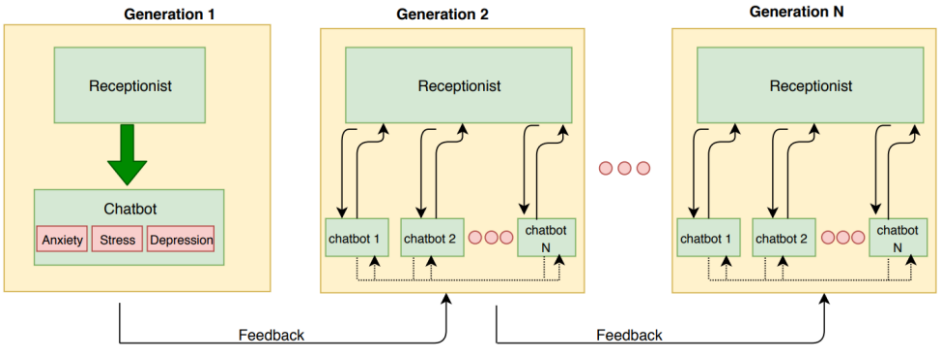

Figure 1. Block diagram of the proposed bootstrapping based chatbot for a mental health conversational agent. The receptionist is where the first patient and chatbot interaction occurs. Generation 1 is a rule-based chatbot, and with time, each subsequent generation will use Natural Language Processing and Machine Learning and less rules to guide the conversation to a more human-like form.

Based on the feedback from *generation 1*, ***Generation 2*** is created. For generation 2, Machine Learning and Natural Language Processing (NLP) techniques will be used to a) reduce the complexity of the chatbot and b) refine the rule set of each chatbot. For example, in generation 1, the receptionist end of the chatbot will provide the user with a list of symptoms for the user to choose from. In generation 2, the list will be removed and a more natural conversation using NLP will be implemented. Furthermore, two different types of machine learning techniques; namely, supervised and reinforcement learning can be employed for Generation 2. Supervised learning techniques along with an encoder-decoder can be used to directly map patients' dialogues to physicians' responses. In case of reinforcement learning, the chatbot can be trained through trial-and-error based conversations with either physicians or a rule-based user simulator. The NLP techniques will be used for feature extraction from the text streams exchanged between chatbots and patients. After data is collected, feedback from patients and medical consultants will be sought to validate and improve the chatbot.

From generation 2 and onwards, the chatbot will be split up into a number of chatbot subsets that are specialized in assessing each common mental health disorder such as anxiety or depression. As such, newer generation chatbots will only assess a patient based on a specific screening test at a low and more in-depth level. For example, if a person writes in the receptionist chatbot that they feel "sad," this may lead the chatbot to call up the anxiety GAD7 test. If results of the GAD7 test show moderate to low anxiety, the chatbot would call up the depression assessment tool, PHQ2, to conduct a quick depression screening. Depression is tested in this stage because anxiety does not appear to be the primary cause behind the patients' "sadness." If the PHQ2 test shows a moderate to high level of depression, the chatbot will call up the PHQ9 questionnaire item which is a deeper level of screening and assessment for depression.

It is worth noting that specialized chatbots (e.g., for depression or anxiety) are modular and can thus evolve parallel to each other. It is entirely conceivable that anxiety bots could be further evolved than, e.g., depression bots based on the volume of patient interactions. This modular design of our approach is tied together by the receptionist chatbot who takes some brief assessment before delegating patients to the expert chatbots. As shown, each expert chatbot operates with two goals: a) to corroborate the assumed condition of the patient and b) seek evidence severity relating to the mental health condition. If evidence for the hypothesized condition is lacking, the patient will

be sent to another expert chatbot specialized in assessing the second, most likely condition. This division into modules, while designed to make the overall system easier to maintain, is completely transparent to the patient, who is handed over seamlessly and thus experiences smooth interactions as though they were with a single entity.

To provide quality assessment on the evolutionary process of training and refining chatbots, generations will not be rolled out immediately from one generation to the next, but rather depend on the number of interactions each chatbot has with the users. The more the chatbot interacts with users, the more it will improve based on the feedback mechanisms provided by patients and psychiatrists. We will periodically monitor the predictive models generated and validate them with an increasing number of expert users to reduce bias and increase variety of the expert scores. Only if the new generation outperforms the old generation, based on user and expert feedback, a generation update is performed and the process is repeated for the next generation. Chatbots modules that are not used, for example, Schizophrenia, will remain in their first generation and may later be removed in favor of a direct referral to a human expert following a survival of the fittest approach.

3. Conclusion and Future Work

In this work, we described a bootstrapping based approach for developing a mental healthcare chatbot starting from a simple rule-based expert system. Our proposed approach iteratively moves towards a more sophisticated platform with a diversified set of specialized chatbots. Each chatbot is specialized in a particular mental disorder in successive generations of the chatbot using a survival of the fittest approach. We envision each generation of chatbots to mine the data necessary for their evolution into the next generation, while at the same time specializing and improving from generation to generation. Ultimately, we envision our system to be populated by a rich diversity of chatbots specialized to assess and pre-diagnose a wide range of mental health issues.

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DeepCNPP: Deep Learning Architecture to Distinguish the Promoter of Human Long Non-Coding RNA Genes and Protein-Coding Genes

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Abstract. Promoter region of protein-coding genes are gradually being well understood, yet no comparable studies exist for the promoter of long non-coding RNA (lncRNA) genes which has emerged as a global potential regulator in multiple cellular process and different diseases for human. To understand the difference in the transcriptional regulation pattern of these genes, previously, we proposed a machine learning based model to classify the promoter of protein-coding genes and lncRNA genes. In this study, we are presenting DeepCNPP (deep coding non-coding promoter predictor), an improved model based on deep learning (DL) framework to classify the promoter of lncRNA genes and protein-coding genes. We used convolution neural network (CNN) based deep network to classify the promoter of these two broad categories of human genes. Our computational model, built upon the sequence information only, was able to classify these two groups of promoters from human at a rate of 83.34% accuracy and outperformed the existing model. Further analysis and interpretation of the output from DeepCNPP architecture will enable us to understand the difference in transcription regulatory pattern for these two groups of genes.

Keywords. deep learning, convolution neural network, long non-coding RNA, promoter

1. Introduction

Although the human genome project [1] primarily focused on the protein-coding genes exclusively, long non-coding RNA (lncRNA) genes [2], which do not encode a protein, later, emerged as a potential global regulator for different cellular processes and have shown to be involved in different diseases including cancer [3, 4]. Given the diversity in biogenesis for lncRNAs, their low-level expression and conservation make them more cryptic than protein-coding genes. Therefore, it becomes more challenging to understand their regulation and functional relevance in different pathways and diseases [4].

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To better understand the differences between these two groups of genes, many computational methods have been developed to distinguish the non-coding regions from the coding regions of the genome across multiple species [5]. But very few studies focused on comparing the difference in their promoter regions, which is considered as the key regulatory region for genes. In order to understand the difference in global transcriptional regulatory pattern of protein-coding genes and lncRNA genes, we need to investigate their promoter regions thoroughly. To achieve this goal, previously, we developed a traditional machine-learning models to classify these two groups of promoters using genomics, epigenomics and regulatory information in the promoter regions [6]. We used different sequence-related features (k-mer, palindromes, skewness etc.), chromatic states [7] and the putative transcription factor binding sites (TFBSs) [8] that could bind in the promoter region of these two groups of genes to elucidate their differences in transcription regulation. Though gene expression, transcription factors (TFs) controlling the genes and epigenetic information are crucial to understand the transcription regulatory network of genes, yet there is a scarcity of such information. For example, we do not have gene expression data for all cells/tissues in human; we do not have ChIP-seq data for all known TFs across all cell types in human. So, it is always advantageous to build a computational model using sequence information only so that it can work independent of other available factors. Here we interrogated, at genome-wide scale, to test the hypothesis that only DNA sequence information of the promoter region is well enough to elucidate the underlying pattern of promoter of lncRNA genes from protein-coding genes. To reach in conclusion, we set up this problem as a machine learning classification framework for classifying two broad groups of gene promoters using sequence information only.

Recently convolutional neural network (CNN) has shown to achieve ground-breaking results in the classification of images [9]. The examples of using CNN in biological problems are increasing in recent time as well [10]. Though we are the first to introduce the machine learning model to distinguish the promoter of lncRNA genes and protein-coding genes, no deep learning (DL) based system has been developed for the classification of promoters from human lncRNA genes and protein-coding genes. Therefore, it is unknown whether DL based architecture can achieve reasonable accuracy in classifying the promoter of lncRNA genes and protein-coding genes. So, the objective of this study is to build a DL based architecture to check the effectiveness of such a network structure in this particular problem. Hence, we introduce DeepCNPP (deep coding noncoding promoter predictor), the first DL based architecture to classify the promoter of these two broad groups of genes using the sequence information of the promoter region only. DeepCNPP outperformed the existing model [6] considering all evaluation metrics.

2. Methods

We downloaded the publicly available promoter dataset from our previous study [6]. The dataset contains promoter information of 18,787 protein-coding genes and 18,487 lncRNA genes. We considered the [-1000, +1000] region of transcription start sites (TSS) as the putative promoter region of genes as prescribed in [6]. The promoter sequence was fetched from the human genome (hg19 version). Each nucleotide of promoter sequence was encoded using one-hot encoding approach of four length vector, A:(1,0,0,0),

C:(0,1,0,0), G:(0,0,1,0) and T:(0,0,0,1). The two-dimensional encoded promoter sequences were used as input to build DeepCNPP architecture (Figure 1).

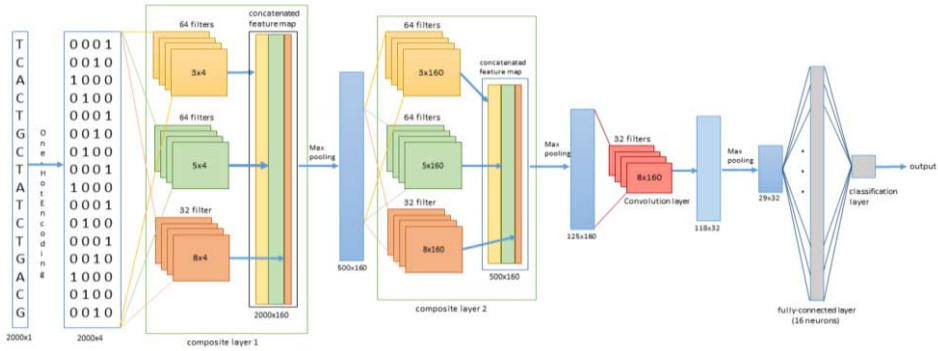

Figure 1. Proposed architecture for DeepCNPP.

We used one-dimensional convolution operations, commonly used for sequence data analysis, in our model. Keeping consistency with the convolution layers the max-pooling operation used were also one-dimensional, having size of 4. DeepCNPP consists of two inception-like [11] layers (hereafter referred to as composite layers) followed by one conventional convolutional layer, and finally, two fully connected layers. Each composite layer is a cascade of three convolutional layers with filter size 3, 5, and 8, respectively. We used 64 kernels of size 3 and 5, and 32 of size 8. The outputs of these convolution layers are then concatenated along the feature axis to produce a feature map that acts as the input to the next layer. Using convolutions of multiple sizes in one layer helps the network analyze the layer's input at different scales, and produces a feature map for the next layer incorporating information from different visual levels. DeepCNPP has two of these composite layers one after another with dropout and max pooling layers following each. After these two composite layers, the network has a regular convolution layer containing 32 kernels of size 8 with dropout and max-pooling layers following. The last two layers of the network are fully connected layers of size 16 and 1 (the final classification layer for coding promoter (0) and non-coding promoter (1) prediction), respectively. The first fully-connected layer has a dropout layer after it for regularization. We used ReLU as the activation function for the inner layers, and sigmoid for the classification layer. The dropout rate for the composite and the convolution layers was 0.4, and for the fully connected layer, 0.5.

We trained our model using the Adam [12] optimization algorithm using a minibatch size of 256. We used the default values for the β1 and β2 parameters for Adam, and used the stochastic gradient descent with warm restart [13] as the learning rate scheduler with a minimum and maximum learning rate of 3x10-5 and 10-3, respectively. We used Keras for implementing the DeepCNPP. The model was trained on GeForce GTX TitanX (Pascal) on single GPU machine for 400 epochs. Each epoch took around 40 seconds to complete. We used 10-fold cross validation to evaluate the performance of our model.

3. Results & Discussions

In the training process of DeepCNPP, we considered the promoter regions of lncRNA genes and protein-coding genes as positive and negative class respectively. We used the following metrics to evaluate the performance of the model: Sensitivity= (TP)/(TP+FN), Specificity = (TN)/(FP+TN), Accuracy = (TP+TN)/(TP+FN+FP+TN), where TP, FN, FP, TN stand for true positive, false negative, false positive and true negative respectively. Using 10 fold cross-validation, we achieved 83.88% sensitivity, 82.81% specificity, and 83.34% accuracy (see Table 1). From Table 1 we can notice that DeepCNPP outperformed the existing model in all evaluation metrics.

Table 1. Summary of model performance for DeepCNPP and the previous model.

Model	Sensitivity (%)	Specificity (%)	Accuracy (%)
Previous model [6]	82.77	80.60	81.69
DeepCNPP	83.88	82.81	83.34

4. Conclusion

We developed DeepCNPP, the first deep CNN based architecture to classify the promoter of lncRNA genes and protein-coding genes from human and it outperformed the existing model in all evaluation metrics. In future, we will investigate the output from different filters at different layers of CNN to interpret the model. The interpretation of the model will help us to better understand the transcription regulatory pattern of these two groups of genes. In addition to improving the proposed methods, we will extend this for other model organisms.

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DeepDSSR: Deep Learning Structure for Human Donor Splice Sites Recognition

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Abstract. Human genes often, through alternative splicing of pre-messenger RNAs, produce multiple mRNAs and protein isoforms that may have similar or completely different functions. Identification of splice sites is, therefore, crucial to understand the gene structure and variants of mRNA and protein isoforms produced by the primary RNA transcripts. Although many computational methods have been developed to detect the splice sites in humans, this is still substantially a challenging problem and further improvement of the computational model is still foreseeable. Accordingly, we developed DeepDSSR (deep donor splice site recognizer), a novel deep learning based architecture, for predicting human donor splice sites. The proposed method, built upon publicly available and highly imbalanced benchmark dataset, is comparable with the leading deep learning based methods for detecting human donor splice sites. Performance evaluation metrics show that DeepDSSR outperformed the existing deep learning based methods. Future work will improve the predictive capabilities of our model, and we will build a model for the prediction of acceptor splice sites.

Keywords. deep learning; convolution neural network; bidirectional long short-term memory; donor splice sites

1. Introduction

More than 90% of mammalian genes are believed to be processed through an alternative splicing mechanism, which is crucial to understand the gene structure and transcript variants [1]. The exon-intron/intron-exon boundaries, where the splicing occurs, are called splice sites (SS), and introns are cut out from the pre-mRNA in the SS region [1]. The SS at the exon-intron boundary is called donor SS (DSS), and a highly conserved dinucleotide of GT is observed at the intron start side. The SS at the intron-exon boundary is called acceptor SS, and a highly conserved dinucleotide of AG is observed at the intron end side. However, SS identified by read aligner is not always reliable as there is a high chance of false mapping of short reads over a large reference genome [2]. Therefore

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absolutely precise computational model for identifying SS is necessary to identify the accurate gene structure and their transcript variants.

There are many existing methods that use traditional machine learning methods to predict human DSS [3-6]; they perform reasonably well. Recently deep convolutional neural networks (CNNs) have shown to achieve ground-breaking results in the classification of images [7]. The examples of using CNN for biological problems have increased recently, and in many cases, deep learning (DL) methods have been shown to generate more accurate results than traditional hand-curated feature-based machine learning methods [8]. Based on our literature search, we found three DL based architectures to predict the DSS. Naito developed DSSP, which used CNN and long short-term memory (LSTM) [9] based architecture to predict the DSS [10]. Zhang et al. developed DeepSplice, a CNN based model, to predict the human DSS [11]. Du et al. developed DeepSS, a two-layer CNN based architecture to predict DSS from humans and other organisms [12]. Naito and Zhang et al., both groups have used 1:10 ratio of true:false DSS and Due et al. used a ratio of 1:5 of true:false DSS sequence to report the model performance.

In this study, we have developed a novel deep learning architecture, DeepDSSR (deep donor splice site recognizer), using CNN [7] and bidirectional LSTM (BLSTM) [9] to predict the donor splice sites in human. Considering several metrics of model evaluation, DeepDSSR, outperformed the existing DL based models in predicting human DSS.

2. Methods

We collected publicly available human DSS dataset from HS3D [13]. This dataset contains information on 2,796 true DSS and 90,924 false DSS. The length of each sequence is 140 nucleotides and the conserved GT dinucleotide resides at the 71st and 72nd position of each sequence. Since this is an imbalanced dataset, and previously published DL based methods [10-12] used true/false DSS ratios of 1:1, 1:5, or 1:10 for evaluating their models, we also used these three ratios in our evaluation to compare the performance of our model to the existing DL based models.

Our first step was to encode each input sequence using one-hot encoding, where each nucleotide of DNA was represented by a vector of length four, A:(1,0,0,0), C:(0,1,0,0), G:(0,0,1,0) and T:(0,0,0,1). These two-dimensional encoded sequences were then used as an input to the DeepDSSR architecture (Figure 1) for training and validation.

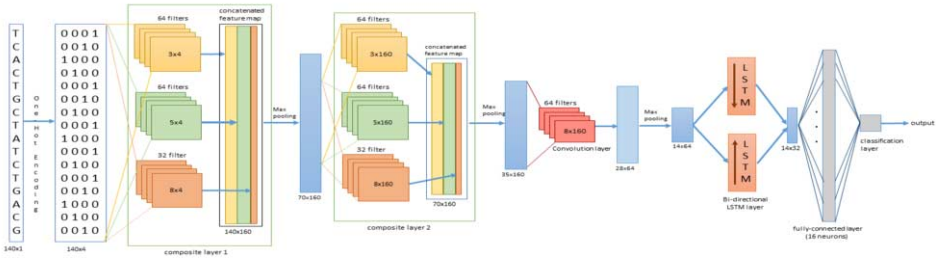

Figure 1. Proposed architecture for DeepDSSR

Our proposed network architecture consists of four layers, listed here in the order they are applied to the input: a pair of Inception-like [14] layers (hereafter referred to as

composite layers), one conventional convolutional layer, a BLSTM, and two fully connected layers which include the output layer. Each composite layer consists of three, parallel one-dimensional convolution layers with a filter size of 3, 5, and 8, respectively. We used 64 kernels of size 3 and 5 and 32 of size 8.

We used two composite layers one after another with dropout and max-pooling layers for dimensionality reduction and regularization, respectively. After the two composite layers, a regular one-dimensional convolution layer with 64 kernels of size 8 was added into the network. We then add a dropout and a max-pooling layer. The next module, BLSTM, analyzes the output of this convolutional layer from two directions to discover left-to-right and right-to-left patterns that influence the label of this DNA sequence. The last two layers of the network are fully connected layers of size 16 and 1, respectively. The final layer is for classification: true DSS (1) and false DSS (0) predictions. The first fully-connected layer also has a dropout layer after it for regularization. We used ReLU as the activation function for the inner layers and sigmoid for the classification layer. The dropout rates for the two composite layers, the convolution layer, BLSTM layer, and the first fully-connected layer, are 0.4, 0.5, 0.6, 0.25, and 0.70, respectively. The max-pooling layers we used were one-dimensional and had a kernel size of 2.

We trained our model using the Adam [15] optimization algorithm and binary cross-entropy loss. We used the default values for the β1 (0.9) and β2 (0.999) parameters for the optimizer and used stochastic gradient descent with warm restart [16] as the learning rate scheduler with a minimum and maximum learning rate of $3x10^{-5}$ and 10^{-3}, respectively, and a cycle length of 5 epochs. We used a batch size of 512.

We used Keras for implementing the DeepDSSR. The model was trained for 300 epochs on a single GPU machine having a GeForce GTX TitanX (Pascal). Each epoch took between 2 to 20 seconds to complete, depending on the version of the dataset (1:1, 1:5, or 1:10).

3. Results & Discussions

In the training process of DeepDSSR, we considered the true DSS and false DSS as the positive and negative class, respectively. To evaluate the performance of the model we used the following three evaluation metrics that were considered for most of the existing DL based models, Sensitivity (Sn) = (TP)/(TP+FN), Specificity (Sp)= (TN)/(FP+TN), and Matthew's Correlation coefficient (MCC):

$$MCC = (TP * TN - FP * FN)/\sqrt{(TP + FP)(TP + FN)(TN + FP)(TN + FN)},$$

where TP, FN, FP, and TN stand for true positive, false negative, false positive, and true negative, respectively. The performance of the model was evaluated using 10-fold cross-validation (see Table 1).

Table 1. Performance of DeepDSSR and other existing DL based tools for human DSS prediction. *: Since the value of these metrics were not explicitly mentioned in the article [12], the values shown here are approximated through visual inspection from "Figure 4" of the corresponding article. NA: Not available in the literature

Model (data ratio)	Sensitivity	Specificity	MCC
DeepSplice (1:1)	NA	NA	NA
DSSP (1:1)	97.88	95.36	93.33
DeepSS* (1:1)	97.50	92.50	91.00
DeepDSSR (1:1)	**97.50**	**96.42**	**93.93**
DeepSS* (1:5)	95.50	97.50	90.50
DeepDSSR (1:5)	93.57	**98.21**	**90.88**

DeepSplice (1:10)	95.71	93.76	NA
DSSP (1:10)	90.31	98.75	87.99
DeepSS* (1:10)	NA	NA	NA
DeepDSSR (1:10)	91.43	**98.85**	**89.15**

From Table 1, we can observe that for the dataset with 1:1, 1:5 and 1:10 ratios, our model achieved 93.33, 90.88, 89.15 MCC, respectively, and it outperformed, considering MCC as an evaluation metric, all the existing DL based models [10-12] for all three data sets subsampled at the same ratio. Additionally, for 1:1 dataset, DeepDSSR outperformed all the existing methods in terms of all three evaluation metrics (MCC, Sn and Sp). For 1:5 and 1:10 ratio datasets, DeepDSSR achieved a Sp that surpasses all the existing methods' corresponding metric but at the cost of ~2% Sn for the 1:5 dataset. For the 1:10 dataset, our model outperformed DSSP in terms of Sn.

4. Conclusion

The paper introduced a new deep learning architecture, namely DeepDSSR, for the prediction of human donor splice sites. Experimental results were presented, which show that DeepDSSR outperforms existing DL models in terms of MCC and sensitivity. Future work will focus on improving the performance of DeepDSSR and building a new model for the prediction of acceptor splice sites.

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Understanding the Impact of Clinical Training on EHR Use Optimization

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Abstract. Electronic health records usability creates challenges to the delivery of care. This paper presents a novel approach to user analysis. Fixation counts have been analyzed to identify differences among physicians of 3 experience levels – residents, fellows and attending physicians. The findings indicate that users with different training levels had varied experiences while interacting with the same interface. EHRs will always be used by a variety of user groups, each with their own unique characteristics and therefore user analysis must be an important component of EHR usability testing. Eye tracking technology could serve as a valuable tool in this context.

Keywords. Electronic health records, eye-tracking, fixation, usability, user analysis.

1. Introduction

Federal policies in the United States mandated the usage of electronic health records (EHRs) to improve the quality and delivery of healthcare. Subsequently over 86% of physicians reported that they were using EHRs [1]. However, there are multiple cognitive, financial, security/privacy, technological, socio-cultural, and workforce challenges that need to be overcome to be able to experience maximum benefits [2]. Usability issues form a major portion of the cognitive challenges and the incorporation of usability in EHR design has always remained inferior to product designs in other industries [3].

User analysis is the process of identifying the various types of users and their respective characteristics. In this case, it could include users of different experience levels and specialties. User analysis is the first step in the TURF framework of EHR usability introduced in 2011. It can help us design systems with knowledge and information structures that can satisfy the users' requirements and workflows [3].

Eye tracking refers to the process of tracking eye movements or the absolute point of gaze (POG) in the visual scene. It has been employed in assessing Human Computer Interaction (HCI) and in different fields like Psychology and Neuroscience [4]. The objective of this paper is to assess the relation between clinical training and the efficiency

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of finding information in the EHR by using the fixation count data obtained via eye tracking, as a proxy indicator for users' search efficiency.

2. Methods

Medical intensivists with different training levels were recruited from a south-eastern academic medical center in the U.S. Participants were made to wear the Tobii© Pro eye-glasses, and then asked to perform a total of 21 routine tasks using the EHR, in a simulation lab shown in Figure 1. Participants were recruited through electronic flyers and emails. Inclusion criteria included having a current role in the medical ICU, and having experience using the institutional EHR for routine medical ICU service.

During this interaction, their eye motions were tracked. Subsequently, the motion patterns were mapped to the screenshots of four sections of the EHR – Chart Review, Flowsheet, Results Review and Summary Overview.

The 21 tasks mentioned above were split between four different, yet commonly encountered clinical case scenarios. In the first one, participants were asked to review the record of a middle aged female patient diagnosed with multisystem organ dysfunction, determine the course of treatment recommended by consulting clinical teams and modify medication orders accordingly. The second scenario involved an elderly patient brought in to the hospital at night with acute hypoxic respiratory failure. Participants were asked to identify the changes in the respiratory status of the patient that took place throughout the night, as well as the changes in the mechanical ventilator settings. They were also made to analyze microbiology reports. The third case was that of a young male patient admitted with sepsis. Participants were asked to assess the clinical notes, laboratory results, and treatment records and manage abnormal test results. For the fourth case, participants were made to review the record of a middle aged male patient suffering from trauma, and post-operative heart failure with volume overload. They were asked to identify changes in the patient's weight over the last few hospital visits, and manage orders for medications and IV fluids.

The primary outcomes of this study were training-based fixation counts generated from the eye-tracking glasses. Fixation counts were extracted using the Tobii© software, categorized by experience level, and compiled into a spreadsheet. For every participant, total fixation counts were computed. Then, fixation counts were calculated for each of the four EHR screens of interest. ANOVA, two-sample t tests, and paired t tests were used to perform statistical analysis in Microsoft Excel©.

3. Results

A total of 25 medical intensivists comprising 11 residents, 9 fellows, and 5 attending physicians were recruited for this study. The overall baseline fixation count was 283.34 for residents, 184.31 for fellows, and 289.15 for attending physicians, as shown in Figure 1. The difference between the three groups was marginally significant ($p = 0.0853$). On comparing group pairs, the difference between residents and fellows was particularly significant ($p = 0.0232$). Group fixation count differences were also analyzed by the individual screens. While the difference was statistically significant for the Results Review screen ($p = 0.0481$), it was not significant for the other three (Chart Review: $p = 0.7015$, Flowsheet: $p = 0.2056$, Summary Overview: $p = 0.8402$).

From Table 1, it can be seen that among the three groups, residents were found to have significantly different fixation counts for each of the 4 screens (p = 0.0021). For all 3 groups, the fixation counts were the highest for the Results Review screen (Residents: 480.45, Fellows: 244.33, Attendings: 387.2) and least for the Summary Overview screen (Residents: 149, Fellows: 129.33, Attendings: 118.6). Overall, attending physicians had the highest fixation counts for the Chart Review (328.6) and Flowsheet (322.2) screens while the residents had the highest counts for the Results Review (480.45) and Summary Overview (149) screens. The fellows had the lowest fixation counts for three out of four screens (Chart Review: 188.44, Flowsheet: 202.88, Results Review: 244.33). Attendings had the least counts for the Summary Overview screen (118.6).

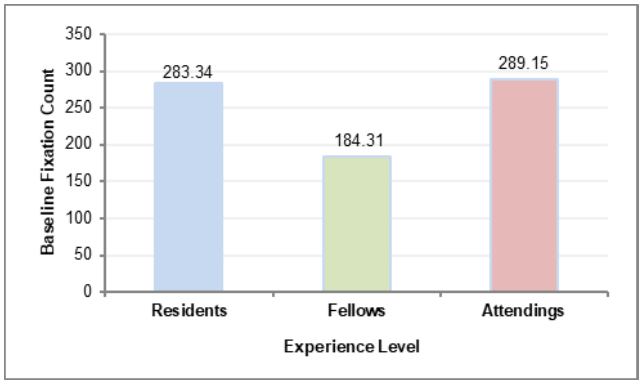

Figure 1. Baseline Fixation Counts by Experience Level.

Table 1. Comparison of Fixation Counts on the 4 screens for each User Group.

Role	Chart Review	Flowsheet	Results Review	Summary Overview	P value
Resident	212.45	291.45	480.45	149	0.0021
Fellow	188.44	202.88	244.33	129.33	0.4551
Attending	328.6	322.2	387.2	118.6	0.4714

4. Discussion

Findings from this study show that there were differences among participants based on their clinical training levels. The fixation count denotes the number of fixations in an area of interest and is thought to be negatively correlated with search efficiency. A poor arrangement of display elements can also be associated with high fixation counts. Attending physicians having the longest fixation counts seems contrary to the common belief that the efficiency of interaction with EHRs improves with clinical experience. The findings also bring to attention that a common interface can produce different experiences among different categories of users.

Findings of this study show that clinical training impacts EHR use. However, all subgroups found the Results Review screen to be the most difficult to find information, justified by the higher average fixation counts compared to the other screens. Summary

Overview screen had the lowest fixation counts across all groups suggesting good information organization, which makes it easy to locate information.

Recruitment of physicians belonging to only one specialty, the inclusion of only a single site and single EHR system, and the lack of inclusion of non-physician healthcare providers are some of the limitations of this study. Another limitation was the unequal distribution of participants, where there were more residents and fellows than attending physicians. Lastly, we were unable to establish a training baseline. Our participants differ with respect to their previous experience with the particular EHR system used in the study. The conceptual model of every EHR system is unique and we admit that consistent training and familiarity with a system is required to enable reasonable comparison of results across EHR systems. This requires more targeted recruiting and standards for task-level training from the researcher's part [5].

A more granular analysis of each screen using customized areas of interest may help to identify problematic sources and explain the differences noted for the 4 screens among the same user groups. Broadening the scope to include physicians of other specialties as well as non-physician healthcare providers may provide us more valuable insight into usability issues.

Eye tracking could serve as a usability tool to evaluate EHRs and have the potential to play an important role in user analysis. Unlike traditional methods such as surveys which can be used to obtain collective users' perceptions on the usefulness and usability of an EHR system, eye tracking can help to identify individual usability problems that can be improved [6]. It has the added advantage of reducing reactivity where participants tend to alter their behavior as a result of being monitored, as they have relatively lesser control over their natural eye movements. Data associated with eye tracking software is usually generated every 30Hz, and is usually precise and accurate. Finally, it can have a significant impact on EHR design improvement by helping researchers determine whether participants are missing key UI elements, which content attracts and which is unnecessary, and how the user accomplishes his goals [7]. The typical users of EHRs differ in their experience, education background, computer skills, cognitive capabilities, perceptual variations, age related skills, and cultural backgrounds [3]. Therefore, it is crucial to take into consideration the unique requirements of each user type in the design of useful systems that can live up to high expectations [5].

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Novel Eye-Tracking Methods to Evaluate the Usability of Electronic Health Records

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Abstract. The Electronic Health Record has become a staple today in every hospital and clinic, thanks to policy changes advocating its use. However, its full potential can be realized only when it is easy to use and compliant to the needs of the different user subgroups. This study uses a novel approach of eye tracking to assess and differentiate EHR usability based on gender. Though the findings were not suggestive of a significant gender-based difference, they did indicate that the design and layout of screen elements have a significant influence on the search efficiency for both user groups and this point could be relevant for future EHR design.

Keywords. Electronic health records, eye tracking, fixation count, usability.

1. Introduction

An effective electronic health record (EHR) design is one which caters to the requirements of its different user subgroups. Analysis of users along with factors influencing their preferences can be used to optimize usability. Research suggests that men and women process signals received from stimuli differently [1-3]. Studies also show that men and women differ in their aesthetic choices and preferences [3-5]. The visual appeal of an interface can influence whether it is perceived as useful, enjoyable, and easy to use [3,6].

Eye tracking refers to the process of tracking eye movements or the absolute point of gaze (POG) in the visual scene. It has been previously employed in assessing human – computer interaction (HCI) and neurocognitive studies [7]. Fixations and saccades are two important measurements of eye tracking. A fixation is a brief moment, where the eye halts on a word or word group, and the brain processes the visual information. Common fixation metrics include fixation count, duration and position. Fixation counts are negatively correlated with search efficiency and are indicative of a poor design layout [8]. Despite showing promise in HIT usability research because of the close relation between visual stimuli and attention mechanisms [8], a systematic review found that the usage of eye tracking technology in this field was still in its infancy [9]. The goal of this paper was to employ eye tracking to evaluate the interaction of physicians with the EHR,

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and specifically to investigate and differentiate EHR search efficiency based on gender by exploring fixation counts generated by eye-tracking glasses.

2. Methods

Intensive Care Unit (ICU) physicians with different experience levels from a south-eastern academic medical center were recruited for this study. Participants were observed while interacting with the EHR and asked to perform reviews of four patient records. Participants were recruited through electronic flyers and emails. Inclusion criteria mandated a current role in the medical ICU, and experience using the institutional EHR during medical ICU service.

The first case record to be examined was that of a middle aged female patient diagnosed with multi-organ dysfunction. Participants were asked to determine the advice provided by consulting clinical teams, and manage medication orders accordingly. For the second case, participants were asked to review the clinical notes, microbiology lab reports, and flowsheets and determine changes in the respiratory status and mechanical ventilator settings for an elderly female patient suffering from acute hypoxic respiratory failure. The third case involved a young male patient diagnosed with sepsis. Here, participants were asked to assess the clinical flowsheet, the laboratory data, and the treatment chart, and manage abnormal test results. The fourth case dealt with a middle-aged male patient diagnosed with post-operative heart failure and volume overload. Participants were asked to describe the changes seen with the patient's weight over a particular time period, and to manage IV fluid and medication orders.

During this interaction, their eye movements were recorded using the Tobii© eye tracker glasses. Their sequential eye positions for the entire recording were then mapped to the screenshots of the four most frequently used pages of the EHR – Chart Review, Flowsheet, Results Review and Summary Overview. The primary outcomes of this study were the fixation counts, which were extracted using the Tobii© software, and categorized by gender. Baseline values were calculated for all the participants overall, as well as for the gender subgroups, and for the duration of the entire recording as well as by page. The values were compiled into a spreadsheet and ANOVA, Independent t tests, and Paired t tests were employed for statistical analysis using Microsoft Excel©.

3. Results

A total of 25 physicians comprising 12 males and 13 females participated in this study. The overall baseline fixation count was 217.04 for males and 283.02 for females. This difference was not statistically significant ($p = 0.12$). The fixation counts were higher for women compared to men for all 4 pages. However, the difference was only marginally significant for the Summary Overview page [Male – 101.17, Female – 167.85, $p = 0.094$) and statistically insignificant for the other three (Chart Review ($p = 0.36$), Flowsheet ($p = 0.25$), Results Review ($p = 0.76$)].

Table 1 shows the performance of each group for the 4 pages. Each gender subgroup demonstrated a significant difference in their fixation counts for the different pages [males ($p = 0.01$), females ($p = 0.09$)]. For both genders, the highest fixation counts were associated with the Results Review page (males – 362.5, females – 390) and the lowest

counts with the Summary Overview page (males – 101.17, females – 167.85), as can be seen in Figure 1.

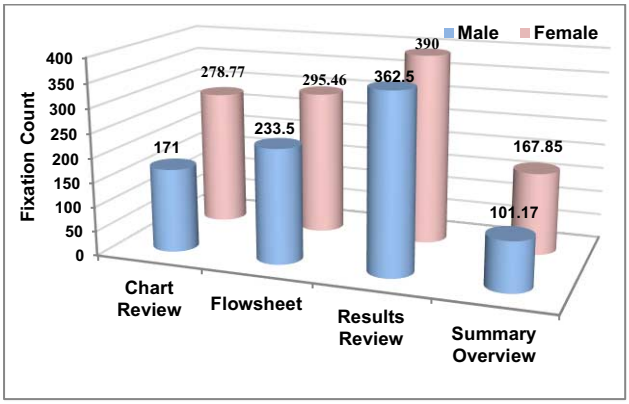

Figure 1. Fixation counts per screen

Table 1. Fixation Counts for each gender subgroup.

Gender	Chart Review	Flowsheet	Results Review	Summary Overview	P value
Male	171	233.5	362.5	101.17	0.0104
Female	278.77	295.46	390	167.85	0.0922

4. Discussion

Findings from this study indicate that although there was only a minimal gender based difference, the overall ranking of EHR pages by search efficiency, was similar among both gender groups which implies that the layout of visual elements in the EHR has an impact on the efficiency of information retrieval from it by users, as each of the four pages selected had different screen layouts. Furthermore, based on the fixation counts, one can conclude that the Summary Overview screen was more efficient than the rest in terms of information display.

A systematic review of the methodological trends in EHR usability studies showed that surveys, think-aloud, and heuristic evaluations were the most frequently employed usability testing methods. The most common validated surveys used were the System Usability Scale and the Questionnaire for User Interaction Satisfaction. Nielsen's Usability Heuristics was the most frequently used heuristic evaluation. Although surveys are useful for gathering self-reported data about the user's perception of an EHR system, they do not allow evaluators to identify individual usability problems that can be targeted for improvement, a process that is at the core of usability evaluations. Furthermore, a number of surveys and heuristic methods that are available are not standardized [10].

Eye tracking surpasses other usability techniques in reducing the concern of reactivity where participants tend to change their behavior due to being observed because natural eye movements and fixations are being documented. Additionally the quality of data collected by eye tracking technology is accurate and precise, and this method

provides flexibility in terms of research locations [11]. It can have a significant impact on EHR design improvement by helping researchers determine whether participants are missing key UI elements, which content attracts and which is unnecessary, and how the user accomplishes his goals [12].

Eye tracking also has certain limitations. The results can be influenced by the usage of contact lenses, glasses, and pupil color. Such studies require considerable financial, time, and, labor resources. Lastly, eye tracking technology focuses on foveal vision (focused, central vision) and not peripheral vision, which accounts for 98% of our visual field [11]. Therefore, it cannot be used as the sole evaluation but must always be accompanied by appropriate retrospective and introspective methodologies to be able to glean the complete picture [11,12]. This particular study has limitations in terms of involving a single-site, physicians of only one specialty, and a single EHR system.

In conclusion, eye tracking methods can serve as a complementary usability tool to evaluate EHRs as it can help us determine the elements responsible for cognitive overload and stimulation that can drive better design. The fact that results can vary among different sub groups should instigate designers to make it mandatory to involve representatives of the different subgroups of users throughout the software design cycle.

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Development and Usability of Mobile-based Healthcare Protocols in Kenya

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Abstract. Healthcare protocols have been shown to improve the quality of health service delivery by offering explicit guidelines and recommendations for clinicians who are uncertain about how to proceed in a given clinical situation. While various modalities are used to implement protocols, few rigorous evaluations of protocol use exist in low-resource clinical settings. This study aimed to develop mobile-based protocols (MBPs) and test their usability against currently used paper-based protocol (PBPs). Satisfaction, efficiency and effectiveness of the protocols were evaluated through a think-aloud usability exercise, in-depth interviews, and through a questionnaire. Compared to PBPs, satisfaction scores were higher with MBPs (83.8 versus 66.8, p=0.0498), number of errors lower with MBPs (2/25 versus 5/25, p=0.1089), with average time for task completion higher with MBPs (23.3s versus21.6s, p=0.7394). MBPs offer more satisfaction and trend towards being more effective as a dissemination modality for healthcare protocols in low-resource settings.

Keywords. Evidence-Based Medicine, Clinical guidelines, Usability, mLearning

1. Introduction

Clinical care guidelines are systematically developed to assist health practitioners with the optimal approaches to care for patients based on the best available rigorous evidence[1]. These guidelines reduce variations that exist in performance of treatment procedures, ensuring that patients receive consistently high-quality care, regardless of where or by whom they are being treated.[2]To implement care guidelines, many institutions have developed or adapted care protocols, which provide precise details of how to best implement the guidelines, taking into consideration available resources and clinical-setting constraints.[3] By nature, protocols are most useful when they are easily accessible to providers during patient care. However, in numerous settings, such as many in low- and middle-income countries (LMICs), only paper-based care protocols (PBPs) are available in booklets, as charts on walls, or as protocol documents in paper files. On occasion, protocols are available as soft-copies on computers or viewable on websites. Given the mobile nature of care providers within and across institutions, PBPs have proven suboptimal, as they are not easily portable when needed during care.

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With increasing ownership of mobile devices (including smartphones and tablets) by providers in LMICs, a unique opportunity exists to implement innovative strategies for timely access and use of protocols. Smartphone use in LMICs has doubled in the last two years, driven by falling prices. In 2017, over a third of mobile connections in Africa were through smartphones, with ownership predicted to rise to 85% by 2025.[4] Evidence suggests that use of mobile devices provides easy and timely access to information, allows healthcare professionals to be efficient at work, and gives providers instant access to evidence-based decision support and patient management tools to improve clinical decision-making.[5]Innovative use of mobile devices, through mLearning applications (apps), offers an opportunity to improve protocol availability and use in care within LMICs. However, few organizations in LMICs are using mobile-based protocols (MBPs), and little rigorous implementation-science based research exists on the potential role of this approach at improving care practice in these settings.

In this paper, we describe the adoption of approved care protocols into a robust mLearning application. We further describe outcomes of usability testing of the MBPs compared with PBPs in an LMIC study setting.

2. Methods

Study Setting: This study was conducted in November 2017 in the Pediatric unit of a large teaching referral hospital in Western Kenya. This institution already uses PBPs through two protocol booklets, namely the *Hospital-based Child Health Protocol* and the *Ministry of Health Basic Pediatric Protocol*.[6]Participants in the study included physician trainees who routinely use these PBPs to care for pediatric patients.

Developing Mobile-based protocols (MBPs): For MBPs to be useful within LMICs, they need to work offline, be cross-platform, and have to work on low-end devices. For our implementation, we customized the mobile version of the Modular Object-Oriented Dynamic Learning Environment (Moodle) application.[7] Moodle is a robust open-source learning platform with a customizable cross-platform mobile app, allowing for configurable course administration user and activity management. We modified the Moodle app to incorporate relevant site-specific user-interfaces, and incorporated all 33pediatric protocols, via HTML and CSS, as content within the app (Figure 1). Protocols were downloadable to the mobile app from our cloud-based kenyamedicine.com server.

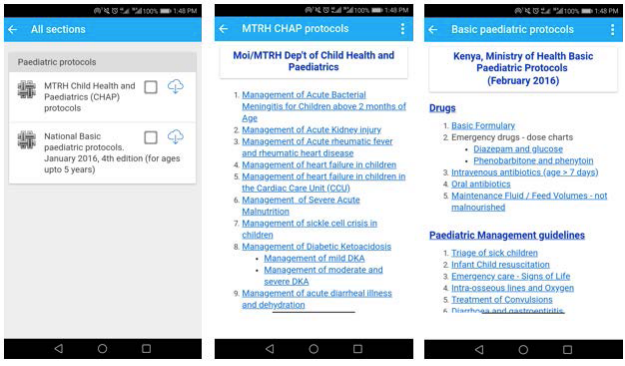

Figure1. User interfaces of the developed MBPs App

Implementation and Usability Testing: The focus of our evaluation was the usability of the MBPs, when compared to the current PBPs. Our usability testing used five subjects, who were all providers and all of whom underwent written informed consent. These providers were randomly selected from the group who routinely use PBPs to care for pediatric patients.

The MBPs application was installed on the practitioners' mobile devices, with a learning period of one month provided.

During the formal usability testing, each provider was asked to perform 5 protocol-related tasks using the available PBPs and those same tasks using MBPs, while thinking aloud. Tasks focused on finding and demonstrating ability to use particular protocols. A researcher observed errors and task completion, recorded time-to-complete tasks, took notes and audio recordings. Satisfaction was evaluated through an interview at the end of the session using a 10-item system usability scale (SUS). Efficiency was measured by the average time taken to perform each task, while effectiveness was measured by task completion rate and number errors made. Average SUS scores and activity completion times were compared between MBPs and PBPs using paired t-tests, while error rates compared using chi-squared test. Given the small sample size, these comparisons were used to only detect largest differences, with no power to detect small differences. Audio recordings were transcribed and analyzed thematically.

3. Results

Usability study participants included 3post-graduate physicians and 2 medical students, of whom 60% were female. Participants completed all tasks for both PBPs and MBPs. Compared to PBPs, average satisfaction scores were higher with MBPs (83.8 versus 66.8, p=0.0498) (Figure 2). Of total of 25 tasks performed, providers made 2 errors using MBPs and 5 using PBPs (p=0.1089). On average, participants took more time to complete tasks with MBPs versus PBPs (23.3s versus 21.6s, p=0.7394).

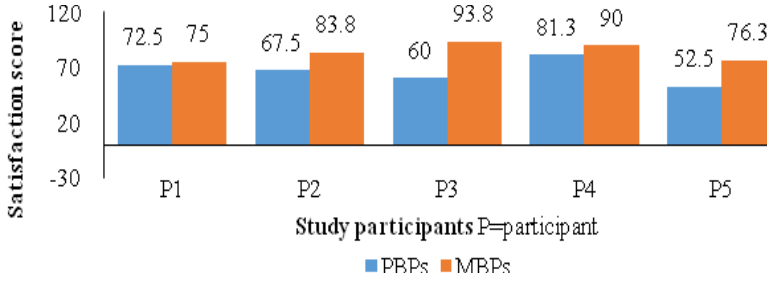

Figure2. Satisfaction scores with MBPs versus PBPs

From in-depth interviews, the most prominent challenges for PBPs cited by three of five participants were: (a) some PBPs being too big to fit into pockets, (b) some PBP booklets lacking table of contents making searching difficult, and (c) forgetfulness by

providers to carry PBP booklets. 3 of 5 participants had no problems with MBPs. The other two mentioned some MBP challenges, including: (a) lack of an option for note-taking in the app (1/5), (b) inadequate phone storage space (1/5), and (c) slow devices (1/5).

4. Discussion

This usability study shows that MBPs, implemented within cross-platform, open-source mobile learning applications, demonstrate a significantly higher satisfaction level compared to PBPs within the resource-limited clinical settings of Kenya. Further, in comparison to PBPs, fewer errors were made by participants while using MBPs. These findings are consistent with those from a systematic review on relative effectiveness of use of handheld devices versus paper-based systems at significantly reducing discharge order errors.[5] The high MBP SUS score could be attributed to usability considerations made during design of the application. Average time for task completion trended higher for MBPs versus PBPs. This finding points to an important consideration when implementing new systems for busy providers. Feedback from study participants during the usability test and the in-depth interviews provided insight into better ways of designing MBPs to meet the user needs. The MPBs system has now been rolled out for broad use and evaluation within the institution.

5. Conclusions

MBPs as compared to PBPs provide better effectiveness and satisfaction as a modality for implementing healthcare protocols in low-resource clinical settings. However, contextualized design and implementation of the MBPs, in close collaboration with healthcare workers, should be emphasized in order to support ownership and uptake.

6. Acknowledgements

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Entropy-based Dyslalia Screening

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Abstract. This paper's objective is to present a proposed solution of Computer-based Speech Therapy System (CBST) for dyslalia screening. The problem of Speech Sound Disorders (SSD) is enunciated, and a brief presentation of several general CBST solutions is made. An Entropy-based method is proposed and the current state of advancement in the development and experimental validation of this solution is presented and discussed. Conclusions related to future improvements of the method are drawn based on the consequences identified in the final section.

Keywords: entropy, speech therapy, dyslalia screening

1. Introduction

Dyslalia, an articulation disorder determined by organic or functional issues of the organs of speech, is the most frequent language disorder among primary school children. Its symptoms are distorting, substituting, omitting/adding and inverting speech sounds (phonemes) in pronunciation. According to a systematic review of the literature [1] prevalence estimates range as high as 25% for 5-7 year-old children and 25%-30% of dyslalic children are also dyslexic-dysgraphic. Undiagnosed and consequently untreated Speech Sound Disorders may lead to behavioral disorders and damage the children's school performance. The main objective of this research project is to provide an automated SSD screening solution.

The traditional approach to speech and language assessment involves using a large amount of worksheets (speech therapy evaluation forms), drawings and other materials, it is time consuming and it produces a lot of paperwork, putting therefore the accuracy of the collected data at risk. Automated or semi-automated speech analysis solutions improve the assessment process. Several semi-automated solutions are presented below. *Logomon* [2] is a complex CBST equipped with a Fuzzy-Logic based speech analysis Expert System which provides assisted diagnosis based on mixed input: Speech Language Pathologist (SLP) and Computer Tests (9 scores for each mispronounced phoneme). Grigore et al. in their study [3] describe a solution for the classification of correct/incorrect pronunciations of consonant /r/ extracting from the audio signal the standard deviation of homologous Mel-Cepstral coefficients throughout the phoneme

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and performing an assessment based on a *k*-NN classification algorithm (comparison to a set of known classes of manually selected phonemes). The study Self-Organizing Maps For Identifying Impaired Speech [4] also proposes a solution for the identification of mispronunciations of the phoneme /r/ in Romanian based on extraction of the alternating component of signal's envelope and use of extracted parameters as feature vectors in a Kohonen Neural Network-based classification stage. Yin et al. in their study [5] present the techniques used to identify phoneme mispronunciations by Spanish-speaking children, proposing a semi-automated assessment (pronunciation labeling by non-expert human labelers and optimization of acoustic and pronunciation models in a phonetic decoder). A study by Al-Nasheri et al. [6] uses Auto-correlation and Entropy features in different frequency regions as well as several Voice Disorder Databases to detect and classify voice pathologies. A detailed description of all the feature extraction algorithms and assessment methods briefly described above is provided in [7].

2. Method

The method used in our study is based on the calculation of the information content carried by each audio message (segment) so as to assess the similarity between 2 sound waves and, consequently, be able to detect phoneme mispronunciations. The algorithm was devised to compare 2 sound wave segments: the SLP's pronunciation (standard pattern) and the child's pronunciation (sample pattern) of the same word.

A (non-automated) decision was made to segment the word pronunciation into syllables inasmuch as a syllable will always contain a vowel, which carries a higher energy content being therefore more easily analyzable (Figure 1). The steps of the algorithm are: performing analog-to-digital conversion of the sound wave (using Audacity 2.3.0 – open software) for both standard and sample patterns, splitting the stereo signal down to mono (44100 Hz), segmenting the mono track of a word into syllables (for example: *RĂ-DĂ-CINI*, the Romanian word for *roots*), extracting the amplitude values (in Linear, csv format) from each syllable segment (Sample Data Export in Audacity), creating a table with SLP's and each Subject's exported data in separate columns, filtering out the negative values in each column (syllable), representing the Line Chart of the remaining positive amplitude values, and finally displaying the 6th order polynomial trend line for the positive values of each syllable (Figure 2).

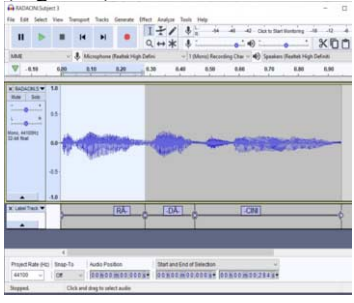

Figure 1. Syllable segmentation.

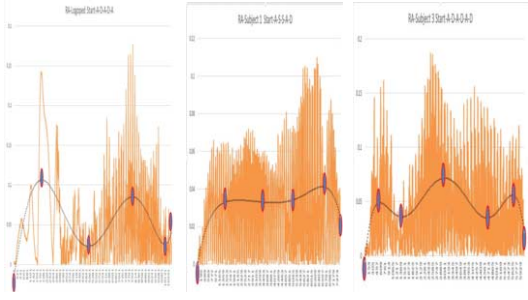

Figure 2. 6th order Polynomial Trendlines for syllable "*RĂ-*".

The trend line of every audio segment is analyzed and a table, representing the alphabet, is filled in. The alphabet consists of 3 letters: A (ascending), D (descending)

and S (stable, curve variation less than 10%). Peaks and troughs are identified within the 6th order polynomial trendline and the corresponding letters (A, D or S) are assigned to them. Once the elements of the alphabet are identified a transition matrix is filled in so as to take into account the fashion in which such elements succeed one another within the analyzed segments. Markov's stochastic process is used to deduce the probability of transition of the system from state *n* to state *n+1* based solely on state *n*. One transition matrix is created for the SLP's pronunciation and each Subject's pronunciation of the same word grouped together (SLP+Subject1, SLP+Subject2 etc.) and the matrix is filled in with the alphabet letters (Table 1 below). The syllable probabilities are then calculated.

Table 1. Example of alphabet letters and transition matrix.

Alfabet	Total
A	12
D	9
S	4
	25

	A	D	S
A	2	7	3
D	7	1	
S	2	1	1

The entropy is calculated for each syllable based on the transition probabilities calculated above and the entropy values are compared.

$$H(X) = E\left[I(x_i)\right] = \sum_{i=1}^{n} I(x_i) \bullet P(x_i) = \sum_{i=1}^{n} P(x_i) \bullet \log_2 \frac{1}{P(x_i)} \quad (1)$$

For sound samples administration and processing an original Cloud-based software infrastructure was developed and used [8].

3. Results

To validate the results of the algorithm a preliminary observational study was performed on a sample population of 30 subjects aged 6 (from primary school classes). The children were asked to pronounce a series of Romanian words containing target phonemes in the initial, medial and final position from a standard speech therapy assessment form and audio recordings were made. The observational experiment focused on the pronunciation of the Romanian consonant /r/ given its high level of acoustic intensity oscillations that enable a clear discrimination of the amplitude values. Out of a total of 30 subjects, the algorithm successfully discriminated 19 cases, which means a matching rate of 63.3% with the SLP's opinion (Table 2 below).

Table 2. Synthesis of results for "RĂ-" syllable.

Subject	Entropy RA- Syllable	SLP's opinion and comments on pronunciation of syllable RA-	Algorithm discrimination matching SLP's opinion (YES/NO) + Algorithm result
SLP	0.329939789	Incorrect (Formation in progress)	YES (Incorrect)
Subject 1	0.074917077	Insufficiently formed vibration of R	
SLP	0.341652934	Incorrect (Formation in progress)	YES (Incorect)
Subject 2	0.185917006		
SLP	0.496853219	Correct	YES (Correct)
Subject 3	0.496853219		
SLP	0.440930926	Correct	YES (Correct)
Subject 4	0.440930926		
SLP	0.271202218	Incorrect (Formation in progress)	YES (Incorrect)
Subject 5	0.176106945		
...	...	...	...
Subject 27	0.155755484		
SLP	0.381218722	Correct (Consolidation in progress)	NO (Incorrect)
Subject 28	0.126500821	(Vowel E added in between R and Ă)	
SLP	0.314570164	Incorrect (R substituted by L)	YES (Incorrect)
Subject 29	0.0136434		
SLP	0.430240166	Correct (Consolidation in progress)	YES (Correct)
Subject 30	0.499569595	* Subject trills slightly (graseiază usor)	
SLP	0.191040104	Correct (Consolidation in progress)	NO (Incorrect)
Subject 31	0.023588481	* Subject derives R from T	

4. Discussion and Conclusions

More rigorously determined syllable segmentation rules are needed to obtain more accurate results. The successful classification rates of the other studies taken into consideration are above 78%. To achieve higher levels of accuracy other acoustic parameters (frequency) of the audio signal must be considered. The introduction of additional alphabet letters or of subdivisions thereof might lead to a more refined discrimination, i.e. indicating the sub-category of dyslalic disorder. One major limitation of the observational study was the use of the pronunciation of an adult as standard pattern to be compared to the pronunciations of children. The (lack of) quality of the audio signal also influences the accuracy of the results.
Further audiology data exploration is needed in order to extract the mathematical model of the various filtering processes performed on the speech signal by the auditory apparatus. Our future research will consist in further refining the proposed algorithm, determining its limitations, comparing its accuracy with other algorithms and building a database of acoustic parameters for the Romanian language. Experiments on a large scale are to be performed in the near future in order to improve and validate the methodology as well as the infrastructure [8] developed to implement it. The automated detection and classification of amplitude values would roughly correspond to the movements of the tympanic membrane, which are amplified by the ossicles of the middle ear and transmitted into the cochlea through the oval window. Sound frequency is processed in the inner ear (cochlea) before the filtered audio signal is fed into the auditory cortex via the auditory nerve. We expect further investigations to improve the accuracy of the algorithm, using mathematical modelling to refine the existing algorithm and to achieve better results.

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Development of an HL7 FHIR Architecture for Implementation of a Knowledge-based Interdisciplinary EHR

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Abstract. The treatment of multimorbid patients confronts physicians with special challenges. Complex disease correlations, insufficient evidence, lack of interdisciplinary guidelines, limited communication between physicians of different specialties, etc. complicate the treatment. To improve the present care situation for multimorbid patients we describe a development approach for an interdisciplinary Electronic Health Record (EHR). As part of the Dent@Prevent project, which aims to improve the intersectoral care of patients with correlating dental and chronic systemic diseases, the proposed EHR will first be tested in the field of dentistry and general medicine. Based on the HL7 FHIR standard the proposed EHR uses a modern three-tier (client-server) architecture. Crucial element of the EHR is a knowledge base, which comprises components for mapping diseases with their complex correlations, integrates patient reported parameters and classifies information in evidence levels. Using the FHIR standard the described elements need to be transferred into the data schema of FHIR resources. The development of an EHR to improve the treatment of multimorbid patients needs to be tailored to the specific needs of multimorbid patients. An interdisciplinary EHR offers the potential to facilitate communication between patients and physicians and provide them with evidence-based information on disease correlations. The next step is to test the practical implementation and applicability for further interdisciplinary disease correlations.

Keywords. Interdisciplinary care, Electronic Health Record (EHR), Decision Support System (DSS), Multimorbidity, Chronic systemic disease, Noncommunicable disease, Dental disease, HL7 FHIR.

1. Introduction

The treatment of multimorbid patients is a great challenge of modern medicine. Complex correlations and interactions of diseases can cause i.a. higher mortality, increased disability and functional declines, and decreased quality of life [1]. Nevertheless, the

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treatment of chronic diseases is often administered on a disease-specific basis, respectively in medical specialties [2].

Especially, the field of dentistry is largely self-sufficient. Although multiple and complex correlations between various dental and chronic systemic diseases are widely known [3], the cooperation and communication between general practitioners (GPs) and dentists is still limited [4]. The gaps in intersectoral care between dentistry and general medicine offer a significant potential for improvement [5]. In addition, a solution for the existing problems could be transferable to other medical specialties.

The Dent@Prevent project [3] aims to improve the current collaboration between GPs and dentists by implementation of modern information technologies. To improve intersectoral care a prototype of a knowledge-based EHR is developed, which represents highly complex disease correlations and considers them for interactive decision support.

With HL7 FHIR a modern standard is available, which should be suitable to meet the described requirements. Therefore, this article elaborates how a FHIR architecture can be developed for the use case of multimorbid patient treatment. The proposed EHR-architecture will be implemented and tested within Dent@Prevent for the care of patients with correlating dental and chronic systemic diseases.

2. Methods

FHIR is a standard developed by HL7 international, which supports data exchange between software systems in healthcare. FHIR is resource-based and relies on modern web-based API technologies and standards (e.g. REST, XML, JSON, TLS/SSL, ATOM, HTTPS, OAuth2) [6]. FHIR uses a client-server architecture. Therefore, our approach suggests a three-tier architecture, with a presentation, application and data layer. For Dent@Prevent the presentation layer needs to display relevant information to patients and health care providers in a convenient way.

At the application level, all data must be processed appropriately and efficiently to provide stakeholders with relevant information. For better regulation and prevention, multimorbid patients should get information about disease risks and known correlations. For the attending physicians important information of the opposing field of expertise need to be made available.

On the data layer a knowledge base must store all information about diseases and their possible correlations between each other transparently and easily accessible. The data scheme of the knowledgebase must be transferable to FHIR resources. To achieve this all relevant information have to be mapped within the attributes of suitable FHIR resources, and the resources themselves must logically refer to each other to appropriately represent the knowledge model.

3. Results

The knowledge-based FHIR EHR was modelled on three layers as follows:

The **presentation layer** enables patients and health care providers to easily check, enter, edit or delete information. For the integration of patients, Dent@Prevent has already developed mobile applications to collect Patient Reported Outcome Measures (PROMs) for iOS and Android by using the development frameworks ResearchKit and ResearchStack [7]. The PROMs were specifically developed with dentists, GPs and

patients using the Delphi method [8] to collect relevant information for intersectoral collaboration. The patient data collected via the mobile applications is transferred to the EHR via an interface and made available to the attending physicians. Due to the large amount of heterogeneous data, the presented information for patients and practitioners must be filtered and comprehensible presented (e.g. sorted by relevance or disease).

On the **application layer**, information management is the most important factor. Collected data are analyzed to call subsequent functions and to request supporting information from the knowledge base. Additional processing is necessary for decision support and risk calculations on the basis of PROMs. Furthermore, the collected heterogeneous data must be transferred correctly into the data scheme of the data layer. The application layer is consequently responsible for the correct incorporation of the collected data into the attributes of appropriate FHIR resources and the generation of links between the resources on the data layer.

The **data layer** is divided into two sublayers for knowledge and data representation. The knowledge base consists of three components.

1. The first describes diseases and their interrelations among each other, by using instances of the *Condition resource* that reference each other.
2. The second comprises information collected directly from the patient. This includes validated risk questionnaires (e.g. FINDRISK [9] for detection of diabetes), to determine the presence of additional diseases. This information can be mapped through the *Questionnaire* and *RiskAssessment resource*.
3. The third is used to categorize information from the first and second component into evidence levels. Because of the heterogeneity of data it is sensible to present the stakeholders (patients and physicians) the source and reliability (evidence) of the information. To assess evidence, the resources *Evidence*, *qualityOfEvidence* and *strengthOfRecommendation* can be used.

4. Discussion

The newly developed EHR architecture, using the FHIR standard and 3 layer modeling, shall provide the flexibility and expandability necessary to address the complex correlations of multimorbid patient treatment. FHIR was chosen, because the standard is expected to cover the requirements of the described EHR architecture.

For a good patient support the structure must be specific enough to support certain diseases with their associated correlations, but also flexible to expand with other diseases and correlations. To achieve this the knowledgebase is designed to be modularly expandable. Additionally FHIR offers to customize and extend resources, while still being backwards compatible.

To improve the care of multimorbid patients a better integration of the patient into the treatment process is sensible. In order to increase patient participation, the proposed EHR offers the patients to provide health information by themselves i.a. to calculate the risk for the development of additional diseases and informs about (possible) disease correlations.

A challenging factor in the implementation of the proposed EHR will be the mapping of all knowledgebase components into FHIR resources. The implementation will show, how suitable the 80/20 design scheme *'focus on the 20% of requirements that satisfy 80% of the interoperability'* meets the presented requirements.

The main problem to be solved is to improve the interdisciplinary information exchange between physicians, treating a common multimorbid patient. An interdisciplinary EHR, which facilitates the data acquisition and sharing between patients and their attending physicians, offers the potential to improve communication and coordination to the benefit of multimorbid patients.

5. Conclusion

Due to its complexity, the interdisciplinary treatment of multimorbid patients is still a great challenge, which is difficult to improve even with modern information systems. An EHR specifically developed for such treatment cases could offer the potential to improve communication, coordination and data exchange between patients and their attending physicians. In the planning and development of interdisciplinary EHR, the special needs of multimorbid treatment cases must be taken into account very carefully.

Further development is necessary to verify the practical implementability and usability of the planned EHR. The results of this work are to be transferred for the intersectoral care of multimorbid patients by different medical specialties. The applicability of the EHR architecture for other interdisciplinary disease correlations of different specialties must be evaluated in the further progress.

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Utilization of a Novel Patient Monitoring Dashboard in Emergency Departments

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Abstract. Purpose: To study the clinical use of a novel patient monitoring dashboard at two Emergency Departments in Denmark in order to evaluate the clinician's perspective and their use of the dashboard. Method: Data was gathered by participatory observations of the clinicians' workflow and dashboard interaction, as well as interviews about the clinicians' attitudes towards the system. The data collection process took place during the system's intervention process from September to December 2018. Result: 65 nurses, 28 physicians and two assistants were observed in total for 62 hours. The 59 hours of the observation was focused on the interaction with the systems. Additionally, 10 nurses and two project nurses were interviewed, giving their statements about the use of the dashboard. Conclusion: Based on observation, it is concluded that the temporal use of the dashboard is 3 minutes and 10 seconds, out of the 59 hours system interaction. Furthermore, the nurses claimed that they needed further training, as an explanation of the minimal interaction with the system.

Keywords: evaluation, ER, health informatics, clinical decision support.

1. Introduction

Most health organizations are investing in multiple information systems, in order to improve healthcare delivery in a secure and efficient way [1]. Coherence between the system's functionalities, the organisation's needs, and work patterns is expected. However, due to technical difficulties and adaptation of systems into the daily work routine, the adoption of new information systems can be challenging [2].

In Emergency Departments (ED) patient´s diagnoses and treatment are derived from their background history and observable symptoms [3]. In this regard, observation and registration of vital signs are essential for patient care, in order to identify and handle unexpected deviations [3].

Registration of vital signs are often intermittent and adherence to protocol varies [4]. To address this issue, a novel patient monitoring dashboard, coined the Patient Deterioration Warning System (PDWS) is being evaluated in a clinical trial (NCT03375658 on ClinicalTrials.gov). In order to reduce risk of deterioration, the current patient monitoring equipment collect vital signs frequently. However, this automatic procedure generates a large amount of data which challenges the overview and clinical decision making in order to identify deterioration risk for specific patients. The

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PDWS aims to help clinicians keep track of all patients who have been attached to a patient monitor by structuring and assessing the automatically registered vital signs.

Thus, the PDWS ensures that each registered vital sign is included in the clinical assessment of the patient's condition [3]. The effect of the PDWS is currently being evaluated in the EDs of Odense University Hospital and Hospital of South West Jutland, both located in Region of Southern Denmark.

The aim of the study is to gain insight into the challenges of implementing a new system, such as the PDWS, by assessing the clinician's understanding and usage of the new system. The use of the PDWS is assessed by registering interaction time with the system. This is supplemented with time recording of the other systems; Clinical logistic system (Cetrea), the Electronic Health Record (EHR) (Cosmic), Philips IntelliVue Information Center (PIIC), telephone, and the Emergency Medical Call (EMC) to assess the overall temporal use of the systems in a busy clinical environment such as emergency department.

2. Methods

As the intention of the study was to obtain an in-depth understanding of the clinician's behaviour during the evaluation period of the PDWS, qualitative methods were applied, and participatory observations were used to collect data. Furthermore, this approach allowed us to establish interviews with the clinicians.

Data were gathered in two phases from the two departments where PDWS was evaluated. In the first phase *systematic* observations were performed [5]. The clinician's interaction with PDWS was systematically registered. Interaction was defined as; when the clinicians look at, or use, the system at any purpose. Furthermore, *direct* observation was used, which is a strategy that points out the observer's attendance to clinicians and allowing for interviewing the participants in action. The behaviour of the caregivers was systematically recorded using a customized multi-timer, when they were present in the office [5].

The second phase consisted of interviews, where 10 staff nurses and two project nurses were selected randomly for interview. The interviews were transcribed, and afterwards analysed by selecting statements relevant to evaluation of PDWS. In addition, activity time, i.e. the time when clinicians interacted with PDWS, was measured with a multi-timer and compared to the temporal activity of other systems.

3. Results

The ED at Odense University Hospital is organized into six teams, including the emergency ward. The ED at the South West Jutland is organized into five teams. All teams in both EDs have the PDWS available and our observations included those teams, where PDWS was running.

3.1. Clinicians interaction with the system

The observations included 28 physicians, 65 nurses, and two nurse assistants. The duration of observation in total was 62 hours, wherefrom the clinicians used approx. 59

hours using the systems. The remaining three hours were not considered into this study. Overall it was observed that the clinicians interacted with PDWS for a total of 3 minutes and 10 seconds. The results are shown in table 1.

Table 1. Temporal results of the interaction with each of the six systems.

Total *(hh:mm:ss)*	**Total Observation**	**EHR**	**Clinical logistic**	**PIC**	**Tele-phone**	**EMC**	**PDWS**	**Remain-ing time**
62:00:00	59:17:30	43:20:20	8:15:47	01:57:39	05:37:41	00:07:03	00:03:10	03:00:00
100%	95,44%	69,68%	13,15%	2,53%	8,66%	0,11%	0,05%	4,48%

3.2 Clinicians perspective.

During the interviews, one out of 10 nurses mentioned that one has not heard about PDWS and did not have time to get to know the system neither, "*I haven't heard about the system ... But neither did I have time to use the system"*. However, three nurses mentioned that they knew the PDWS, but had not utilized it, since they had several other systems to interact with. Four nurses mentioned that they did not know the system, but they were positive about the idea and would like to use it, if they were instructed in how to use it. Additionally, they suggested that the system should integrate with the EHR. The last two nurses pointed out, that the PDWS system had not been prioritized by the management, "*I do not know it. And I've been told I shouldn't worry about it"*.

Two project nurses, in relation to system use, emphasized the importance of communicating the system's purpose; *"It is important to point out the primary purpose of the system. If the clinicians do not know what the purpose is with the system, it will demotivate them"*. It is important to involve management throughout the implementation and evaluation of the system. As for the graphical user interface of the PDWS, they commented that the graphs are messy and that the more advanced elements should be removed.

4. Discussion

This 62-hour field study was focused primarily on the PDWS, to analyse the use of a newly implemented system at ED. The approach to the study was based on direct observation strategy, which has some downsides, as the clinicians can be affected by the observation. Similar to *Hawthorne Effect* [6], the nurses could act different than usually. At one of the teams, PDWS had been turned off which was not discovered until two hours after the beginning of the clinician's dayshift. The nurses strived to get the system running while the observers were present but did not know how to do it. Furthermore, the clinician's behaviour contradicts their statement that they should not worry about the system, but in this particular situation it turned out that they actually took into consideration. However, we cannot say for sure if they beside the observation time pay attention to the system or not. This can be a bias in relation to the resulting temporal use of the PDWS and the clinician's statements. The bias could have been avoided by using a *discrete* form of direct observation in which the observers provided the clinicians with minimal information about the study [5]. The purpose of the observation could be informed on a general level, in this context the observers could tell the clinicians that their workflow with all system interaction will be studied.

Furthermore, the localization of the PDSW screen in the office was considered to determine if it had any significant effect on the use of PDWS. During the observation process, it was noted that the essential details on PDWS may disappear, due to the screen size. In some departments, the PDWS screen was turned off or frozen due to system failure. This could be solved by contacting the system's developer, however, the clinicians had overlooked this option, as they did not use the system. PDWS was located remotely from other systems and partly hidden by other objects, making the system not conspicuous to the clinicians. In addition, some department teams placed the PDWS next to the clinical logistics system, which has considerably larger screens than PDWS.

During the interviews the clinicians stated that they were missing instruction of the system and information about the system's purpose. Additionally, they did not have time to use PDWS as they already spent lot of time on other systems (Table 1). Furthermore, the feedback from the project nurses emphasized that the purpose of PDWS was unclear, as it is relevant to understand the connection to the system's functions, in relation to their work patterns. Several of them had been told that they should not worry about the system, resulting in minimal knowledge of the PDWS, thus avoiding the use of it. This error information distorts the motivation in the use of PDWS.

5. Conclusion

The receptiveness of a new system in an environment that already has many systems in advance is challenging, as shown in the results of this study. The general workflow at ED consists a lot of system interaction as it appears in Table 1. Out of 95.44% of system interaction, only 0.05% has been used on PDWS. It is important to clarify the main purpose and instruction of the system to the users. This will allow the clinicians to understand the system use and incorporate the new implemented system in their workflow.

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Blockchain Based Network for Tuberculosis: A Data Sharing Initiative in Brazil

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Abstract. Data sharing, information exchange, knowledge acquisition and health intelligence are the basis of an efficient and effective evidence-based decision-making tool. A decentralized blockchain architecture is a flexible solution that can be adapted to institutional and managerial culture of organizations and services. Blockchain can play a fundamental role in enabling data sharing within a network and, to achieve that, this work defines the high-level resources necessary to apply this technology to Tuberculosis related issues. Thus, relying in open-source tools and in a collaborative development approach, we present a proposal of a blockchain based network, the TB Network, to underpin an initiative of sharing of Tuberculosis scientific, operational and epidemiologic data between several stakeholders across Brazilian cities.

Keywords. data sharing, interoperability, blockchain, tuberculosis

1. Introduction

Tuberculosis (TB) is a bacterial infectious disease that represents a significant public health problem in the world. It is estimated that in 2017 approximately 10.5 million people got infected with drug-sensitive TB or with drug/multidrug-resistant TB. Brazil, specifically, is considered a country with a high TB burden, with an estimate of 93.000 TB cases [1].

Data sharing is the practice of making data used for scholarly research widely available to other stakeholders [2]. In the absence of any binding requirement, data sharing is at the discretion of the scientists themselves. Data sharing may be restricted to protect institutions and scientists from use of data for political purposes, as well as to

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protect proprietary interests, national security, and subject/patient/victim confidentiality [3].

Data sharing, information exchange, knowledge acquisition and health intelligence are the basis of an efficient and effective evidence-based decision-making tool. This tool needs to be coherent with the institutional and managerial culture of organizations and services. However, current solutions are usually centralized. A valid approach to overcome these risks is to adapt the Blockchain technology where a decentralized architecture allows each member in the network stores an identical copy of the records and contributes to the collective process of validating and certifying digital transactions for the network based on contracts of strict rules and consensus processes [4].

The main goal of this work is to present a proposal of a blockchain based architecture to underpin sharing of TB scientific, operational and epidemiologic data across 7 (seven) Brazilian cities. We intent to build a permissioned network that will allow safe information exchange that could be, ideally, expanded to a global TB network.

2. Methods

Action Research will be used as the scientific methodological basis for this work, due to its investigative and practical approach, considering the project, besides the theoretical development, has also a practical component [5]. All stakeholders will actively participate in the network conception, development and implementation to cover all necessary requirements for a precise data sharing. Documentation will be produced in each development part and a network prototype will be created to validate the proposed model.

The proposed network model of data sharing focus on the construction of structured nodes for a TB project that involves 7 (seven) Brazilian states' capitals, where each city will be able to manage and share information through the blockchain network. The main goal of this network is to provide an approach to effectively and securely share TB information within a data sharing network, called TB-Network.

Several resources will be used to model and deploy the blockchain network for data sharing, which will be based on the open-source Hyperledger platform. Initially, Hyperledger Composer Playground will be used for network modeling, smart contracts definition and testing of transactions. Then, the generated metadata will be exported to be further deployed in a production environment based on the Hyperledger Fabric framework, which will be instantiated in the private academic cloud computing infrastructure from University of São Paulo.

The initial dataset for the blockchain network will came from the Tuberculosis Ecosystem, a computational health infrastructure that consists on a set of integrated systems that aims to do a better management and exchange of information related to TB in State of São Paulo, Brazil. Furthermore, this ecosystem has a functional and semantic interoperability architecture that enables relevant data exchange with authorized systems [6], which will allow data extraction and sharing over the network.

Also, test applications will be developed to interact with the TB Network. In general, it will be web and mobile based applications. They will be used as a proof of concept of supporting tools that can coexist to enhance relevant data dissemination, increasing quality and completeness of specific categories of data.

3. TB Network: a blockchain permissioned network

We have defined general assumptions about healthcare stakeholders (or network nodes) participating in a data sharing network are presented: i*)* Nodes must understand the data structure and semantics; ii*)* Nodes need guarantees of security and auditability to share or receive data; iii*)* The node controls their records and authorizes who may access it and when; iv*)* Each node are able to manage their access levels, users and data privacy. These assumptions exclude any regulation/incentives that the network itself defines.

We propose the use of a permissioned distributed blockchain solution that uses a key pair (private/public key) and a symmetrical consortium key for data encryption. A consortium distributed storage network will be established consisting of research centers and other approved stakeholders throughout the Brazil. Each member organization will undergo an extensive background check. Permissioned access to the blockchain will be granted by a consortium committee, which will assign the keys. Key based mechanisms allow limits to be placed on the data so that administrators, government agencies, and other agencies only have access to the information needed, not the entire records. Additionally, it will be possible to make some pieces of information publicly available, whenever is necessary (for transparency or open data initiatives).

Data will be the digital asset in the blockchain network. Any data generated involving health information can be stored on the blockchain and will be kept "off-chain" in a distributed storage infrastructure. Identifiers and additional hash codes for such data will be stored in the blocks. That way, we will be able to store a large amount of data without overloading the chain but still rely on blockchain security features.

Such data could be, but is not limited to: scientific investigations, medical device data, administrative records, administrative records, socioeconomic information, population studies, recordings generated from IoT devices, medical records, nursing notes, imaging exams, etc. Data will first endure a process of stripping personally identifiable information leading to the generation of two types of data: i*)* Data that is completely stripped of personally identifiable information (this is the data that can be accessed by approved organizations for large scale data analysis and organizational research); ii*)* Data that could not be stripped of personally identifiable information (this information is only available during patient encounters).

Furthermore, there are some projects working in the idea of connecting different Blockchains, where the main goal is to create “The Internet of Blockchains” [7]. It will allow stakeholders to develop additional blockchain networks and end user applications that will be able to interact with the TB-Network (and with its data) and other interconnected infrastructures through a variety of technologies, such as the resources from the Semantic Web. Upon implementation of the network, our next step will be to evaluate its usability and usefulness. To do this, an evaluation protocol, already in discussion with government entities, will be applied. Other ongoing discussions are related to data processing and how to make it available for students and teachers, besides of the establishment of strategies to record the results and to draw conclusions.

4. Final considerations and future directions

We believe that blockchain can play a fundamental role in enabling data sharing within a network. To achieve that, we have defined the high-level structures and protocols necessary to apply this powerful technology to TB issues. The requirements for sharing

data within the healthcare realm are compelling and simply data exchange is not enough. Our proposal aims to demonstrate that effective data sharing networks require consensus on data syntax, meaning, and security of information [8]. It is important to point out that this project is in consonance with the Brazilian government's project that standardizes the opening of public data, whose guiding principles are found in the Brazilian government's data-entry guide [9].

Additionally, besides of the network first implementation, we intent to integrate the presented blockchain infrastructure with two TB projects of high relevance, whose requirements will incorporate new features, such as a set of interconnected models based on Markov and Machine Learning mechanisms, which are incorporated into an evidence-based clinical algorithm (providing recommendations based on WHO guidelines) [10], and a semantic framework that contains an ontology repository and is able to gather health data from heterogeneous data sources [6].

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Factors Affecting Venture Funding of Healthcare AI Companies

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Abstract. Venture Capital (VC) funding raised by companies producing Artificial Intelligence (AI) or Machine Learning (ML) solutions is on the rise and a driver of technology development. In healthcare, VC funding is distributed unevenly and certain technologies have attracted significantly more funding than others have. We analyzed a database of 106 Healthcare AI companies collected from open online sources to understand factors affecting the VC funding of AI companies operating in different areas of healthcare. The results suggest that there is a significant connection between higher funding and having research organizations or pharmaceutical companies as the customer of the product or service. In addition, focusing on AI solutions that are applied to direct patient care delivery is associated with lower funding. We discuss the implications of our findings for public health technology funding institutions.

Keywords. Artificial Intelligence, Capital Funding, Technology

1. Introduction

As with other innovation systems, also AI technology environment in healthcare is highly driven by capital investment decisions [1]. Capital investment decisions affect the companies' research strategies, and VC investors might affect the target markets and development foci of the companies [1]. Also the decision on which companies are funded and which are ignored affects the developmental trends of the whole industry [2,3,4].

A recent descriptive analysis by Rock Health [5] stated that the venture capital (VC) funding of digital health companies applying AI/ML has grown in a similar way as the digital health VC funding overall. In the United States, 121 digital health companies leveraging AI/ML have raised a total of $2.7B with 206 deals from 2011 to 2017, which is slightly over 10% of all venture dollars invested in digital health during that period. The VC funding of AI Health companies has distributed unevenly and certain technologies have attracted significantly more funding than others. While companies with high R&D focus have been successful in gathering funding, companies with value propositions focusing on applying AI/ML to direct patient care delivery have been more modest in raising funding. It has been suggested that one of the reasons for the difference in funding amounts is that there are fewer risks in using AI to improve business functions instead of patient treatment [5].

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In this study, we aim to find initial evidence of the factors influencing VC funding of AI companies operating in different areas of healthcare. Based on the recognized preferences of VC investors in recent years, we chart out two hypotheses: **H1:** Companies the technology of which is used in direct patient care delivery receive less funding than other companies. **H2:** Companies the technology of which is mainly paid by research organizations and pharmaceutical companies or healthcare providers and insurers, receive more funding than mainly patient-paid technologies.

2. Data and Methods

There exists little standardized data on initial VC capital funding for AI/ML startups. Our database consists of funding information of 106 companies found from Crunchbase.com web portal. We selected those 1434 companies that had listed "Artificial Intelligence" as their technology category and raised more than 250 000 dollars funding. Out of these, 115 were healthcare companies. We left out multi-industry companies who had only narrow focus on healthcare. Remaining 106 companies were included in the analyses. In total, these companies had raised $1,4B in funding. The data were retrieved in June 2017 and June 2018. For companies that were in the datasets in both years, the 2017 data were used for better comparability between companies. We used data from 2017 for 39 companies and from 2018 for 67 companies.

The descriptive statistics are described in Table 1. Additional characteristics for each of the companies were gathered via online exploration on companies' web pages. We added information on whether the company's AI solution was used directly in patient care delivery, and whether it employed machine learning, machine vision or natural language processing technologies. We also added the population data of the companies' headquarter location.

Table 1. Descriptive statistics

Variable	Mean/Percentage	Std. Dev.
Log Total funding amount (MEUR)	1.40	1.61
Applying AI/ML to direct patient care delivery	66 %	0.48
Main Customer: Healthcare providers and insurers	70 %	0.46
Main Customer: Research organisations and pharmaceutical companies	21 %	0.41
Main Customer: Patient	9 %	0.29
Technology: Machine Learning	65 %	0.48
Technology: Machine Vision	22 %	0.41
Technology: Natural Language Processing	28 %	0.45
Continent: Europe & Israel	37 %	0.48
Continent: Northern America	56 %	0.50
Continent: Asia & Australia	8 %	0.27
Log Headquarters city population (Millions)	-0.33	2.05
Log Headquarters cluster population (Millions)	0.75	1.48
Log Headquarters country population (Millions)	4.77	1.43
Founding year (median)	2014	
Company Age	3.85	2.63

OLS multiple regression analysis was used to explore the associations between variables. As a **dependent variable**, we employed the amount of funding raised by the company, retrieved from Crunchbase.com database. We used two different sets of **independent variables:** For **H1**, we evaluated whether the company's technology was used in any phase of the treatment of the patient; coded as a dummy variable. For **H2**, we analyzed whether the main payer-customer of the AI solution was a) healthcare

provider or insurer, b) research organization or pharmaceutical company, or c) patient; coded as a categorical dummy variable.

As a **control variable**, we assessed some non-exclusive technology categories leveraged by companies [6]. We also controlled for the geographical location of the company headquarters, headquarter region's size, country size, and company age. Log transformations were performed on total funding amount and companies' HQ city and country populations due to the prominent right-skewed distribution of these variables. The log transformation remarkably reduced the skewness. Statistical analysis was performed using STATA 15.

3. Results

Initial descriptive analysis suggests support for both hypotheses. The companies applying AI/ML technologies to direct patient care delivery seem to raise less funding per company than those who were not (average funding $11.7M vs. $18.7M per company). Also, in accordance with Hypothesis 2, the companies whose main customer category is patients have raised less funding than companies having research organizations and pharmaceutical companies, or healthcare providers and insurers, as main customers ($1.9M vs. $15.2M and $15.4M, respectively).

Table 2. Regression of log of Total Funding Amount (MEUR) results.

Variable	Model 1	Model 2
Applying AI/ML to direct patient care delivery	-0.64*	
Main Customer: Patients (reference group)		-
Main Customer: Healthcare Providers and Insurers		0.6
Main Customer: Research Organizations and Pharmaceutical Companies		1.36**
Technology: Machine learning	0.38	0.26
Technology. Machine vision	0.7	0.44
Technology: NLP	0.36	0.31
Continent: Northern America (reference group)	-	-
Continent: Europe & Israel	0.48	0.51
Continent: Asia & Australia	1.53**	1.51**
Log Headquarters city population (Millions)	-0.15*	-0.15
Log Headquarters cluster population (Millions)	0.16	0.23*
Log Headquarters country population (Millions)	0.23*	0.2
Company Age	0.21***	0.2***
Constant	-0.74	-1.92
R-squared	0.189	0.214
N	106	106

***$p<0.01$; **$p<0.05$; *$p<0.1$.

The results from the OLS estimation are presented in Table 2. In Model 1, the independent variable of direct patient care delivery shows weakly significant but impactful decrease by the factor of -0.64 (p-value 0.078). This is indicative of companies with AI/ML applications used directly in patient care delivery receiving approximately 48% less funding than other companies. In Model 2, we compared the effect of having research institution or healthcare provider as the main customer to those companies having patients as the main customer. Model's factor for research organizations' and pharmaceutical companies' funding is 1.36 (p-value 0.02). The regression model explained the logarithm of total funding amount, meaning that the regression coefficients β_i can be interpreted as being associated with a change in the dependent variable of the factor of $e^{\beta i}$ indicating that the 1.36 factor of research organizations and pharmaceutical

companies is linked to a 290% increase in funding. The IVs and the control variables explain up to 21.4% of the variance in total funding amount raised. As a check for heteroscedasticity we inspected the distribution of residuals which was close to normal and not very skewed in the kernel density estimate, increasing model acceptability.

4. Discussion and Conclusions

The results give support to our Hypothesis 1 that employing AI solutions directly in patient care delivery is connected with a decrease in funding compared to other solutions. Funders are possibly more cautious for treatment technologies that require a high level of evidence of effectiveness [5]. Also H2 was supported, as the technologies mainly paid by research organizations and pharmaceutical companies received remarkably more funding than those paid by patients. In other words, AI technologies for which the main customer was patient raised significantly less funding than those targeted to research organizations. It could be that research institutions and pharmaceutical companies are more likely to purchase solutions involving high infrastructure investments.

The study has considerable limitations. Crunchbase.com is a US-based platform, and we detected some geographical bias within the dataset. Also due to the small number of companies in the data, longitudinal study design could not be employed. In the future, more robust panel settings should be used, including a wider set of control variables.

As VC investments are a key driver of innovation systems, it is possible that the uneven funding hinders the development of patient-focused health technologies. Furthermore, it should be considered whether public funding institutions ought to have patient-centered AI technologies as a specific target group. This is relevant for policymakers and public health officials defining the role of public technology funders in healthcare.

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Factors Relating to Participation in Quality Improvement and Hospital Accreditation of Health Professions in Kalasin Hospital, Kalasin Province,Thailand

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Abstract. This cross-sectional research aimed to explore the associated factors with participation in the quality improvement processes in Kalasin hospital, Kalasin province, Thailand. The 412 samples were randomized selection and the created questionnaire was applied to collect their opinion. The results showed that level of participation in quality improvement, which called HA of hospital health professionals at high level (average = 3.52, S.D. = 0.86). In aspect of internal factors of samples, positions and role of responsibility were significantly related with quality improvement. Job motivation and support from the organization were positively correlated with participation of HA activities with statistical significance level. Finding can be suggest that the hospital need to support their staff in aspect of focus on patient, human resources development and patient care process. Including to support and staff encouragement to high level of participant all quality improvement quality.

Keywords. Factor relating, Participant, Quality improvement, Hospital accreditation.

1.Introduction

The Ministry of Public Health-MoPH of Thailand has announced policy direction to improve quality of service in all level of care. Particularly quality of service in hospital which called the Hospital accreditation-HA was desirable target to improve standard in healthcare unit. [1]. Kalasin hospital is a public general hospital under control of the MoPH, has adopted the top policy and they endeavored to attempt in participation of HA criterion into practice by defining the strategic direction to focus on becoming a quality accredited hospital [2].There was a strategic issue that was to improve the quality of service to be certified in accordance with the hospital standards and health services [3]. The ultimate goal is the hospital has passed the certification of HA quality standards with continuous and sustainable development (Committee on the Development of Good Governance and Health Quality Organization, 2018).

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However, all successes need to involve activities of health professionals.[4] Therefore, they have to motivate and promote staff in quality improvement to achieved good results for service recipients[5].Regarding to evidence, human factor was an important mechanism enabling the quality development process to sustain on HA [6]. Additionally, staff qualifications, position, career, work experiences, including support from the organization were presented as important factors [7]. In addition, motivation factors was an important according to Herzberg's two-factor theory [8]. These all primary factors in Kalasin hospital, which was developed to a framework for improving the quality of the health service of the organization [9]. Therefore, in order to continuously drive quality work and sustainability of HA process at Kalasin hospital. This research was aimed to study on the factors that related to their quality improvement implement.

2. Methods

This cross-sectional study was conducted in Kalasin Hospital, Kalasin Province, Thailand during July to August 2018.The population such as The hospital officers has 1,515 person.

The population of this study was working in the hospital Kalasin province, including was 1,515 person. Sample size calculated using the sample size calculation formula to estimate the average population If the population is known instead of the formulas, 412 samples were systematically randomized to the number of desired results

The created questionnaire was applied as the research tool. The questionnaire was divided into 2 domains. First domain inquired about healthcare professional information. Second domain queried their motivation and support from the organization to improve the quality of health care professional comes from Herzberg's two-factor theory. This domain employs five-point scale with corresponding interpretations: 1 for Strongly Disagree, 2 for Disagree, 3 for Neither Disagree, 4 for Agree, and 5 for Strongly Agree.

Collect data was conducted by using online questionnaire via the hospital intranet system distributed to the randomized subjects. This research was conducted with permission from the Research Ethics Committee, Kalasin Hospital.

Quantitative data analysis by using computer software package. Descriptive statistics including frequency distribution, percentage, mean, standard deviation inferential statistics, such as Chi- Square and Pearson correlation were analyzed and presented as a previous describe [10].

3.Results

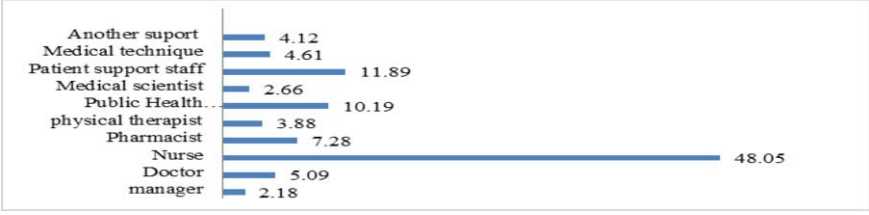

Figure 1. Health care position of studied subjects.

Table 1. The participation in the development and certification of hospital quality of healthcare professional in Kalasin hospital

Participation in the development and certification of hospital healthcare professions	average	S.D.	Participation level
Leadership in the Organization	3.49	0.80	moderate
Strategic management	3.39	0.95	moderate
Focus on patients, recipients	3.72	0.78	Most
Analytical measurement And knowledge management	3.29	0.91	moderate
Human resource focus	3.58	0.92	Most
Patient care process	3.93	0.74	Most
Organizational results	3.24	0.92	moderate
Total	**3.52**	**0.86**	Most

Table 2. Results of the study participation in the development and quality accreditation in hospitals (percent) and chi- Square

healthcare professional attributes	Participation in the development and quality accreditation in hospitals (percent)				chi-Square	df	p-value
	High	Moderate	Less	Total			
Profession					11.633	2	0.001
Nurse	189 (45.87)	67 (16.26)	42 (10.19)	298 (72.33)			
Other professions (doctors, pharmacists, dentists, medical technicians physical therapist, Public Health professional)	36 (8.73)	26 (6.31)	52 (12.62)	114 (27.66)			

The results showed that profession of nurse had correlation for Participation in the development and quality with a statistical significance level of 0.01.

Table 3. Results of relationship analysis of motivation and support from the organization of participation in the development and accreditation of Kalasin Hospital, Kalasin Province

Motivation and Organize support	Participation in the development and certification of hospital healthcare professional of Kalasin Hospital		
	Peason's coefficient of correlation	p-value	Level correlation
Motivation	0.640	0.00*	High
Organization support	0.611	0.00*	High
Total	**0.625**	**0.00***	**High**

Result of the overall motivation factor and support from the organization has a relationship high level positive with participation in the development and accreditation of hospital healthcare professional Kalasin Hospital with statistical significance at the level 0.001 (r=0.625).

4. Discussion of results

From the results of the study, it was found that in general information of health professions in Kalasin hospital the largest number are nursing profession.Current results is agreed with Nathakrit Thump (2016) reported [11]. For the level of participation in hospital development and quality certification, the overall is at a high level of participation.Which when consideredand found to be related of Sathaporn Rattanawariwong (2009)[12].As for the measurement, analysis and knowledge management has a moderate level of participation. From the analysis, it was found that

personnel still lacked understanding of analytical measurements. Therefore did not participate in this process which is consistent with the Chaisuntitrakoon A. (2012) [13]

Supporting from the organization and motivation as a whole has a high level of positive relationships. The participation in the development and quality assurance of personnel in Kalasin Hospital Kalasin Province with statistical significance (r = 0.625, p-value = 0.001).This finding could be explained that support from the organization of administrative resources sufficient and appropriate will allow personnel in Kalasin Hospital to participate in activities with the high-quality development resulting in good results for the organization and the continuous development.

5. Conculsions

To sum up, motivation factors on human focused, work and success were important with organizational support in aspect of staff participation in the processes.

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Physician-Led EHR Customization Tracking Assessments for Pediatric Patients with Turner Syndrome

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Abstract. In 2015, a pediatric endocrinologist designed a progress note in an electronic health record (EHR) system to improve adherence to clinical practice guidelines for pediatric patients with Turner Syndrome. In 2018, to improve upon the note template, a flowsheet containing embedded decision support content from an international guideline was designed and implemented with help from a general pediatrician who was also an Epic Physician Builder. The flowsheet allowed for the creation of discrete data elements for improved consistency and enhanced reporting. The design process may be useful in other EHR customizations.

Keywords. Physician; Customization; Decision support

1. Introduction

Turner Syndrome (TS) is a genetic disorder in which girls are born with one of their X chromosomes missing or incomplete. It is the most common genetic disorder affecting girls and women, present in an estimated 1 in 1,500 to 2,500 live births [1]. The presence of Turner Syndrome increases the risk of a wide variety of diseases, including having congenital cardiac defects, markedly short stature, and infertility [2].

A key challenge for health care providers is to identify any developing issues in TS patients using timely and age-appropriate assessments. While Electronic Health Records (EHRs) are often customized to support clinicians in their diagnosis and treatment decisions, such clinical decision support is frequently absent for less common diagnoses such as Turner's Syndrome. However, many EHRs allow for provider-led customization. Physician-initiated customization is common; a Medical Economics survey found that 65% of physicians were editing or revising vendor-supplied templates [5]. Furthermore, evidence suggests that physicians who customize their EHRs have greater satisfaction and efficiency in their work [6].

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2. Methods

2.1 Initial Note Template Design

In 2015, Jennifer Law, MD, MSCR, a pediatric endocrinologist and Medical Director of the UNC Turner Syndrome Clinic, created and implemented a customized progress note template in Epic, the EHR used by UNC Healthcare, for use when seeing her patients with TS. Dr. Law created an assessment table based on the 2007 clinical practice guidelines. The table listed 24 assessments, along with brief descriptions of each assessment, its implementation schedule and open cells for the date it was last done and any notes.

Table 1. Assessment table template example for hyperopia guidelines (1 of 24)

Assessment Name	Assessment Timing	Date	Notes
Hyperopia	At diagnosis, at age 1-1.5 yr	[Open text, provider-entered]	[Open text, provider-entered]

The customized progress note template consolidated the information visually and provided key information to determine what assessments were needed for each patient. However, the data were unstructured, inconsistently entered, and could not be systematically extracted for reporting. The format of the template could not be updated across patients, because it was not being managed in a central location. The assessment schedule also needed to be updated to reflect the new guidelines issued in 2017 [4]. The project was continued in 2018 with the goal of creating an EHR customization which improved upon the note template.

2.2 Flowsheet Design

Pediatrician Dr. Carl Seashore, one of 16 physicians at UNC Health Care as of 2018 who had completed the Epic-based Physician Builder program, joined the project to provide higher-level customization. For additional input, Dr. Law solicited feedback from her colleagues at other institutions who also specialize in TS.

The list of assessments was based on the 2017 clinical practice guidelines, particularly pulling from a table outlining the list of assessments and the ages at which they were recommended [4]. Nine additional elements were added by Dr. Law and her colleagues to provide an overview of the patient's history or to assist with medication management.

The flowsheet design used the table format of the first customization as its base, with rows representing separate assessments. Headings were used to break up the list into more visually manageable sections and to section the assessments to be conducive to the provider's thought process and workflow. The final sections were listed in the following order:

1. History of diagnosis
2. Treatment at the start of visit (medication monitoring)
3. Assessments to check at every visit
4. Cardiac screening
5. Assessments to be done annually
6. Assessments that are done on multiple year intervals.

The primary discrete data element captured was the result of the last assessment. The result options were intended to capture high level results, such as 'normal' or 'abnormal.' Details as to the results could be captured either in test results or the comments.

Explanatory text or images drawn from the 2017 clinical practice guidelines were added to the design for most of the assessments. These appear on the right side of the screen when the user clicks on each assessment. The text also hyperlinks directly to the 2017 guidelines.

The discrete fields in the flowsheet allow the user to tab through the list of assessments and utilize the auto-fill utility of the drop-down list of choices to make selections quickly, neither of which was possible in the progress note template. Some vital sign data elements, such as weight and blood pressure, were programmed to populate the flowsheet automatically.

Table 2. Portion of final flowsheet design (1 of 34 rows)

Assessment	Choices	Comments	Reference Text
Hip Dysplasia (newborn)	Normal/ Abnormal	[Provider-entered]	Infants may have an increased risk of congenital hip dysplasia. Abnormalities of the lower extremity, including knee alignment and arch irregularities, are common.

3. Results

Dr. Seashore moved the flowsheet to production in August 2018. The flowsheet enabled the collection of 34 new discreet data elements recording the result of critical health assessments. These data were not collected before it was implemented and made possible reports designed to collectively target patients based on assessment results. A companion progress note template was also created to automatically pull in data recorded in the flowsheet (by either an RN, MD, or both). The reference material embedded within the flowsheet has been noted to be helpful both to the pediatric endocrinologist and to other specialties, such as cardiologists. There are plans to share a revised version of the flowsheet with other Epic users with TS patients via the Epic UserWeb.

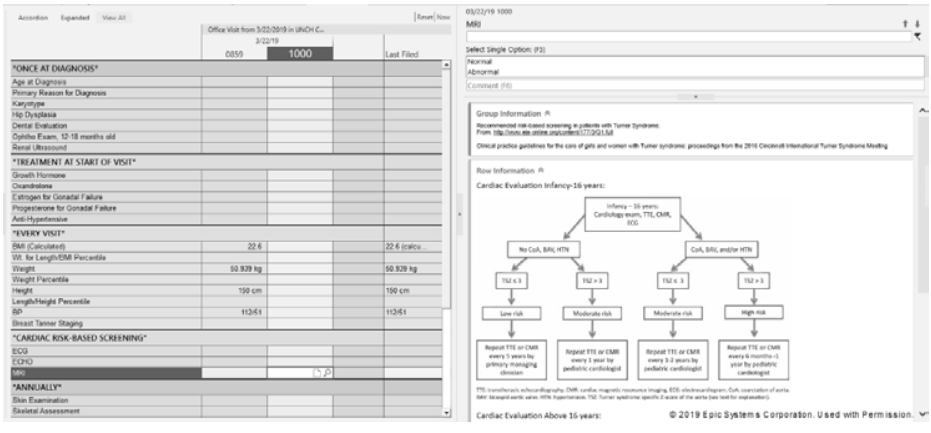

Figure 1. Screenshot of TS flowsheet in Epic. Original in color.

4. Discussion

Using a flowsheet as a base for input appeared to retain the successful design elements of the progress note table, while adding the creation of discrete data fields that could be used in reporting, the ability to include explanatory information from the clinical practice guidelines and the ability to share the design with other TS clinicians. If other TS providers use the flowsheet, there is also potential to pool the data for clinical quality improvement initiatives and research. For local practices, the data from the flowsheet could be used to identify cohorts of patients for targeted interventions or potential sources of research subjects.

5. Conclusions

Physician-led design is an effective method of EHR customization. The clinicians contribute medical knowledge and can prioritize their needs. Physicians with special training in EHR design are valuable resources in EHR customization and clinical decision support. Clinical practice guidelines can be used as the basis of customized clinical decision support in EHRs. The creation of discrete data elements versus unstructured data improves the potential for data consistency and reporting.

The design may be helpful for other diagnoses, particularly those following a similar variety of assessments across different ages. Potentially relevant diagnoses would include Down Syndrome, Prader-Willi and other genetic disorders.

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The Consequence of Repetitive Heavy Object Lifting on the Normal Standing Posture of Factory Workers

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Abstract. Low back pain is one of the most common physical symptom and is frequently related with an abnormal body posture. It may be caused by poor upper body and limb coordination; repetitive lifting of heavy objects or poor working are ergonomics. This study analysis the consequence of repetitive heavy lifting on the normal standing posture of factory workers. To asses the posture malformations the Microsoft Kinect sensor was used to obtain postural data from 88 factory workers. The study has shown that more than 90% of the study group has some sort of postural malformation and lower back pain.

Keywords. Low back pain, repetitive heavy object lifting, body posture, Microsoft Kinect

1. Introduction

Low back pain is one of the most common physical symptoms in the world. It is often related with an abnormal body posture. Poor movement coordination between the upper body and the lower limbs can be a cause for lower back pain development by increasing the load on the bony and soft tissue [1]. Repetitive lifting of heavy objects increases the stress as well on the spinal cord and can causes pain in the lumbar area [2],[3],[4]. If the weight of the object was not assed correctly by the lifter not only a momentarily low back pain can develop but the lifter can lose its balance and injure itself [5]

Another factor that can contribute to the development of the lower back pain is the lack of ergonomics in the working area if the maximal reaching area is exceeded [6]. If the executed movements do not meet the rules for ergonomic movements [7]: on a short-term period, localized lower back pain may develop but on a long term period more severe back problems and postural problems can develop.

The aim of this study is to determine the impact of the repetitive heavy lifting at the workplace in harsh environments on the natural standing position of the human body.

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2. Methods and Materials

The study group consisted of 88 factory workers who are handling 500+ SUV tires daily basis, performing multiple type of heavy lifting: from the ground to a conveyor belt, moving from one conveyor belt to another and flipping of the tires on the same position.

Our goal is to determine what kind of consequence have the described repetitive movements on the workers normal standing position. To scan their relaxed standing position the Microsoft Kinect scanner was used.

2.1. The scanning method

The proposed evaluation method is based on non-invasive, non-irradiant and a marker less tracking method. The core of the evaluation system is the Microsoft Kinect 3D sensor which already has proven its usability in the medical rehabilitation domain [8]. It is capable to track the human body in a standing position and in seated positions [9].

To get a relevant view about the patient's posture several correlations between the tracked joints must be analyzed. For example: it is important to check the alignment of the shoulders, hips and knees. Any misalignment can indicate an abnormal body posture.

The angles between joints is calculated using the following formulas:

$$A \bullet B = (Ax \bullet Bx + Ay \bullet By) \tag{1}$$

$$|A| = \sqrt{Ax \bullet Ax + Ay \bullet Ay} \tag{2}$$

$$theta = \cos^{-1}\left(\frac{A \bullet B}{|A||B|}\right) \tag{3}$$

where A and B are the adjacent joints of the joint of interest and Ax, Ay, Bx and By are the Cartesian coordinates of the A and B points. $|B|$ is calculated using equation (2). *Theta* is the searched angle. Using the skeletal representation and the obtained spatial data about the tracked joints a digital model of the subject's posture is created.

2.2. Tracked body points and measured values

To measure the impact of the harsh working environment on the workers general standing position several spatial properties of the shoulders and the hips are registered: height of the left and right shoulder and the difference between the two heights; the angle created by the two shoulders at the neck; the rotation of the shoulders: if one of the shoulder is significantly deeper than the other one; height of the left and right hip and the difference between the two heights; the angle created by the two hips at the center of the hip; the rotation of the hips: if one of the hip is significantly deeper than the other one.

The raw measurements are saved into a digital CSV type file which contains following: unique anonymized identifier, age, sex, weight, height, BMI (body mass index), height of the shoulders and the difference between the two shoulders, the angle of the shoulders at the neck, rotation of the shoulders and the same properties for the hips.

The most important correlation from our point of view was to correlate the age of the subjects with: height difference between the shoulders which represents the bending

of the upper body; alignment of the shoulders which represents the rotation of the upper body; height difference between the hips which represents the bending of the lower body; alignment of the hips which represents the rotation of the lower body.

These correlations had been chosen because there is a great distribution of ages in the study group (20 to 60-year-old). The most repetitive movements performed under heavy load are done on the lateral, forward as well as on the rotation axes of the human body.

3. Results & Conclusions

In the evaluation process for malicious standing position caused by harsh working conditions 52 young adults (between the ages of 20 and 40) and 36 adults (between the ages of 41 and 60) have been included. In the first group there are 16 females and 36 males and in the second group there are 17 females and 19 males. Every member of the study group has signed a medical and GDPR consent regarding the personal data processing [10]. The study group was created during an event named "Health days" organized by the tire factory.

To analyze the collected date and detect if the subject may have a malicious standing posture wee have compared the difference of the height and rotation of the shoulders and hips with the age of the subject. The results of the evaluation can be observed on the scatterplots below.

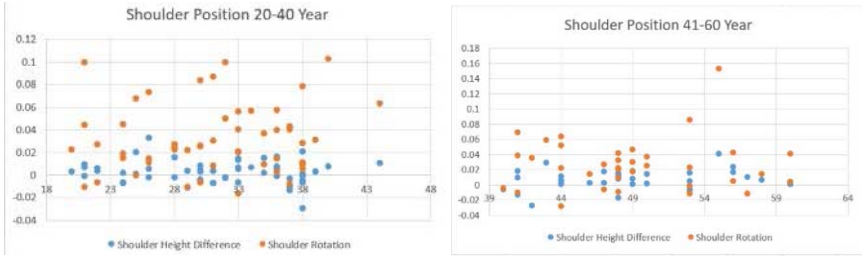

Figure 1. Posture deformation at young adults.

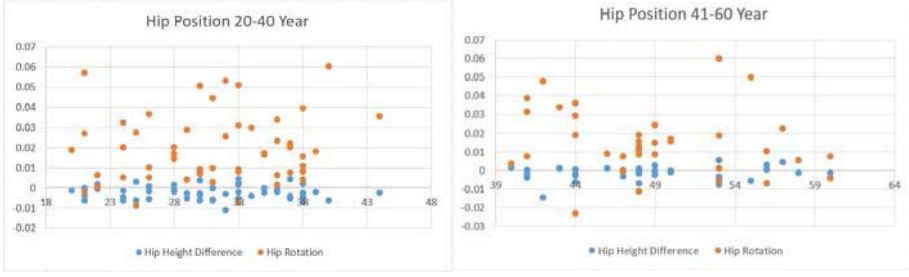

Figure 2. Posture deformations at adults.

The most damage is done on the rotational axes as the workers need to manually reposition heavy loads. The most affected zones are the hips of the subjects because these joints are the most physically stressed during a lifting process. The evaluation has revealed that the younger generation is more physically stressed since the shoulders are more miss aligned than the older generation's shoulders.

Almost 90 percent of the study group has reported lower back pain on various levels using the VAS scale [11].

The repetitive motions on the rotation axes can induce other type of severe spinal cord complications. In this case an active medical supervision and physical therapy is recommended for subjects with existing problems in order to prevent further spinal column and posture complications.

4. Discussion

The results show that harsh working conditions affects young adults as well as older adults. It can be observed from the scatter plots that the younger generations are more affected than the older generations. One possible reason is that the younger generation is executing a harder physical work then the older generation, involving the whole upper body not only the hips and the lower body. An a long term basis this can lead to chronical back pain (lower or generalized) or even more severe back problems like: hyper-kyphosis, hyper-lordosis, herniated disks or some kind of vertebrae problems that can not be resolved with simple physiotherapy.

One possible solution to reduce the risk of future postural and spinal column problems is to introduce more frequent breaks from lifting heavy objects or by creating an ergonomic power assisted working conditions, to reduce the mechanical stress that created on the spinal column at the vertebrae level.

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Named Entity Recognition and Classification for Medical Prospectuses

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Abstract. Structuring and processing natural language is a growing challenge in the medical field. Researchers are looking for new ways to extract knowledge to create databases and applications to help doctors treat patients and minimize medical errors. A very important part in treating a patient is to provide a fair and effective treatment for diseases. In this article we present a method of extracting important information from medical prospectuses, such as a drug-treated condition, a medicine name, a drug type, etc. To extract these entities, we use Stanford NER Tagger trained for prospectuses in Romanian language. The model was trained and tested with 3 types of medication. For each test, the accuracy of the extracted data was calculated. The extracted medical information is used to create databases with structured information that are useful for decision-support applications to check for or find suggestions for the best treatments.

Keywords. Named entity recognition, medical prospectuses, Stanford's CoreNLP, Natural Language Processing

1. Introduction

Natural Language Processing (NLP) is a machine learning area that tries to understand human languages. The most important challenges of artificial language processing are the recognition of speech and the extraction of information. NLP provides specific tools to help program developers extract information from a particular corpus (text) such as tokenizing, tagging part-of-speech, sentiment analysis, segmentation and named entity recognition.

Named Entity Recognition (NER) is a process of recognizing units of information such as names, person names, organizations, locations, numeric expressions, and other important data from unstructured text to automatically detect entities. To support technologically the process there are already existing libraries, as one of the most popular Python libraries with NER capabilities: spaCy, polyglot and Stanford's CoreNLP [1].

Medicine is a very important field in which it is necessary to extract medical terms in order to create assisted decision-making applications to support physicians in providing accurate and effective treatments for every patient. A lot of studies have been

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started in the field of medical information extraction to be used later in creating databases for developing assisted decision-making applications. Most of the studies have been created for English medical texts because all existing libraries of the NER tools are in English, with very few other languages being implemented. In [2] the authors collected electronic medical records from the ophthalmology department of a hospital and provide entity extraction based on Conditional Random Field (CRF). In [3] the CRF and SiMREDA models are used to extract certain medical information. For testing, the authors use the radiology reports in Spanish language. [4] presents an approach in extracting and processing text information from clinical notes. The authors extract three medical entities: symptoms, drugs and generic medical entities from the patient's discharge summaries and doctors' notes from the i2B2 database. The model for extracting data is CRF. For this study, the Stanford NER package has been expanded and modified. In [5] is presented the contribution in the analysis of the clinical text at SemEval-2014. The authors have implemented a system that combines MetaMap tagging and Illinois NER Tagger. The performance of this system was 0.345 F-measure in strict evaluation and 0.551 F-measure in relaxed evaluation.

As results from the presented bibliography, there is a great interest in creating structured databases and extracting conclusive medical information for use in other applications that support the work of physicians and help them taking the best decisions in treating patients.

In order to help the doctors, in [6], [7] and [8] we propose different methods of structuring the medical prospectuses in Romanian language, using sections such as: therapeutic action, administration mode, contraindications, etc. Figure 1 presents the flow of information and the purpose of extracting medical information.

Figure 1. Workflow of the medical information.

In this article, we continue to structure information from prospectuses by extracting medical terms (the active substances in the drugs, the diseases for which the drugs are indicated, the type of drug, etc.) from sections created in earlier research to be used later in creating new medical applications with decision support for physicians in delivering the best treatments.

2. Methods

Based on the results of previous research, in which we have extracted the sections of the drug prospectuses in Romanian [6-8], the next step in extracting medical information is to take each section of the semi-structured prospectuses and extract the information of interest from these sections for their use in creating databases for assisted decision support applications.

To find the medical terms of interest in each section, we use the Named Entity Recognition Tagger with NLTK and Stanford NER tagger [9]. Most of the existing models for NER are designed for English language and specifically for recognizing people, organizations, or locations. Our corpus (therapeutic indications section from prospectuses) is in Romanian and the entities of interest are: drug name, drug type, active

substance, diseases for which the drug is indicated, location of the disease, the bacteria for which certain drugs are indicated and the type of disease for which the drugs are indicated. In the first phase we chose to extract the medical terms only from the therapeutic indication section, and then expand the model to other sections.

In order to extract the terms, we train the model using the Stanford NER tagger library from where we used the ner-tagger algorithm [9] and we create a training file for our model in which we annotated the words in the therapeutic indication section with the following syntax:

Advil MEDICAM	*durerii AFECT*
Ultra O	*de O*
Forte O	*intensitate O*
este O	*moderată TIP_AFECT*

In the training file the annotations are: MEDICAM for the name of the drug, TIP_MEDICAM for the drug type, SUBST_ACT for the name of the active substance of the drug, AFECT for the name of the disease that treats it, LOC_AFECT for locating the disease in the body, BACTERII for the name of the bacteria for which the drug is indicated, TIP_AFECT for the type of disease being treated and O for words that have no meaning for our study. After creating the file, we trained the model with the CRFClassifier from the Stanford NER tagger. Next, we created a Python script in which we used the proposed model and extracted data from files containing therapeutic indications about other drugs, to test its accuracy. In the first phase we used the random training prospectuses to create the training file and tested with a different type of medicine than the one in the training file. In the second phase we used certain types of medication to create the training file, testing with the same type of medicine (eg. antibiotics, analgesics, anti-inflammatory drugs). Figure 2 presents several results of running the algorithm on test files after the model training.

```
Entity is: Lekadol, Expected value is: MEDICAM and Prediction is: MEDICAM
Entity is: paracetamol, Expected value is: SUBST_ACT and Prediction is: SUBST_ACT
Entity is: analgezic, Expected value is: TIP_MEDICAM and Prediction is: TIP_MEDICAM
Entity is: durerea, Expected value is: AFECT and Prediction is: AFECT
Entity is: febra, Expected value is: AFECT and Prediction is: AFECT
Entity is: fenilefrina, Expected value is: SUBST_ACT and Prediction is: SUBST_ACT
Entity is: decongestionant, Expected value is: TIP_MEDICAM and Prediction is: TIP_MEDICAM
Entity is: nasul, Expected value is: LOC_AFECT and Prediction is: O
Entity is: infundat, Expected value is: AFECT and Prediction is: O
Entity is: Lekadol, Expected value is: MEDICAM and Prediction is: MEDICAM
```

Figure 2. Testing results with the proposed model.

The next step was to obtain results on different models and with different test files.

3. Results and Discussion

To test many variants of models, we chose to create more training files and test them with different test files. The first training file consisted of 6 therapeutic indications from 3 antibiotic and 3 anti-inflammatory drugs based on ibuprofen, and we test the model with a paracetamol-based analgesic prospectus. The second, third and fourth training files were created respectively with 1, 2 and 3 antibiotics and were tested on the same type of antibiotics. The fifth, sixth and seventh files were created with of 1, 2 and 3 anti-inflammatory drugs based on ibuprofen and were tested on another ibuprofen-based anti-inflammatory drug and the last training file was created with 1 and 2 analgesics based on paracetamol and tested on another analgesic based on paracetamol. Table 1 shows the test results for each type of model, the lines being colored depending on the type of drugs

used in the training and testing (red color – mixed types of drugs, orange – antibiotics, green - anti-inflammatory drugs, blue – analgesic drugs. In the first column of the table are presented the drugs in the training files, using the therapeutic indications section, the second column contains the test files drugs, in the third column we find the number of entities of interest of the therapeutic action section to be recognized, in column 4 we see the number of elements in the section that have been correctly recognized by the algorithm, and the next two columns contain the accuracy of the entities of interest and all the entities within section, respectively.

Table 1. Result of Stanford NER Tagger on prospectuses therapeutic indications section

Training network drugs (Therapeutic indications section)	Testing drug (Therapeutic indications section)	Test entity of interest	Recognition degree (entity of interest)	Accuracy (entity of interest)	General accuracy
3 Antibiotics + 3 Ibuprofen drugs	**Lekadol (paracetamol)**	25	5	0.20	0.82
Augmentin	**Epicocillin**	60	29	0.48	0.79
Augmentin + Amoxicillin	**Epicocillin**	60	36	0.60	0.84
Augmentin + Amoxicillin + Ampicillin	**Epicocillin**	60	39	0.65	0.86
Adagin	**Brufen**	25	8	0.32	0.84
Adagin + Advil	**Brufen**	25	9	0.36	0.86
Adagin + Advil + Biofen	**Brufen**	25	11	0.44	0.88
Dulsifeb	**Lekadol**	25	6	0.24	0.83
Dulsifeb + Influbene	**Lekadol**	25	15	0.60	0.90

The results show that in the case of training the model with same category annotated drugs therapeutic indications, the accuracy and the number of recognized entities is higher. Currently, the algorithm is trained with a therapeutic indications section of a Romanian prospectus. For the future we will look for other training algorithms and we will test for other sections of interest in the prospectus as well as other prospectuses in other languages.

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The High Technology Measure the Risk of Noncommunicable Diseases, Confidence the Gender in the Prevalence of Health Information for the Decision-Making in Si Sa Ket Province, Thailand

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Abstract. Noncommunicable diseases (NCDs) are incurable disease, which causes by the risk factors. This study aimed to determine the prevalence and distribution of the risk factors associated according to gender. A cross-sectional survey on Health dataset between October 2013 and April 2017 of people, age 13 years and older about 1,245,462 people, using the high technology and the STEPS approach questionnaire by the WHO. The questions included demographic, behaviour and metabolic. The results found that the prevalence of the risk NCDs were 611,099 people(49.07%) Most risk factors was tobacco use in men (p-value<001), waist in women (p-value<001), having diabetes mellitus family in men (p-value<001), having hypertension family in men (p-value<001), alcohol consumption in men (p-value<001), blood pressure in women (p-value<001), blood sugar level in women (p-value<001), BMI in women (p-value<001), and cholesterol level in women (p-value<001). This data indicates that the prevalence of behaviour needs to be concerning and decision-making to prevention.

Keywords. High Technology, Health Data Centre, Risk factors, NCDs

1. Introduction

Noncommunicable diseases (NCDs) are chronic diseases and illness condition slowly and long time, to spend more cost, and incurable with any drugs until to death. The major factors are caused by preventable behavioural risk factors and metabolic factors[1, 2]. People were death by NCDs caused a total of 41 million every year, 71% of all deaths globally, with the age below 70 years old. NCDs such as hypertension, diabetes mellitus are the main causes and most death account for approximately 67% of total mortality in the world and most located in low and middle-income countries [3] 85% of all, policy implementation and provide with the health care with their concern.

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The risk factors of NCDs were included demographic, behavioural and metabolic [1, 4]. Since 2007, Thailand had an increased incidence of noncommunicable diseases total death around 500,000 cases (71.0%) of all death[5]. Therefore the Ministry of Public Health of Thailand provided all hospitals to collect electronic health data records and linked with Health Data Center (HDC). [6] included services in hospitals, health check and health screening in the community. This study aimed to investigate health data records of risk NCDs status and explore determined the prevalence associated with the risk factors of NCDs.

2. Methods

2.1. Design and Population

This method was used in a cross-sectional survey. We used data from electronic health data records were verified quality to ensured, from Health Data Centre (HDC) database of Si Sa Ket Provincial Public Health, included demographics(gender, age, age_group, married status, occupation, education), physical measurements(diabetes mellitus family, hypertension family, alcohol consumption, tobacco use, weight, height, waist, blood pressure), biological measurements (blood sugar level, total cholesterol). A step contains questions related[7, 8] to investigate with standardized of the STEPS Noncommunicable Disease(NCDs) to risk factors approach questionnaire by the World Health Organization[8, 9]. This dataset excluded all cases with missing, duplicate, error information and a case that a physician had diagnosis be NCDs patient.

We selected population by purposive sampling, age was 13 years old and older, lived in this province and registered with a health services between October 1st, 2013 and April 30th, 2017, total 1,245,462 people. Eligibility criteria and scaling were identified a risk factors reference by WHO. This protocol was approved by the Mahasarakham University ethical committees and also passed through from Si Sa Ket provincial public health officials to confidentiality was ensured in the consent form.

2.2. Assessment of variables

This study used dataset included gender, age, age_group, married status, occupation, education, diabetes mellitus family as: yes and no, hypertension family as: yes and no, Alcohol consumption as: yes and no, Tobacco use as: yes and no.

Body mass index (BMI) calculated as weight in kilograms divided by height in metres squared (m^2) then categorized using BMI cut-points recognized by the World Health Organization. this study applied standardized of Thai people as underweight (<18.50 kg/m^2), normal weight (18.50–22.99 kg/m^2), overweight (23.00–24.99 kg/m^2), and obesity (≥25.00 kg/m^2). High waist defined for female as lower (≤80 centimetres), high (>80.0 centimetres), and for male as lower (≤90 centimetres), high (>90.0 centimetres). This measurement was sum lower level of male and female as a lower level, some high level of male and female as high level, then defined lower level as no risk, high level as a risk. Blood pressure level we used the systolic value defined as lower (<100 mmHg.), normal (100-120 mmHg.), high (≥121 mmHg.). This measurement was combined lower level and normal level as no risk, high level as the risk. Blood sugar level defined as lower (<72 mg/dl.), normal (72-99 mg/dl.), high (≥100 mg/dl.). This measurement combined lower level and normal level as no risk,

high level as the risk. Total cholesterol defined as lower (<160 mg/dl.), normal (160-199 mg/dl.), high (≥200 mg/dl.). This measurement combined lower level and normal level as no risk, high level as the risk. The prevalence of categorical demographic, behavioural, metabolic and correlates of NCDs risk factors were compared across gender by using odd ratio (OR) for the difference between proportions, distributed outcomes using descriptive and crosstabs to calculate to the results are presented, levels of $p < 0.05$.

3. Results

The population were registered in Si Sa Ket Province total 1,245,462 people and found the risk people total 611,099 people, 49.07 %.

The investigated with the majority of risk factor were men (50.2 %), age_group were 40-59 years old(24.4%)(min.age 13, max.110, mean 50.97, S.D.21.747), most men were diabetes mellitus family(DM family)(43.0%), were hypertension family(HT family) (17.9 %), were alcohol use (26.9%), were tobacco use (19.0%), while most of women were high blood pressure (23.0%),most women were high blood sugar level (33.3%), body mass index were overweight and obesity(23.4%), waist was over (22.5%) and were high total cholesterol (21.4%). Prevalence of risk factors, most risk factors was tobacco use in men (18.9%), OR 16.789, (95%CI 16.399-17.188, p-value</001), waistline in women (22.5), OR 8.092, (95%CI 7.979-8.028, p-value<.001), Diabetes mellitus family in men (43.0%) OR 1.321, (95% CI 1.303=1.340, p-value<.001), Hypertension family in men (17.9%), OR 1.165, (95%CI 1.152-1.177, p-value<.001). Alcohol consumption in men (26.9%), OR 3.934 (95%CI 3.885-3.983, p-value<.001), Blood pressure in women (23.0%), OR 1.201, (95% CI 1.189-1.213, p-value<.001), Blood sugar in women(33.3%), OR 1.231, (95%CI 1.209-1.254, p-value<.001), BMI in women (23.4%), OR 1.530, (95%CI 1.514-1.546, p-value<.001), Cholesterol level in women (21.4%), OR 1.170, (95%CI 1.061-1.289, p-value<.001).

4. Discussion

A large electronic health data was studied with a cross-sectional survey from the Health Data Centre (HDC)[6, 10] of the Ministry of Public Health, it was shared database to administrators and networks.[11] This study found some population that registered, but more cases were missing some health check data and missing health screening, although health policy and indicators to coverage people. Additional, found that more electronic health data was an error, missing and duplicate. Once, several of software to collect data. Normally the Ministry of Public Health of Thailand provided begin 15 years old and older. This study investigated of a risk factor in the child (13-14 years) found that more risk NCDs also. Nowadays, Thai people had difference lifestyle by gender and others. men risk more women, age_group 40-59 years old most men were diabetes mellitus family were hypertension family, were alcohol use [12], were tobacco use [12-14], while the most of women were high blood pressure [15], most women were high blood sugar level, body mass index were overweight and obesity[2, 15, 16], waist was over and were high total cholesterol.

5. Conclusion

The high technology would be warning and alerts their risk signs by the results found that more people who risk NCDs and the majority were men, but also similarly or difference by gender to risk NCDs by each of risk factor. Health evidence based on electronic health data would be supporting and provides health policy maker and effort to health personnel and people risk NCDs to collaborate their health promotion, prevention, surveillance, monitor NCDs and should be to concern their lifestyle, healthy behaviour and collaboration with their family, community, provider and policy of government to integration with awareness of stakeholder and participants network to solving their problem community, health information to promotion make the better.

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Using Mental Health Indicators to Improve Health Care Management: A Web-based Approach

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Abstract. Mental health indicators are essential for monitoring people's mental health status, developing mental health policies, and evaluating the performance of such policies. The aim of this paper is to describe the development of a web-based tool for mental health indicators capable to support the management of Brazilian mental health care networks. The SISAM is a web information system responsible for management and provision of mental health information in Brazil and it was chosen as the use case of this study. The indicators were developed as a decision support web tool for public health managers. The tool is able to calculate 11 indicators related to inpatient care. A descriptive analysis of all indicators is presented using SISAM data from 2017. The results generated by the tool are promising and could provide improvements on care monitoring, evaluation of possible trends and investments in prevention and promotion in mental health care.

Keywords. Mental health, indicator, health management

1. Introduction

Health indicators are important tools to help management, monitoring and evaluation of the health at all public health levels [1]. Additionally, they can measure and show information about the general level or characteristic of many health topics, such as the health status of a population or population groups, health policy, healthcare system, healthcare resource, natural environment, size and composition of population, and people's perception and value of health [2]. Moreover, the creation of indicators regularly by dynamic information systems is another important tool that can be used by healthcare professionals and stakeholders to improve healthcare [1].

Considering the fact that mental illness is one of the greatest public health issue, the World Health Organization (WHO) elaborated the Mental Health Action Plan for

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2013-2020 [3]. One of the plan aims is the empowerment of information systems and research on mental health care (MHC) by the creation of systems based on indicators use to outline the information needed [3]. Thus, the development and implementation of mental health indicators (MHI) are also essential for monitoring people's mental health (MH) status, developing MH policies, evaluating performance of such policies and comparing and benchmarking performance information among countries [2].

However, the implementation or improvement of specific information systems for MHC containing indicators are very limited [4]. So, one of the few systems for MHC in Brazil is the Information System on MHC (SISAM) [5]. The system is a web-based computerized information system that enables real-time patients and services monitoring in a Mental Health Care Network (MHCN) since 2012 [5]. The region covered by SISAM comprises 26 municipalities, an estimated population of 1,483,715 inhabitants in 2017 and its MHCN includes several types of services in different levels of care [5]. In addition, SISAM manages information about socio-demographic and clinical patient data, outpatient services data and hospital data [5] and, currently, only presents a summary report of the collected data; but it does not generate indicators automatically.

Therefore, the aim of this paper is to describe the development of a web-based tool for MHI capable of support the MHCN management. This study is part of an interpretative study proposing an evaluation model for MHCN focusing on the use of information technologies for its management and applying semi-structured interviews to understand the MHCN management according to its managers and by the definition of an indicator set [6].

2. Methods

The development of the indicators tool was divided into the following steps: (i) definition of the MHI; (ii) definition of the dataset used for the implementation; (iii) implementation of the prototype tool; and (iv) testing and validation of the proposal.

In the first step, we decided to use 11 indicators related to inpatient care in MH that could be calculated from the SISAM dataset that were suggested by a previous study from Delfini [7]. Those indicators were chosen from indicators defined and used in other countries (Canada, Australia and United Kingdom) [7]. Moreover, that study also defined a Minimum Data Set (MDS) for MHC by the comparison with Brazilian and other countries MDS. In addition, it identified that SISAM data contained 87.0% of the suggested MDS [7]. Thus, the previous study also generated conceptual and computational models based on SISAM by using HL7 FHIR and openEHR.

Thus, we decided to use the MHC information of the MHCN comprised by SISAM as the main dataset for the indicators' implementation. In addition, SISAM allows access to integrated data through the eHealth-Interop platform [8]. With this platform, the indicator tool can be adapted to support other systems and other data sets. The platform for health data exchange is implemented based on the Loopback framework [9]. The communication is made through web services, with the support of a terminology server based on the HL7 FHIR standard.

The proposed tool was built to perform the automatic calculation of the selected indicators during a real time query. It will present the available indicators along their definition and it will also provide specific filters enabling the users to achieve greater data disaggregation on temporal, spatial, clinical and socio-demographic aspects. The

chosen filter were time period of interest, patient sex, patient age groups, diagnostics with ICD-10, patient's place(s) of origin, and inpatient service(s). Moreover, each filter is displayed differently according to the indicator chosen because of the measurement differences. Thus, the results from the indicator measurement could be displayed in tables or graphics depending on the user's choice. We used prototyping method in the tool's development. The design of all user interfaces, graphics and tables was made using Bootstrap framework with the template AdminLTE (version 2). For the back-end development, the framework CakePHP was used together with an Apache2 web server, PHP programming language and MySQL database management system.

The tool prototype was tested using use cases to verify its functionalities and its interfaces. All errors and improvements identified at this stage were then addressed and corrected if needed. Finally, we made a descriptive analysis of the indicators reporting the information in the SISAM data from 2017.

3. Results

The indicators selected to be implemented on the proposed tool were: admissions for depression, admissions for MH and behavioral disorders related with alcohol, admissions of children with mental illness, admissions for self-harm, emergency admissions for neurosis, emergency admissions for schizophrenia, admissions for substance abuse, admission for deliberate self-harm in children and youth, hospitalizations for more than 30 days in 1 year, average length of acute inpatient stay, and 28 days readmission rate.

The development process resulted in a preliminary version of the tool. Moreover, the use of the interoperability platform provided a more reliable information, since it was possible to perform data aggregation from information system of MHCN' mental hospitals and national databases to the SISAM data, to identify inconsistencies and to eliminate duplicity. During testing, we identified the need for future incorporation of statistical analyses to the tool results as well as the need to perform usability tests with possible users to verify if the tool meets their expectations and whether there are possible unidentified improvements.

From the descriptive analysis using the MHCN data from 2017, we observed that the admissions rate for depression was 5.32 per 100,000 inhabitants and it was higher for women than men. The indicators for self-harm and deliberate self-harm admissions in children and youth had very low rates regionally, respectively 0.30 and 0.20, because the data only contained information from psychiatric beds. The remaining indicators for admission had higher values for men than women. In addition, the region had a hospitalization rate of more than 30 days equal to 39.49, the 28 days readmission rate equals to 4.63, and the mean length of inpatient stay of 12.16 days. An example of an indicator measurement resulted by the tool can be seen in Figure 1.

The use of the indicators' information resulted from this tool could enable improvements on care monitoring and MHCN organization, evaluation of possible trends, and investments in prevention and promotion. Moreover, this tool would be one of the first to evaluate a MHCN in Brazil, which makes its development extremely important given the shortage or non-existence of such tools in Brazil [4]. At last, the use of this tool will also help to strengthen information dissemination by expanding indicators' knowledge and the use of information systems by professionals and managers, since both are still deficient in MHC.

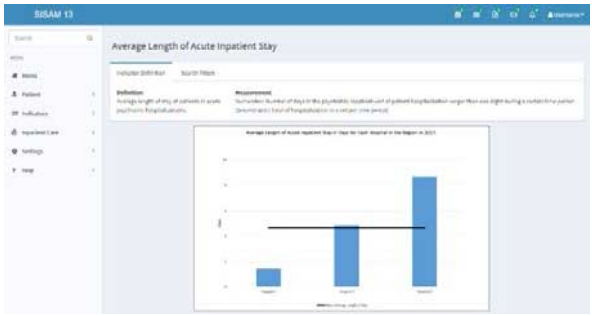

Figure 1. Example of the graphic result from the developed indicator tool of SISAM.

4. Conclusion

The investment in development and research to assist health professionals and managers in MHC management is very important given the increasing burden of MH issues in the population. Thus, the development of the MHI tool in this study is an initiative to assist this scenario in Brazil. As future work, we will search for more indicators beyond those from inpatient care implemented in this study. Our future goal is to include indicators for other areas of care and the MHCN as a whole by searching indicators used in countries with free public health, incorporating information from more databases and interoperating with other sources.

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Actionable Data from Iterative Cognitive Walkthroughs: Creating the Research Roadmap Website as an Interactive Guide to Facilitate Research

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Abstract. The goal of this project was to assess usability and acceptance of a web-based tool after iterative development based on cognitive walkthroughs. The website is a "Research Roadmap", modeled after the NYC Subway map, and designed to help the user navigate the complex structure of research at a large multi-institution organization. A mixed process of evaluation and design was applied; after an initial survey phase, the website was revised, then another cycle of feedback was implemented. Surveys consisted of standardized questions with answers arranged as Likert-type scales and additional written responses. The first phase of survey feedback shaped overall design of the tool. The second phase measured task performance (time-to-completion), perceived ease-of-use, and satisfaction. These ongoing cycles of cognitive walkthroughs provided actionable data that led to redesign of the tool, an improved interface, improved user satisfaction, and 'above average' usability (top 10th percentile) as measured by the System Usability Scale.

Keywords. Usability, User-centered Design Methods, Human-computer Interaction

1. Introduction

Navigating the research landscape in an academic institution may be an arduous task, both for novice and seasoned researchers. Interactive tools were shown to be instrumental in facilitating research processes, however they require iterative implementation guided by user feedback. The Research Roadmap website (RRM) is a robust and comprehensive web-based, centralized tool designed to provide a one-stop shop resource to navigate research processes at the Icahn School of Medicine at Mount Sinai (ISMMS). It provides system-wide navigation of the many "pathways" of the ISMMS research infrastructure and regulatory frameworks. It is an interactive, dynamic, easy to use tool that provides the most current, streamlined and efficient access to administrative processes, external regulatory requirements, internal policies, most current news, education and training opportunities toward the conduct of the highest quality research. Locally designed and built, it is a tangible, immediately accessible and continuously available web-based tool and platform for the dissemination of "tips" and "best practices". The goal of the RRM

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is to increase productivity by reducing the discovery time for research teams to understand research methods and processes. Historically, however, the process of iterative development was not supplemented with formal surveys and cognitive walkthroughs.

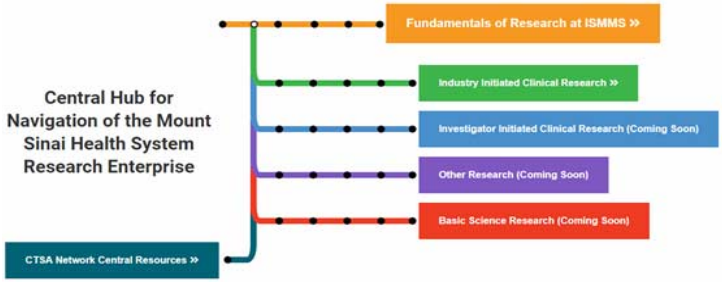

Figure 1. Research Roadmap Landing Page

2. Methods

2.1. System Design

System design has been guided by the Cognitive Theory of Multimedia Learning which posits that information should be structured on learning principles accounting for working memory and cognitive load [1]. To facilitate ease-of-use, the RRM home page displays a table-of-contents organized like a subway map (Figure 1); each 'stop' on the subway represents a separate subpage with information relevant to that topic, arranged in a specific sequence. For each subpage, color-coded links are arranged along the top and left side of the screen (Figure 2).

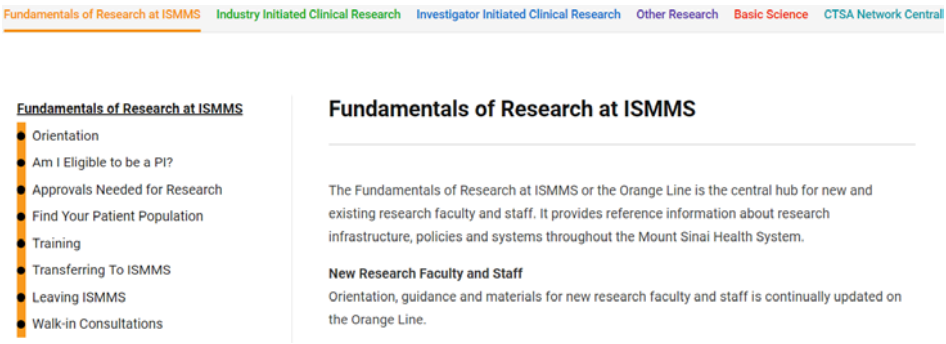

Figure 2. Research Roadmap subpage with color-coded links along top and left side

2.2. Study Design

Participants were given a packet of instructions and multiple surveys upon sitting down at a workstation. Surveys consisted of standardized questions with answers arranged as Likert-type scales and additional written responses. A 9-item baseline questionnaire to record demographics and familiarity with technology was collected immediately. To

ensure participants evaluated the website only and not other aspects of the interface such as the desktop or application launcher, the starting website was already displayed on the web browser.

Table 1. Task Performance

	Task Accomplished (%)	Help Needed (%)	Accomplished Time (sec) Mean ± SD
Task 1	100	0	8.6 ± 16.6
Task 2	100	0	8.0 ± 21.2
Task 3	100	7	12.3 ± 26.7
Task 4	100	7	34.8 ± 19.5

Cognitive walkthroughs were then arranged into two phases. In Phase 1, subjects browsed the RRM freely and provided written feedback on their surveys. Feedback was aggregated and informed website modifications that were implemented prior to the next phase of cognitive walkthroughs. For Phase 2, participants naïve to the website were given similar surveys, and asked to perform four representative tasks. These tasks were timed, and requests for help were also noted. Participants then graded each task on a scale of 1 (very difficult) to 5 (very easy) using a 3-item survey of the following questions: 1) How difficult or easy was it to complete this task? 2) How satisfied are you with using this application/system to complete this task? 3) How would you rate the amount of time it took to complete this task?

Once all tasks were completed, the participants were given an exit survey including the 10-item System Usability Scale (SUS).

Table 2. Task Self-Assessment

Task Self-Assessment	Mean (SD)
Task 1: Find and go to 'Fundamentals of Research at ISMMS' (Orange Line)	
Difficulty	5.0 (0.0)
Satisfaction	5.0 (0.0)
Amount of Time	4.8 (0.5)
Task 2: Find and go to 'Orientation'	
Difficulty	4.8 (0.5)
Satisfaction	4.8 (0.5)
Amount of Time	4.6 (0.7)
Task 3: Find and go to 'Approvals Needed for Research'	
Difficulty	4.2 (1.0)
Satisfaction	4.3 (1.2)
Amount of Time	4.2 (1.0)
Task 4: Find and go to 'Study Submission Workflow' in 'Industry Initiated Clinical Research' (Green Line)	
Difficulty	3.9 (0.9)
Satisfaction	4.0 (1.1)
Amount of Time	3.9 (1.0)

3. Results

Twenty-one surveys were captured in the first phase, and fourteen in the second phase.

Phase 1 feedback was primarily written responses, and informed overall design choices and content, which were implemented for the second phase. Phase 2 feedback included performance metrics (Table 1), task self-assessments (Table 2), and the System Usability Scale.

4. Discussion

The RRM - with its familiar 'subway-system' design - helps users navigate a complex research infrastructure. For evaluation, cognitive walkthroughs were chosen since they focus on ease-of-learning, exploratory learning, and support task-specific inspection [2].

Changes implemented after Phase 1 improved results for 'The website is visually appealing' score without significant impact on 'The Research Roadmap is easy to navigate' score (Table 3).

Table 3. Results Compared

Results Compared	Mean (SD)
Phase 1 Results (select)	
The website is visually appealing	3.5 (1.2)
The Research Roadmap is easy to navigate	4.0 (1.0)
Phase 2 Results (select)	
The website is visually appealing	3.9 (0.8)
The Research Roadmap is easy to navigate	4.1 (0.6)

Phase 2 added objective and subjective measurements, via task time-to-completion, and Task Self-Assessment, respectively. Tasks were selected in increasing order of complexity; results of both the Task Performance and Task Self-Assessment reflect this relative increase of difficulty (Table 1, Table 2).

After completing all tasks, participants were given the System Usability Scale. Scores for each user were calculated in the usual way and thus normalized; the mean score was 80.8 ± 9.5 (Figure 3), which corresponds with the top 10th percentile and an 'above average' rating for usability.

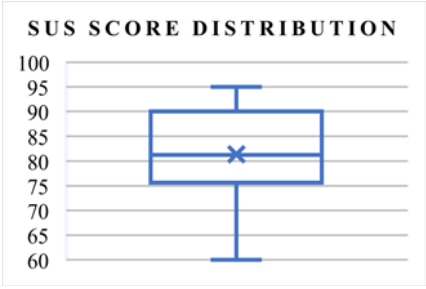

Figure 3. System Usability Scale, score distribution

5. Conclusion

Cognitive walkthroughs offer valuable insight for web-based products and can lead to appreciable increases in user satisfaction when used with iterative cycles of development.

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Health Professionals' Perceptions of Information Quality in the Health Village Portal

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Abstract. Information quality has an important role in health care as digital services provide patients and healthcare professionals more opportunities for searching and utilising information. Information quality is one of the key factors affecting user satisfaction, perception of digital service usability and intention to use the service. The conceptual framework for this study was the updated Information Systems Success Model of DeLone and McLean. The study was conducted in the context of Health Village, a digital interactive and secured portal providing health services to patients and citizens. The purpose of the study was to survey health professionals' perception ($n = 91$) of information quality and its effect on user satisfaction. Concerns were raised about the interoperability of the portal with other health information systems and the ease of finding information. Generally, in the Health Village portal, information quality was considered relatively high.

Keywords. Data Quality, eHealth, Health Information Systems.

1. Introduction

Digital health services can be viewed as health information sharing or actual health care interventions that are delivered using information and communication technology, regardless of time and place [1-2]. The development of digital health services plays an important role in involving citizens in maintaining their own activity and wellbeing, but also aims to enhance the efficiency and quality of health services [3]. Citizens may be positively motivated to use digital health services that complement existing services [4]. Good information quality can increase positive attitudes among patients towards the use of health information technology and care quality, and it also has a significant effect on perceived usefulness, user satisfaction, and the intentions of healthcare professionals to use a system [5-12]. Information quality has also been proven to enhance service

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performance and quality, enable better access to resources and facilitate communication [13-14]. The concepts of health information and quality can be considered from different points of view, as patients search and evaluate information differently and emphasise different criteria than healthcare professionals [15].

The context of this study was the Health Village portal, which is a digital interactive secured portal that includes several hubs. The hubs are designed for specialised health care and aim to offer a platform to citizens, patients and professionals for specialised medical digital healthcare services, such as information, assessment tools for self-care, symptom navigators and digital treatment pathways. The information content of the Health Village portal is available to registered patients and healthcare professionals, as well as, in part, publicly to all citizens. The quality of information produced by professionals and patients plays a central role both in open sites and in digital pathways designed for registered patients [16].

The conceptual framework for this study was the updated and adapted DeLone and McLean Information Systems (IS) Success Model [11]. In this study, information quality was operationalised in terms of completeness, uniqueness and relevance and was assessed from the viewpoint of the user. The purpose of this study was to determine health professionals' perceptions of information quality in the Health Village portal. The effect of information quality on user satisfaction was also assessed.

2. Methods

The e-questionnaire consisted of 50 Likert scale statements of which 10 assessed health professionals' perceptions of information quality (Table 1). Statements were based on DeLone and McLean's IS Model (2003). One open-ended question assessed future development needs in the Health Village portal. Questions were validated by reference to earlier studies, and finally given to a group of experts to adjudge content validity.

Table 1. Information Quality Dimensions in the Questionnaire

Information dimension	Question
Completeness	
	The information in Health Village services is flawless.
	The information in Health Village services is up to date.
	The information in Health Village services is unambiguous.
Uniqueness	
	I can find the information that patients have entered into the service easily.
	I can utilise the information individually.
Relevance	
	I can find information easily.
	The information presented in the service is useful.
	The information in the service is based on evidence.
Form	
	The information available in the service is distinctly presented.
	The information I have saved in the service can be used in a flexible way.

The data was collected from 15th August to 9th September 2018 from healthcare professionals (nurses, physicians and other professionals) working on the Virtual Hospital 2.0 Project at five Finnish university hospitals. A total of 91 of the 501

respondents completed the questionnaire. Statistical analysis was conducted on the quantitative data. Answers to the open question were analysed using content analysis.

The study was conducted in an ethical manner and in accordance with good research practices. The confidentiality and informed consent of the respondents were maintained. The data maintenance cycle followed the principles of the University of Eastern Finland.

3. Results

Half of the survey respondents represented two university hospitals. Nearly 90% of the respondents were women and 80% had an academic degree. Half of the respondents had 20 years or more of work experience in the health sector, and nearly half were nurses (48%).

The main findings indicate that the respondents were mostly satisfied with the information quality in the Health Village portal. They shared the view that information in the portal is up to date (99.3% agreed) and flawless (87.8% agreed). They also mostly agreed that the information available in the service is unambiguous (83.3%), current (93.3%) and evidence-based (83.3%). According to the respondents, the information is easy to utilise individually in clinical pathways (61.1%) and they indicated that they could find information that patients had provided quite easily. The study also confirmed a positive relationship between information quality and user satisfaction in the path analysis.

Answers to the open questions ($n = 17$), which related to information quality–related issues, focused on challenges of interoperability with other information systems, such as patient information systems. Concerns over ease of finding information and the real uses of information by health care professionals and patients were also described, as well as transparency, timeliness, reliability and originality of information.

4. Discussion

The main purpose of the study was to assess perceptions of information quality. This was regarded as an important topic as information sharing plays a crucial role in digital services [2-3]. This study confirmed earlier studies' results that information quality affects system usage and user satisfaction [6-11]. Thus, our findings of the relatively high quality of information in the Health Village portal gives new insights for development. Despite its contribution, this study has limitations. First, the research concerned only the Health Village portal; other interactive portals should be considered as well. However, the Health Village portal is a national initiative, and thus the results are relevant in all university hospitals in Finland. Second, larger sample sizes are needed to make broader generalisations. Third, only the information quality was statistically significant and therefore considered in this paper as an example. Other constructs of the DeLone and McLean IS Success Model (1992, 2003) should also be taken into account, such as privacy and security issues of information systems. Fourth, information quality was only assessed from the viewpoint of health professionals, so future research is needed to examine the perceptions of customers and registered patients. To deepen understanding of quality dimensions affecting users' behaviour, a multi-method approach could be useful and contribute to understanding of the phenomenon at a deeper level.

5. Conclusions

This paper reported on an empirical examination of information quality using the DeLone and McLean IS Success Model [11] as a predictive model. The DeLone and McLean IS Success Model considers, in addition to information quality, the service and system quality. Nevertheless, the results validated the objectives of this study, and information quality can be said to have an influence on user satisfaction.

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From Tertiary to Primary Care – Understanding Context in the Transfer of Digital Headache Service Pathway

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Abstract. A digital service pathway for managing chronic headache has been designed in tertiary care in Finland. The digital tool facilitates self-management by providing exercises, information and messaging opportunities for patients. However, the largest potential benefits are in primary and occupational care. Thus, the purpose of this study was to explore the needs and requirements of primary and occupational care actors for better understanding of the context in the transfer of the service. The study was performed as a single embedded case study. The qualitative data was collected through semi-structured interviews with 16 informants from different organizations and analyzed with Gioia-methodology. This study gathers important empirical knowledge about the meaning of context and transferring digital health interventions from one context to another from clinician and management perspective. Nine key contextual differences were identified and six main expectations emerged.

Keywords. Telemedicine, Headache, Health Services

1. Introduction

Clinicians and researchers at Helsinki University Hospital (HUH) have developed a digital service pathway for chronic headache patients in tertiary care. The service offers alternative methods for treatment and provides support throughout the care pathway. The service helps patients to recognize and manage the characteristics of their headaches. Trained nurses act as headache coaches who supervise the progress of patients along the pathway. There is a messaging feature through which the clinicians can be contacted in case of questions or worries.

Headache is one of the top ten most common diagnoses in the world in 2016 besides being the second most common cause for disability [1]. In a Danish study, tension-type headache led to the loss of 820 workdays in 1000 persons [2]. Thus, improving the care for headache is economically important [3]. Offering the service to wider groups of patients, including primary and occupational care patients could increase the impact. Occupational health care is a Finnish model for organizing primary care for working-age

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people, where the employer provides and pays for the health services to support employees' work ability. This study concerns this move of the service from tertiary to primary care.

Researchers have recognized the difficulty of transferring healthcare interventions successfully into other contexts [4,5]. Contextual understanding acts as a basis for developing successful digital health services [6]. One way to analyze the phenomena is through a design science approach called CIMO logic, where the situation is modeled with context, intervention, mechanism, and outcome [7]. The purpose of this study was to investigate the contextual factors, which affect the transfer of a digital health intervention into other contexts. We also examined what features are valued considering the digital care of headache patients in the target contexts of primary and occupational care. **RQ1:** *What are the key contextual differences between tertiary, primary, and occupational care in digital headache treatment?* **RQ2:** *How do the differences influence the needs and expectations of the service providers for the digital service pathway?*

2. Methods

The study was performed as a single embedded case study with two units of analysis, public primary care and private occupational care. The data was collected by conducting 16 semi-structured interviews structured around the CIMO-framework [7], 10 within primary care context and 6 within occupational care context. Theoretical and snowball sampling were used. Data collection was finished after the data saturated. The public primary care organizations were from several parts of Finland with different population characteristics. The occupational care informants were from two major national service providers. Data was analyzed with Gioia-methodology and thematic analysis [8].

3. Results

Table 1 presents the identified contextual differences between the three healthcare organization types: patient population, resources, continuity of care, preventive approach, payer, IT infrastructure, adoption of digital tools, procurement, and success evaluation.

Table 1. Contextual differences

Contextual dimension	Tertiary care	Public primary care	Private occupational care
Patient population	Selected and chronic patients	Wide array of patients with multiple problems	Working-age people, mostly tension headache
Resources	Specialized physicians and nurses	Primary level physicians and nurses, possibility to consult	Primary level physicians, possibility to consult specialized physicians in-house depending on the contract
Continuity of care	Fixed treatment periods, good follow-up during that	Continuous relationship with the patients, but patients are not actively monitored	Continuous follow-up of customer organizations and the patients. Named clinicians for each customer
Preventive approach	Mainly reactive treatment	Preventive care in some areas	Algorithms which aim to spot patients in risk

Payer	Hospital districts	Municipalities or co-operation districts	Customer companies
IT infrastructure	No digital treatment tools before headache service pathway.	Every area has their own system. ODA-project in some areas.	Some digital infrastructure, e.g. chats, surveys and self-management plan tools.
Adoption of digital tools	Not under study	Apart from ODA, no consistent plans for future.	Digital development programs, strategic fit is assessed.
Procurement	Not under study	Available resources and skills vary a lot.	Systematic procurement according to predetermined needs.
Success evaluation	Indicators: Headache days and intensity, medication, headache impact on life, quality of life, anxiety and depression, patient satisfaction, absences from work.	Resources and skills to measure success vary a lot. Cost efficiency through decreased service use is central.	Intervention-specific indicators are developed. Effect on ability to work is essential.

The informants underlined six main mechanisms they expected to produce good outcomes: capability to self-management, emotional support, willingness to self-management, more accurate care decisions, environment level intervention and prevention, and usability. First, the digital service encourages patients' self-management and makes patients better informed. Second, digital emotional support could reduce the need for excessive contacts due to anxiety. Third, besides supporting the patients' capability to self-management, also supporting their willingness to it would be important. Fourth, the tool should help in enabling professionals to provide more accurate care for the patients. Fifth, occupational care actors discussed the importance of environment level actions. Finally, usability was emphasized.

4. Discussion and Conclusions

The implications for the headache intervention developers were analyzed with regard to outcomes and intervention features. From public primary care perspective, the cost aspect was emphasized. In private occupational care, evidence is wanted on the effects on ability to work and sick leaves. Considering new features compared to the existing solution, both primary care and occupational actors were interested in self-diagnosis features. The primary care informants called for service personalization, particularly regarding age and headache intensity. The effects of the context on the desired outcomes and the mechanisms that produce these outcomes through an adapted intervention are illustrated in Figure 1.

This study gathers important empirical knowledge about the meaning of context and transferring digital health interventions from one context to another from clinician and management perspective. This study also has certain limitations. The findings from a single service pathway in the Finnish healthcare system cannot be generalized to other digital solutions in other countries, although several contextual similarities might arise.

In conclusion, nine key contextual differences were identified and six main expectations emerged in relation to the transfer of a digital headache service pathway from tertiary care to the contexts of public primary care and private occupational care.

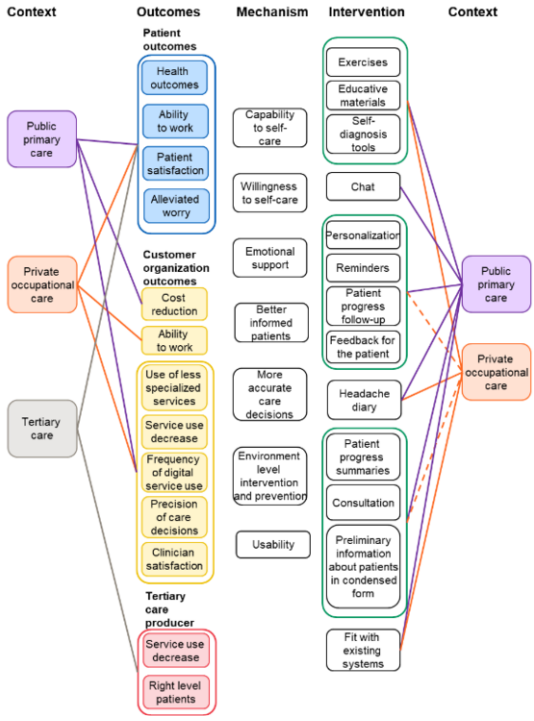

Figure 1. Influence of the context on outcomes and mechanisms through an intervention.

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Virtual Planning of Extra-Intracranial Bypass with Numerical Investigation of Hemodynamics

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Abstract. Planning of bypass surgery for patients with complex cerebral aneurysms is a very complicated task. It is important to take into consideration personal anatomy and hemodynamics and make additional investigations, but unfortunately, they don't give a guarantee of good postoperative results. Recent medical imaging and computational fluid dynamics (CFD) can be helpful for the prediction of effectiveness of selected surgical technique. In the current research with the use of CT and PC-MRI data we applied computational modeling in order to make quantitative assessment of potential changes of blood flow distribution after the surgery. Virtual version of bypass surgery showed preservation of sufficient blood flow, what was confirmed with modeling results after operation. Moreover, successful verification with PC-MRI data in control sections was made. The research has shown that virtual planning with the estimation of blood flow changes can be introduced into clinical practice for simplifying and increasing efficiency of planning process.

Keywords. CFD modeling, intracranial aneurysm, extra-intracranial bypass, hemodynamics

1. Introduction

Aneurysmal dilatation of the cerebral arteries is a serious life-threatening condition. Rupture of intracranial aneurysm is the main cause of non-traumatic subarachnoid hemorrhage, which is characterized by a high frequency of mortality and disability [1].

Most unruptured aneurysms are asymptomatic and are accidentally detected during neuroimaging. After the diagnosis was confirmed the management of the patient is either a monitor or surgical treatment which aims to turn off the aneurysm from the bloodstream. Which intervention is appropriate for the certain patient is decided on the basis of the formation size, rupture risk stratification and clinical symptoms. In most cases the microsurgery or endovascular treatment are used [2]. However, traditional methods may not be feasible in the case of giant aneurysms, which the dome size is more than 25 mm.

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Standard approaches to the removal of such formations are ineffective, and surgeons resort to total occlusion of the parent artery proximal to the lesion. If the parent artery is a large main vessel, the stagnation of blood flow can lead to ischemic changes in respective brain region. To avoid such an outcome, surgeons use revascularization methods of bypassing the pathological area with anastomosis [3].

Estimation of relevance of bypass and its efficiency in future is the main task during bypass surgical planning. Nowadays, the balloon occlusion test with CTA is used for such purpose. Such interventions may lead to ischemia and rupture of giant aneurysm. Moreover, it's very important to take into consideration complex anatomy of vessels and hemodynamic characteristics in the area of interest, because higher bloodstream in the healthy nearby artery can lead to various complications [4].

Looking for safer and more accurate methods of planning reconstructive neurovascular surgery, researchers are increasingly applying methods of mathematical modeling. Calculations with computational fluid dynamics (CFD) software allow quantifying the hemodynamics of a particular patient and taking into consideration various options changing initial anatomy without any invasive interventions. However, currently there are only a few studies of virtual surgical planning with quantitative assessment of hemodynamics [5,6]. Thus, the purpose of the current research was the evaluation of the possibility of applying CFD in patient-specific bypass surgical planning.

2. Material and methods

In the research we used CT and PC-MRI preoperative and postoperative data of a patient with thrombosed giant (33x34x36 mm) saccular aneurysm of the left internal carotid artery (ICA). It was decided to form an extra-intracranial wide-lumen anastomosis between the external carotid artery and the M3 segment of the middle cerebral artery (MCA) using the radial artery as a graft with occlusion of the cervical segment of the left ICA.

Post-processing of DICOM data was performed on the "Gamma Multivox D2" workstation (Gammamed-Soft, Ltd, Russia) [7]. After semiautomatic segmentation of vascular structures, three-dimensional models of the patient's arterial system were reconstructed. Then the models were exported to a commercial finite element software ANSYS Workbench 19.2 (ANSYS Inc., USA) [8]. The elimination of geometry defects was performed, and the surgery was simulated by removing part of the ICA and placing the anastomosis according to the tactics developed by surgeons. In total, three models based on the geometry of the patient's vessels before ("Preoperative" and "Virtual bypass" models) and after surgery ("Postoperative" model) were built for the study (Figure 1).

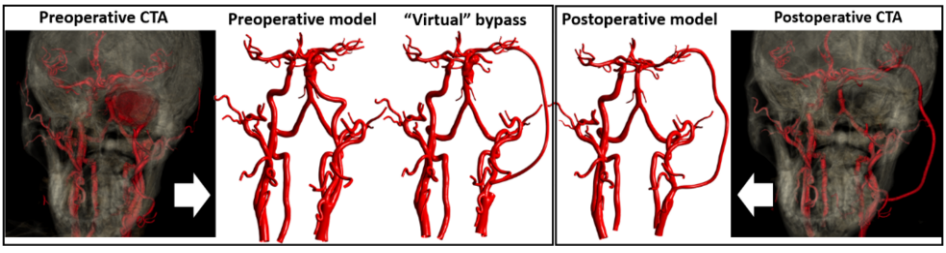

Figure 1. 3D models of the vascular geometries.

The discretisation of computational domains to finite elements and calculation were performed using the ANSYS CFX. Due to the fact that the considered part of the vascular system included large and rather rigid cerebral vessels, the elastic properties of the arterial wall and the non-Newtonian nature of the fluid were not taken into account in this study. As boundary conditions, the linear velocities before and after surgical treatment obtained during PC-MRI at the input and the opening condition at the outputs were used. The full simulation included two cardiac cycles with a total duration of 1.82s. In order to verify the simulation results, linear velocities in the selected sections of the anterior (ACA) and middle cerebral (MCA) arteries were also recorded during preoperative PC-MRI (Figure 2).

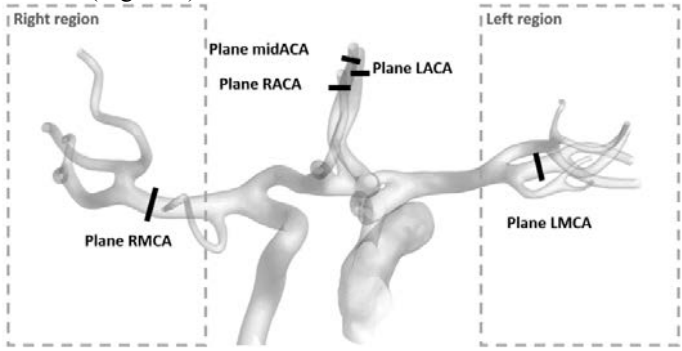

Figure 2. Control sections and regions.

3. Results

To check the correctness of the calculation, the comparison of maximum values of linear velocity of blood flow obtained from PC-MRI and results of the calculation in the corresponding sections was carried out (Table 1).

Table 1. Comparison of maximum linear velocity values in regions of interest for PC-MRI and CFD.

Location	PC-MRI Velocity, m/s	CFD Velocity, m/s
Plane LACA	0,485	0,464
Plane midACA	0,448	0,432
Plane RACA	0,347	0,322
Plane LMCA	0,311	**0,268**
Plane RMCA	0,634	**0,430**

The comparison showed a good agreement of the values in the branches of ACA, but the simulation results were lower for the sections of both MCA. Such effect may be the result of using the same values at the outputs of the computational domain.

To assess the effectiveness of the chosen intervention tactics, the total blood volume passing through each branch of ACA and MCA during the second cardiac cycle was estimated. Simulation of virtual operation indicated the efficiency of the anastomosis and showed a stable increase of the volume per cycle in all observed branches compared with the results of the "Preoperative" model. The data for the real "Postoperative" model was ambiguous, almost all outputs showed a marked redistribution of blood flow between the branches compared with the distribution in the "Preoperative" and "Virtual bypass" models. However, if we make comparison of the total volume in the areas of ACA, left and right MCA (Table 2), there is a general tendency to increase blood supply in the left part of the models with anastomosis by 40% compared to the situation before the

operation, which suggests a possible minimisation of the risk of ischemia on the side of the lesion due to the chosen revascularisation method.

Table 2. Values of the total blood volume per cardiac cycle in different regions and changes compared with preoperative model.

Location	Volume per cardiac cycle for different models, ml		
	Preoperative	Virtual treatment	Postoperative
Left region	1,35	1,9 (↑41%)	1,94 (↑43%)
Right region	1,66	1,83 (↑10%)	1,4 (↓15%)
ACA branches	1,52	1,98 (↑30%)	1,58 (↑4%)

The presented data also indicates that virtual planning predicts the probable absence of decline of the blood supply to the brain through the branches of the carotid arteries in the conditions of the cessation of blood flow along left ICA. The model of real geometry after surgery confirms this assumption; the decrease in blood flow is recorded only on the right side and represents only 15% loss. The result conformed to the clinical outcome. During the control of the patient's condition 3 months after the operation, the normal functioning of the shunt, thrombosis of left ICA and aneurysm with a decrease of its size were noted. Neurological symptoms were absent.

4. Conclusion

Thus, the experience of calculation of hemodynamic parameters in the virtual planning of bypass surgery showed that this direction is promising and relevant for use in practical medicine. However, in further research it is necessary to pay attention to the complexity of boundary conditions at the outputs to obtain more accurate results consistent with the patient's data, as well as to conduct studies on a large sample, as these issues were main limitations of the study. If verification of predictive capabilities will be successful, the technique can be implemented in the clinical practice and become a useful support tool for surgeons. It will allow planning the most effective surgery strategy for a particular patient more accurately, reducing the risk of intra- and postoperative complications without unnecessary medical manipulations, and, in general, improving quality of health care provision for patients with intracranial aneurysms.

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A Platform for Collection and Analysis of Image Data on Stroke

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Abstract. Identifying imaging biomarkers (IBs) of stroke remains a priority in neurodiagnostics. There is a number of different methods for image analysis and learning rules applicable in this field, but all of them require large arrays of DICOM images and clinical data. In order to amass such dataset, we have designed a platform for systematic collection of clinical data and medical images in different modalities. The platform provides easy-to-use tools to create formalized radiology reports, contour and tag the regions of interest (ROIs) on the DICOM images, and extract radiomics data. Subsequent analysis of the obtained data will allow identifying the most relevant IBs that predict clinical outcome and possible complications. The results of the analysis will be used to develop predictive algorithms for stroke diagnostics.

Keywords. Stroke, imaging biomarkers, big data, machine learning, decision support system

1. Introduction

One of the most relevant directions in modern medicine is the identification of imaging biomarkers (IBs), or characteristics of physiological and pathological processes that can be assessed through analysis of medical images [1]. Research and adoption of IBs to clinical practice could expedite the analysis of medical images, help in the search for predictors of acute conditions, improve the diagnostics process, and, as a result, the quality of healthcare. Process of IBs identification includes following stages [2]: 1) data selection; 2) segmentation of regions of interest (ROIs); 3) feature extraction; 4) statistical analysis and modeling.

Identifying IBs would be particularly helpful in diagnostics of stroke, one of the leading causes of mortality and morbidity. The first priority in stroke diagnostics is evaluation of the stroke type in order to determine the appropriate treatment. The main difficulty in the research of the stroke IBs is the absence of representative datasets containing both images and clinical data. There are some datasets for image analysis in MRI or CT perfusion that are openly available to the research community [3,4]. A lot of

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scientists proposed mathematical models based on these datasets, international registries, or their local databases [5]. But the first-choice modality for primary stroke diagnostics in Russia is nonenhanced CT. In view of a limited number of such datasets, the aim of this project was to develop a platform that allows gathering of comprehensive information on stroke patients, both clinical data and DICOM images.

2. The Platform Design

The developed platform contains a package of client-server applications for Microsoft Windows: medical documentation module, DICOM images module, module for extraction of image characteristics. Data is stored in a Microsoft SQL database, and DICOM images are stored separately in a networked storage. DICOM images module supports importing images from portable devices as well as connecting to the healthcare facilities' PACS with the anonymization feature for the stored data. Connection to the facilities' archives is realized through DICOM Q/R and DICOM-Retrieve protocols. The platform also includes functionality for integration with electronic health record system to optimize the process of data entering.

2.1. Medical Documentation Module: Gathering Clinical Data

For every patient the following clinical data was entered into the platform:

- Clinical diagnosis (in accordance with the classification adopted in Russia, one of the following groups was assigned: transient ischemic attack, ischemic stroke, haemorrhagic stroke)
- Risk factors (arterial hypertension, diabetes mellitus, cigarette smoking, obesity, alcohol consumption, and others)
- Clinical case data (outcome, length of hospital confinement, treatment method, scores for different neurological scales: NIHSS, mRS, GCS)

Formalized radiology reports of: cerebral CT without contrast, cerebral CT angiography and cerebral CT with contrast were also included. Special screen forms with formal fields were developed to simplify the entering of clinical information into the system (Figure 1).

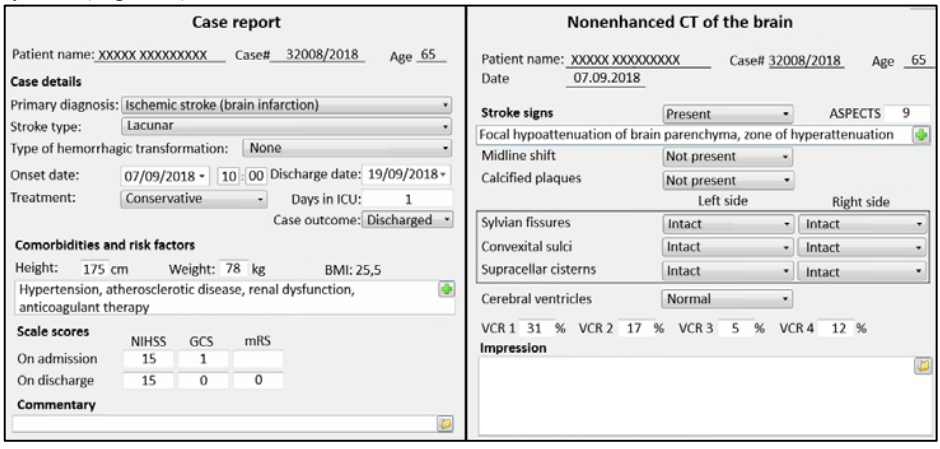

Figure 1. The user interface for entering clinical data and radiology report (nonenhanced brain CT).

2.2. DICOM images module: Segmentation and Tagging

A tool for contouring and tagging the ROIs was created based on a free hand technology that allows users to easily contour pathological formations and tag them accordingly. In order to enhance the efficiency of contouring an algorithm that fills in the contour was developed. The algorithm works by interpolation of contours made manually by the radiologists on separate slices of the CT. As a result of the finished contour a 3D ROI reconstruction is created (Figure 2), and the range of mathematical parameters is calculated.

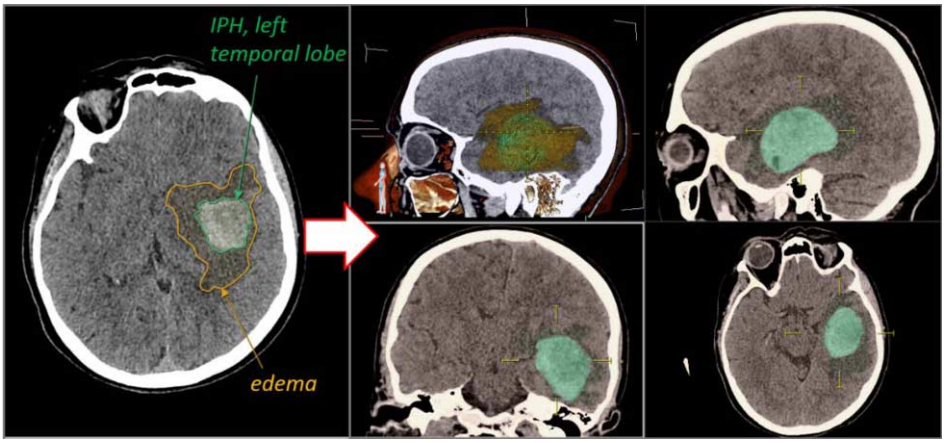

Figure 2. An example of image with segmented and tagged areas (ROI) of intra-cerebral haemorrhage and edema.

A thesaurus of tags for the ROIs was developed with the participation of the radiologists. The localization of a lesion, vascular zone in case of watershed lesions and other characteristics of a lesion were registered by tagging. Types of lesions included ischemic and hemorrhagic stroke (with intraparenchymal, intraventricular, and subarachnoid subtypes). There were also additional tags for areas of edema, lacune, aneurysm and others. Operational comfort in the process of tagging was ensured by the means of trigram search.

2.3. Module for Feature Extraction

The module for extraction of image characteristics was built by means of an open source library PyRadiomics [6]. Features describing ROIs intensity, morphology, spatial and histogram distribution can be calculated and exported to analytic packages in .csv format.

3. The First Implementation In Healthcare Facility

The platform was installed in N.V. Sklifosovskiy Scientific Research Institute of Emergency Care. So far, we have collected data on a hundred stroke patients with 170 CT reports with corresponding DICOM images that were uploaded from the Institute's PACS. Three radiologists reviewed, contoured and tagged the ROIs on the CT images. In total, there are about 20000 contours, and for all them different features will be calculated in the follow-up process.

At the beginning of the implementation numerous peculiarities related to data entry and clinical terminology were revealed. Additional algorithms tracking outliers, missing values, and tags incompatibility were developed to minimize the amount of data entry errors.

This work will be continued by adding more cases, including control cases of patients that have known risk factors for stroke, but have not developed any clinical signs of the stroke yet. The resulting dataset will be anonymized and published for open use.

4. Conclusion

During this research a platform for collection and analysis of stroke images was developed. Currently its functionality covers almost all stages of workflow of IBs identification except for the stage of feature analysis and modeling. In comparison with concurrent projects the developed platform has several advantages. Most of existing software programs do not support integration of clinical data in conjunction with imaging data and calculated parameters. Many of such programs have a narrow field of application. Some are designed only for contouring of ROIs, some for calculation of ROI parameters, thus prompting the researchers to combine multiple software products that can lead to compatibility issues. There is also an option to assess the parameters over time, if there are several CT protocols for the same case.

The project's long-term goal is to identify predictive IBs for stroke in order to assess and calculate individual stroke risk levels. A health management system that estimates individual risk of stroke for patients and produces a preventive measure plan to reduce risk levels is now in testing, and the results of presented work will be introduced into this system [7].

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Quality Indicators for Mental Health in Primary Care – A Comparison Between Literature Review Methods

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Abstract. Evidence regarding quality indicators in primary health care is a major need for better mental health management, monitoring and decision-making. In this paper, we compared two methods of retrieving quality indicators for mental health in primary care by means of an umbrella review, that included eight systematic reviews, and of grey literature. From the umbrella review, 48 primary studies that composed the 8 revisions were analyzed. A total of 94 quality indicators for mental health in primary care were found with the umbrella review, while 2000 indicators were found using the grey literature method. Sixty-eight indicators (3.2% from total) were common to both methods. Both methods can be complementary and useful in order to identify quality indicators.

Keywords. Mental health, primary care, quality indicators, knowledge management.

1. Introduction

The World Health Organization (WHO), through the Mental Health Action Plan for 2013-2020, has the strengthening of information systems, evidence and research on health and mental illness as one of its four priority objectives [1].

Several available documents aggregate, describe and present quality indicators in many areas of primary health care (PHC), such as mental health. The use of indicators is an opportunity for improvement and to achieve the goals basing the clinical practice in best available evidence, through quantitative parameters (planning, organizational, clinical) aiming at better processes and results [2,3].

The structure of quality of health care was proposed by Donabedian and Fleming, categorizing quality indicators in structure, process and outcome [3]. Importantly, for a

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process to be a valid measure of quality, it must be closely related to a result that people care about [2,4,5]. The non-indexed literature has been increasingly valued for the knowledge management improvement, including the introduction of a method for synthesizing this information in support of "classical" systematic reviews [6].
The objective of this study was to compare the obtained results between two methods of retrieving mental health quality indicators in literature, i.e. by means of a systematic (umbrella) review and the non-indexed guidelines and databases, as grey literature.

2. Methods

Based on the results of an umbrella review on PHC indicators, which followed the standards of the "PRISMA Statement" [7] (PROSPERO registration CRD42019124170) and used "AMSTAR-2" as an instrument for quality and risk of bias analysis [8], eight contexts were identified (mental health, chronic disease, women health, services assessment, dental care, orthopedics preventive medicine and infectious disease), allowing for comparisons on health services performance. In the context of mental health, eight systematic reviews with low risk of bias were included. For the present analysis, the primary studies included in these 8 systematic reviews were selected, thus creating a list of evidence-based indicators, categorized by the dimensions of care (structure, process and outcome) [3] and sub-contexts (dementia, depression, bipolar disorder and others).

In parallel, we identified other indicators used/proposed worldwide as grey literature, i.e. what is produced at all levels of government, business, universities, industry in print and electronic formats, and not controlled by scientific peer review publishers [9,10]. This non-indexed approach was carried out through exhaustive research on the internet, contact with colleagues and international organizations that have produced documents, guidelines and databases [11,12] on mental health quality indicators such as World Health Organization (WHO), Organization for Economic Co-operation and Development (OECD), Agency for Healthcare Research and Quality (AHRQ), and others. As this list was not standardized, that is, there is not a clear or complete categorization of levels of care, we were not able to perform the analysis of which indicators were directly related to primary care. Therefore, we performed a careful analysis of the primary studies selected in the systematic reviews resulting from the umbrella review. Those indicators were subsequently searched for among non-indexed setlist.

3. Results

The indexed reviews retrieved 94 indicators from the 480 primary articles, using the umbrella review method.

Using the non-indexed literature method (grey literature), we found 2000 indicators (not specific for primary care). A total of 68 indicators for mental health in primary care were found in both lists of retrieved indicators (72.3% of the indexed result). Most frequent indicators were those related to the control, monitoring and follow-up of patients during treatment, such as coordinated care, continuity of care and preventive measures like the misuse of substances in serious mentally ill patients. Other quality indicators were related to prescription, dosage and monitoring of drug treatment with

psychotropic drugs. Some indexed studies indicators, for instance extra pyramidal effects monitoring, sedation side effects, and patients with delayed diagnosis of serious mental illness, do not appear in general guidelines from the grey literature (table 1).

Table 1. Indicators by context and type of search source

Context of Care	Indexed (n, %)	In both sources (n, % of indexed)
Serious Mental Illness	48 (51.1)	39 (41.5)
Depression	26 (27.7)	19 (20.2)
Dementia	10 (10.6)	6 (6.4)
Medication Control	4 (4.3)	0 (0)
Patient Data	2 (2.1)	1 (1.1)
Other Contexts	4 (4.3)	3 (3.2)
Total	94 (100)	68 (72.3)

4. Discussion

The emergence of the context of serious mental illness comes from the concern of health providers and the scientific community about mortality in these patient groups, which have resulted from increased standardized mortality rate in the last few years [13,14].

In this paper, we verified if the indicators found in the indexed literature were also addressed in the grey literature. Our results highlight important differences in both approaches. The common indicators for the two types of research sources contribute to a more general approach, with indicators related to the coordination of care and care per se (e.g. patients enrolled in the mental health program, disease monitoring/follow up, drug control). Some important indicators related to primary care in the context of mental health were not found in the grey literature, such as extra pyramidal effects monitoring, sedation side effects, and patients with delayed diagnosis of serious mental illness. An hypothesis for these differences might be explained by the fact that governments and administrations are more concerned in evaluating the health system and its functioning than in its improvement.

As a limitation, the analysis in non-indexed source of quality indicators in primary care was not possible due to the lack of information regarding the characterization and categorization in levels of care which should be explored in future work in this area.

5. Conclusion

Evidence-based medicine improves every day its knowledge management methods and technologies, and our study shows that there is more to be improved on the topic of rigorous synthesis in the literature. Our work reveals that the indicators selected in the indexed literature are being used in a consistent but incomplete way by non-indexed guidelines and documents. There is a need for a normalization of the presentation of the indicators, including the characterization and categorization (e.g. in levels of care) for subsequent analyzes referring to what the grey literature could aggregate from the indexed literature and the primary care practices in mental health. The analysis of the composition of mental health care indicators in primary health care in both contexts should be valued and encouraged in order to decrease the lack and the loss of relevant information. The found differences emphasize the importance of using scientifically

validated indicators in the clinical practice and health services, as it is also important that the indicators routinely used in multiple services are submitted to scientific validation, namely through peer reviewed publications.

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Enhancing Precision in Gesture Detection for Hand Recovery After Injury Using Leap Motion and Machine Learning

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Abstract. This paper presents an improved solution for detecting gestures with a better precision using the Leap Motion sensor and Machine Learning support. A neural network is trained to recognize a hand rotation gesture expressing the grade of recovery, with a supination and pronation exercise. The supination-pronation movement is divided into 4 levels because the users are not usually able to perform a complete rotation gesture in hand recovery after injury. The neural network is trained with data representing the hand rotation angle measurements on the x, y and z axes. The Neural Network training is based on the Tensorflow library. 3 tests were carried out to test the network and eventually a 96% gesture-detection accuracy was achieved.

Keywords. Leap Motion, gestures, hand rehabilitation, neural network, machine earning

1. Introduction

Gesture recognition is more and more used in various fields such as: medicine, engineering, education. Gestures may be classified as static or dynamic, alphanumeric or gestures representing actions. Gesture detection is done with various devices: Leap Motion, Microsoft Kinect, RFID tag, linear optical sensor. All these devices work with software applications based on algorithms able to recognize certain gestures. The gesture-detection algorithms use different mathematical formulas considering 3D environment [1] distances, angles [2].

As reported in literature, neural networks have lately been more frequently used in gesture detection. They are trained to recognize gestures using image (frame) processing algorithms, Motion Fused Frames (MFFs) [3] or different methods based on frame extraction on the image entropy or density groupings [4]. In the medical field neural networks are used to assess the motor dysfunction in patients suffering from Parkinson's disease [5], to classify the evolution of the disease. The detection and classification of the gestures for the Leap Motion sensor is also achieved via different machine learning techniques [6] and using the Tensorflow library [8]. The Leap Motion sensor is used to detect gestures representing the letters of the American Sign Language alphabet, where detection is performed by using a neural network which can recognize the alphabet letters

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[7]. The gesture-detection accuracy for the neural network according to the literature goes beyond 90%.

The objective of our work presented in this paper is to develop a new gesture for the Leap Motion sensor, which is detected with the aid of a neural network. This gesture will be used in medical recovery and it represents the hand rotation on an x axis by a maximum of 180 degrees (supination - pronation), the gesture being divided into 4 levels. The neural network will predict the recovery level 1, 2, 3 or 4 (degree of disorder for hand joint). The advantage brought using the neural network is that the levels will be set by the physician and the neural network will be trained to classify them. The neural network training will be based on the Tensorflow library which will use various data (the hand rotation angle on all the axes, x, y, z) stored in a database.

2. Methods and tools

The 3D/2D application editor Unity version 5.6 was used to build a 3D Desktop application where the users may visualize how they move their hands. External software packages, which allow the connection to the Leap Motion device, were included in the application. Leap Motion SDK (Software Development Kit) version 2.3 for Unity was used and for the 3D model we used 2 3D virtual hands imitating the movement of the users' real hands (Figure 1).

Data related to the virtual hand rotation will be introduced in the database with the assistance of this 3D application. Thus the users must perform supination - pronation movements for each recovery level (Figure 1). The recovery level division is realized in such a fashion that for each level the user must rotate the hand to an angle of approximately 45 degrees. When the user starts performing the supination and pronation movements the data related to the rotation angles for all the axes (x, y, z) of the hand will be stored in the database.

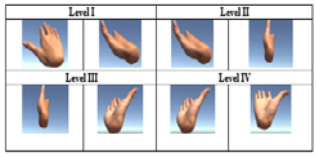

Figure 1. Recovery predetermined positions (4 levels)

2.1. The Database and TensorFlow Platform

The data pertaining to hand rotation were stored in a MySQL database. We created two tables of two columns each: hand rotation value and rotation level. The first table is used to train the neural network with data supplied by the physician, while the second table is used to test the accuracy of the data for the trained neural network. The hand rotation value is stored in the table as a string of characters described as follows: rotation_angle_x, rotation_angle_y, rotation_angle_z, representing the hand rotation value on the x, y and z axes, respectively. The type of hand rotation is stored in the table as a string of characters, and it describes the recovery level in relation to the hand rotation, which may be a level 1, 2, 3 or 4.

The Tensorflow library is an open-source platform created by Google for machine learning. For this particular case we used it to train a network in order to detect the

rotation gesture for each level. A Python script was implemented where the data of each table in the database, exported in .csv (comma-separated value) files will be trained. The detection accuracy of the rotation gesture trained by the neural network is obtained based on this script and on the .csv file data. Each file (generated after populating the database) contains approximately 2000 data which describe the hand rotation for a certain level. The number of 2000 pieces of data in the database is given by the frames that the Leap Motion device captures, i.e. approximately 115 frames per second. Thus the hand rotation exercise is performed for approximately 17 seconds.

3 data extraction modes describing the rotation gesture were approached for a best possible detection and accuracy of the hand rotation gesture. Thus different detection accuracy values were obtained for the trained neural network, presented in Table 1. The rotation movement is performed by the user in both directions during the test, so that both the supination and the pronation are assessed. Each data extraction gesture describing the gesture is explained below.

Table 1. Rotation gesture detection accuracy for each data extraction mode

Test	Accuracy	Number of elements for the neural network training file
Test 1	45.6%	2000
Test 2	74.3%	2000
Test 3	96%	2000

2.1.1. Mode 1

In this gesture-describing data extraction mode, in our case the rotation angles on the x, y and z axes for each level the hand rotation starting point is the same for each level. Therefore at level 1 the user will perform a rotation movement of approximately 45 degrees (β_i – the rotation angle measurement). For each level the user increases the rotation of the hand by approximately 45 degrees: β_{i+1} = 90 degrees – measurement of the rotation angle level 2, β_{i+2}=135 degrees – angle measurement level 3 and β_{i+3} =180 degrees – measurement of the rotation angle level 4. For this data extraction mode a 45.6% rotation gesture recognition accuracy was obtained, because confusions are made between the data pertaining to a level to another level.

2.1.2. Mode 2

For the 2nd gesture-describing data extraction mode the starting point for each level is different. Thus the users perform in turns the hand rotation gesture, starting from different positions of the hand for each level. The users will perform pronation and supination movements for every single level. After training the neural network and the text data of the .csv files an accuracy of 74.3% was obtained. This is much better than the first mode because we no longer have the same starting point for each level. However, for better accuracy certain filtering's must be performed so as to eliminate the level confusion data.

2.1.3. Mode 3

In the 3rd gesture-describing data extraction mode a data filtering is performed for each level so that each level will be described differently and the hand rotation starting point is no longer decisive for the gesture detection accuracy. Every hand rotation gesture for

each level is performed up to a maximum level where the user can no longer perform it (the pain threshold). For the level 1 of the rotation gesture the user performs a rotation movement. The maximum rotation angle on the x axis of the hand is memorized and when the user performs the rotation for level 2 only the data which are greater than the specific maximum angle of level 1 will be introduced in the database. This process will be repeated until the user manages to rotate the hand and go through all the levels. This data extraction method had the highest performance, achieving an accuracy of 96%.

3. Conclusions

The current paper presents a new gesture detection method improving the accuracy for hand recovery after injury using the Leap motion sensor and machine learning techniques. Using different data extraction modalities describing the hand rotation gesture - pronation-supination movement – and using as support the open access platform Tensorflow we achieved a 96% accuracy. The 3rd extraction modality proved to be the most efficient, where the data filtering was done for each level for the palm rotation x axis. We divided the gesture in 4 levels to match them with the degrees of injury due to the fact that an injury limits the rotation depending on the severity of the injury. Using the 3rd modality for the data extraction each level will supply the maximum angle for each patient/user that will extend the movement until reaches the pain threshold. For a future accuracy improvement we will use for data filtering besides the maximum angle on the x axis, also the maximum angles on the y and z axis for each of the 4 levels.

As future developments we will train the neural network for different new gestures. We will compare the efficiency and the quality of gesture detection with the classical one using the mathematical formulas with distances and surfaces.

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Using Big Data to Uncover Patient Determinants of Care Utilization Compliance in a Student Dental Clinic

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Abstract. This study aims at assessing the relationship between social determinants of health (SDH) and dental care utilization compliance in a student dental clinic. Electronic dental records (EDR) were queried based on visit codes and evaluated using descriptive and inferential statistics, and binary logistic regression. Overall, characteristics of 16,474 visits were analyzed to identify potential predictors of appointment compliance. Factors affecting compliance with treatment plans prescribed at comprehensive care visits were identified in a cohort of 6,105 patients. Determinants of compliance with a comprehensive care visit following triage visits were analyzed in a cohort of 5491 patients. Results indicated that certain patient characteristics were associated with either increased or decreased compliance with dental care utilization. We concluded that EDR can be instrumental in identifying patterns of care utilization and determinants of patient compliance based on SDH.

Keywords. Electronic dental record, care utilization, social determinants

1. Introduction

Many psychosocial determinants of oral health have been proposed and researched, but the precise relationship that they have with dental care utilization is complex and remains largely ill-defined [1-5]. Utilization of data from electronic dental records to support public health research and initiatives has been proposed [6]. However, minimal research currently exists which utilizes documentation of social history in electronic dental records. It is proposed that implementation of this type of documentation and evaluation of the relationships between psychosocial history and dental care utilization could lead to improved oral healthcare outcomes in the future.

2. Methods

The electronic dental record (EDR) system AxiUm at Columbia University College of Dental Medicine in the city of New York was used to generate an analytical data set

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comprising visits made by adult patients between November 2016 and June 2018. The resulting dataset included demographics, visit history, and self-reported patient survey comprising 147 questions documented in a section of medical history form of the EDR.

Descriptive statistics, chi-squared tests, and logistical regression analyses were carried out to study the relationship between social determinants of health (SDH) and dental care utilization compliance in a student dental clinic. To analyze patient compliance with treatment plans prescribed at comprehensive care visits, a dataset of 6105 patients who underwent a comprehensive care evaluation based on the visit codes (D0150 or D0120) was generated which included all planned and completed procedures from treatment plans prescribed at comprehensive care visits with dates and provider information for the comprehensive care visit. High compliance with a treatment plan was defined as completion of at least 75% of the prescribed procedures. To assess patient compliance with a comprehensive care visit following triage visits, we analyzed a dataset of 5491 patients who underwent a triage visit based on the visit code D0140T which included dates of a triage visit and a closest (if any) comprehensive care visit that followed the triage visit. Characteristics of 16,474 scheduled visits were analyzed to identify potential predictors of patient appointment compliance which was coded as kept or not kept with latter including both cancelled and failed visits. For each of the three study cohorts, potential predictive features were chosen by identifying characteristics that were significantly different between high compliance (≥75%) and low compliance groups based on chi-squared test for categorical variables and ANOVA for continuous variables. These variables were then used in stepwise logistic regression models which resulted in the final set of predictive features for treatment plan compliance model #1 (D0150 or D0120), model #2 for compliance with comprehensive care visit after triage (D0140T), and appointment compliance model #3 (AC).

Table 1. Patient socio-demographic and appointment information

	D0120 or D0150		D0140T		AC	
Variables	**N=6105**	**%**	**N=5491**	**%**	**n=16474**	**%**
Sex						
Female	3864	63.3%	3525	64.2%	10208	61.9%
Male	2241	36.7%	1966	35.8%	6266	38.1%
Ethnicity						
African American	453	7.4%	447	8.1%	1439	8.7%
Asian	93	1.5%	69	1.3%	280	1.7%
Caucasian	410	6.7%	370	6.7%	1054	6.4%
Hispanic	3013	49.4%	2912	53.0%	8050	48.9%
Other	2136	35.0%	1690	30.9%	5651	34.3%
Compliance						
High (≥75%)	2255	36.9%	1926	35.1%		
Low (<75%)	3850	63.1%	3565	64.9%		
Appointment						
Cancelled					1410	8.6%
Failed					2391	14.5%
Kept					12673	76.9%

D0120 or D0150=comprehensive care cohort, D0140T=triage cohort, AC=appointment compliance cohort, N=number of participants, n=number of appointments

Table 2. Binary logistic regression models for the compliance with treatment plan (D0120 or D0150) and compliance with comprehensive care visit after triage (D0140T)

Dependent variable	**D0120 or D0150 (N=6105)** *high compliance (≥75%)*				**D0140T (N=5491)** *high compliance (≥75%)*			
Variables in the Equation	χ^2	**p**	**OR**	**p**	χ^2	**p**	**OR**	**p**
Age	39.6	**	0.994	**				
D0120 or D0150(1)	71.019	**	0.591	**				
Predoctoral dental student providers	145.187	**	3.187	**	12.577	**	0.773	**
Emphysema	4.102	*	0.324	**				
Radiation Treatment	6.388	*	1.729	*				
Technical / Vocational training	5.319	*	1.527	*				
A little uneasy	5.671	*	0.800	*				
Recall or Active					183.787	**	0.329	**
Do you smoke or use any form of tobacco products now or in the past?					27.274	**	0.720	**
Narcotics					9.643	**	0.166	*
Are you taking birth control pills?					6.966	**	1.402	*
Have you ever had orthodontic treatment (worn braces)?					16.136	**	1.288	**
Do you often have toothaches?					24.162	**	0.667	**
Parent(s) / Guardian(s)					22.462	**	1.498	**
Anxious					12.732	**	0.677	*

χ^2=chi-squared value, p=statistical significance, OR=odds ratio, **: p<0.01, *p<0.05, N=number of patients

3. Results

Patient socio-demographic and appointment information is provided in Table 1 which was comparable across all three patient cohorts used for analyses. High compliance with treatment plans (≥75% of prescribed procedures) was found in 36.9% of patients who underwent a comprehensive care evaluation (CCE). CCE visit followed a triage assessment in 35.1% of patients seen for a triage visit. Among 16,474 scheduled visits, 76.9% were reported as 'Kept,' 8.6% - 'Cancelled,' and 14.5% - 'Failed.'

With over 150 initial characteristics, application of chi-squared test and ANOVA reduced dimensionality for the models #1-3 to 18, 39, and 43 features, respectively. Application of stepwise logistic regression further reduced dimensionality of the models as follows: (#1) age, visit type (D0120 or D0150), predoctoral dental student providers, emphysema, radiation treatment, technical/vocational training, and being uneasy with the treatment plan completion, (#2) predoctoral dental student providers, recall or active, use any form of tobacco products now or in the past, narcotics, taking birth control pills, history of orthodontic treatment, frequent toothaches, Patent(s)/Guardian(s), and being anxious for the follow-up with comprehensive care visits after the initial triage visit, and (#3) sex, ankle swelling, being pregnant, history of dental extractions, frequent toothaches, swelling of mouth or jaws, spouse/partner (only), child/children (only), technical/vocational training, postgraduate degree, unreliable transportation, lack of money/insurance coverage, being relaxed, tense, and anxious. Tables 2 and 3 present results from chi-squared tests and odds ratios from the logistic regression models.

Table 3. Binary logistic regression model for appointment compliance (kept=1; failed/cancelled=0)

	AC (n=16474)			
Dependent variable	***Appointment was kept***			
Variables in the Equation	χ^2	**p**	**OR**	**p**
Sex (male=1)	13.829	**	1.111	*
Do your ankles swell?	5.277	*	0.843	*
Are you pregnant?	7.967	**	1.898	**
Have you ever had dental extractions?	9.004	**	1.118	**
Do you often have toothaches?	12.299	**	1.149	*
Do you have any swelling of your mouth or jaws?	46.300	**	1.647	**
Spouse/Partner (Only)	9.916	**	1.219	*
Child/Children (Only)	7.578	**	0.853	*
Technical / Vocational training	14.729	**	1.682	**
Postgraduate Degree	6.933	**	1.288	*
Unreliable transportation	14.404	**	0.646	**
Lack of money/insurance coverage	22.184	**	1.305	**
Relaxed	9.330	**	0.894	*
Tense	13.079	**	1.294	**
Anxious	8.080	**	1.201	*

AC=appointment compliance, χ^2=chi-squared value, p=statistical significance, OR=odds ratio, **: $p<0.01$, *$p<0.05$, n=number of scheduled appointments

4. Discussion

Significant associations between specific individual risk factors and dental care utilization compliance were observed in this study. Results such as these could be used to identify patients who may be at risk for lack of follow-up and contribute to improved dental care delivery in the future [7]. Collection and use of information stored in electronic dental records shows promise in evaluating the relationship of psychosocial determinants of health in the utilization of dental services. This study indicates that future research could benefit from the implementation of comprehensive psychosocial history questionnaires and analysis of electronic dental records.

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Mining Electronic Dental Records to Identify Dry Socket Risk Factors

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Abstract. The goal of this study was to investigate risk factors for developing dry sockets in patients after dental extractions. Data were collected directly from electronic dental records (EDR) and were utilized for selecting dry socket cases and controls to conduct a nested case-control study. Case-control matching was based on sex, age range, maxilla-mandible location, and anterior-posterior location. From 83 self-reported health survey questions, 7 questions were found to have predictive potential based on a significant chi-squared test. Stepwise conditional logistic regression showed a statistically significant association between the development of dry socket and a history of serious illness (OR=1.4; 95% CI:1.02-1.95), cancer (OR=2.6; 95% CI:1.13-5.83), and frequent mouth sores (OR=1.9; 95% CI:1.09-3.33). These results corroborated previous reports on potential involvement of impaired immune response in dry socket development. EDR may be an important source for uncovering predictive factors that play a role in prevention and management of oral health.

Keywords. Dry sockets, electronic dental record, case-control study

1. Introduction

Alveolar Osteitis (AO), also known as Dry Socket (DS), is one of the most common complications following a tooth extraction [1]. It is diagnosed by the appearance of an empty healing socket, a missing blood clot, or exposed bone in the socket, with the patient reporting an increase of postoperative pain one to three days after an extraction [2]. These findings can be caused by the dislocation or dissolution of the blood clot in the extraction socket [3]. Its overall incidence has been reported with variability and has been found to be as high as 30% for 3rd molar extractions [4].

The etiological factors contributing to DS are not readily agreed upon, nor are the signs and symptoms present upon diagnosis. Multiple risk factors have been suggested for the development of AO, but the lack of systematic evidence prevents the implementation of effective prevention strategies in routine dental care [5]. Much of the data available on treatment and prevention is empirical and not evidence-based [3-5]. The goal of this study is to utilize data collected in the electronic dental records (EDR) at Columbia University College of Dental Medicine (CDM) to identify the prevalence

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and potential predictors of AO. No similar project has been done using data from a dental school clinic to assess the DS risk factors.

2. Methods

2.1. Data Source

The data were derived from electronic dental records of patients seen at Columbia University's College of Dental Medicine (CDM).

2.2. Data Collection and Analysis

This study retrospectively analyzed EDR of patients with dry sockets diagnosed at CDM between August 2011 and May 2017. We ran a query on the CDM database for EDR containing either the diagnostic code Z1820, or the phrases "dry socket" and "alveolar osteitis," or containing a variation of those two phrases. The queries were conducted in the Oracle database containing data from axiUm, an EDR system (Exan Group, Las Vegas, NV, USA). To conduct a case-control study, 274 cases of dry socket were matched to 548 cases of non-dry socket. They were matched based on sex, maxilla-mandible, anterior-posterior, and age ranges. A case-control study was selected due to the known gaps in documentation in EDR [6] and successful use of case-control design in previous risk factor studies based on EDR data [7].

After selecting the final 274 pairs, we analyzed 83 self-reported health survey questions answered by the patients at their recent clinic visit to compare frequencies between cases and controls using the chi-squared test. The self-reported questions were related to patients' medical histories, diseases, medications, pain, and other factors. Based on this comparison, potential predictive factors for dry socket development were selected. Then a stepwise conditional logistic regression was carried out with these predictive factors as independent covariates and dry socket as the dependent variable. The forward stepwise selection was used with entry criteria based on the significance of the score statistic and removal criteria based on the probability of a likelihood ratio statistic (entry: $p \leq 0.05$, removal: $p \geq 0.10$).

3. Results

EDR analysis identified 274 case observations in which dry socket occurred and paired them with 548 control observations in which dry socket did not occur. The matched variables included sex, extraction sites, and age range as shown in Table 1.

A chi-squared test was performed separately for each of the 83 health survey questions. The cross-correlation, chi-squared statistic, and odds ratio analysis were used to identify potential predictive factors of dry socket. In the univariate analysis, answers to seven questions were found to be significantly different between cases and controls: "*Have you had any serious illness, operation, or been hospitalized in the past 10 years?"* (Chi-squared test statistics (χ^2)=6.307, statistical significance (p)=0.012, odds ratio (OR)=1.484); *"Do you have any Allergies?*" (χ^2=4.359, p=0.037, OR=1.483); *"Sinus Problems (Sinusitis)"* (χ^2=5.154, p=0.023, OR=1.876)' *"Cancer history"* (χ^2=6.953,

p=0.008, OR=2.897); *"Have you had any serious trouble associated with any previous dental treatment?"* (χ^2=4.330, p=0.037, OR=2.505); *"Do you have frequent sores in your mouth?"* (χ^2=6.508, p=0.010, OR=2.030); and *"Hepatitis history"* (χ^2=6.125, p=0.013, OR=4.763). These seven questions were chosen among the 83 health survey questions as predictive factors of dry socket in the conditional logistic regression model (Table 2). The other factors did not show statistically significant difference.

Table 1. Patient characteristics in control and case groups

			Dry Socket		
			No (n=548)	Yes(n=274)	Total
Sex	Male	Count	182	91	273 (33.2%)
	Female	Count	366	183	549 (66.8%)
Maxilla-Mandible Location	Maxilla	Count	122	61	183 (22.3%)
	Mandible	Count	426	213	639 (77.7%)
Anterior-Posterior Location	Posterior	Count	534	267	801 (97.4%)
	Anterior	Count	14	7	21 (2.6%)
Age Range	≤19	Count	20	10	30 (3.6%)
	20-39	Count	282	141	423(51.5%)
	40-59	Count	146	73	219 (26.6%)
	≥60	Count	100	50	150 (18.2%)

Table 2. Risk factors significantly associated with dry socket

			Dry Socket					
			No	Yes	Total	χ^2	p	OR
Have you had any serious illness, operation, or been hospitalized in the past 10 years?	No	Count	395	174	569	6.307	0.012	1.484
		%	72.1%	63.5%	69.2%			
	Yes	Count	153	100	253			
		%	27.9%	36.5%	30.8%			
Do you have any Allergies?	No	Count	464	216	680	4.359	0.037	1.483
		%	84.7%	78.8%	82.7%			
	Yes	Count	84	58	142			
		%	15.3%	21.2%	17.3%			
Sinus Problems (Sinusitis)	No	Count	519	248	767	5.154	0.023	1.876
		%	94.7%	90.5%	93.3%			
	Yes	Count	29	26	55			
		%	5.3%	9.5%	6.7%			
Cancer History	No	Count	538	260	798	6.953	0.008	2.897
		%	98.2%	94.9%	97.1%			
	Yes	Count	10	14	24			
		%	1.8%	5.1%	2.9%			
Have you had any serious trouble associated with any previous dental treatment?	No	Count	539	263	802	4.330	0.037	2.505
		%	98.4%	96.0%	97.6%			
	Yes	Count	9	11	20			
		%	1.6%	4.0%	2.4%			
Do you have frequent sores in your mouth?	No	Count	520	247	767	6.508	0.010	2.030
		%	94.9%	90.1%	93.3%			
	Yes	Count	28	27	55			
		%	5.1%	9.9%	6.7%			
Hepatitis History	No	Count	545	267	812	6.125	0.013	4.763
		%	99.5%	97.4%	98.8%			
	Yes	Count	3	7	10			
		%	0.5%	2.6%	1.2%			

χ^2=chi-squared value in case-control frequency comparison; p=statistical significance, OR=odds ratio in conditional logistic regression

After identifying potential parameters, a conditional logistic regression was conducted using a stepwise procedure to select the final set of factors that best predict dry socket. The stepwise conditional regression analysis, as shown in Table 2, indicated that the best predictive model in this study population comprised three of the seven variables from the chi-squared test. The final risk factors were as follows: "Have you had any serious illness, operation, or been hospitalized in the past 10 years? (OR= 1.410, 95% confidence interval for OR (95%CI)=1.020~1.949)," "Cancer (OR=2.564, 95%CI=1.129~5.827)," and "Do you have frequent sores in your mouth? (OR=1.904, 95%CI=1.090~3.327)". These risk factors were significantly associated with DS in addition to the parameters used for case-control matching. Sex, age range, and extraction location were used for matching and could not be entered into conditional logistic regression.

4. Discussion

There was a statistically significant association between dry socket and history of serious illness, hospitalization, cancer and frequent sores in mouth. A possible factor which links these three conditions together to dry socket is immune regulation. Cancer suppresses the immune system by activating inhibitory pathways which enables them to evade detection [8]. A recent theory [9] suggests DS is caused by the death of the osteoblasts lining the extraction socket, which leads to increased fibrinolytic factors around the blood clot, causing dissolution and destruction of the clot. Based on this theory of DS's apparent connection to the immune system, in patients with immune dysregulation, the immune factors required for clotting may not reach the socket, or may not function optimally, increasing these patients' risk of developing a DS post extraction. Further studies employing broader spectrum of risk factors and methodologies are warranted [10].

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A Hybrid Recommender System to Guide Assessment and Surveillance of Adverse Childhood Experiences

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Abstract. Adverse Childhood Experiences (ACEs) are negative events or states that affect children, with lasting impacts throughout their adulthood. ACES are considered one of the major risk factors for several adverse health outcomes and are associated with low quality of life and many detrimental social and economic consequences. In order to enact better surveillance of ACEs and their associated conditions, it is instrumental to provide tools to detect, monitor and respond effectively. In this paper, we present a recommender system tasked with simplifying data collection, access, and reasoning related to ACEs. The recommender system uses both semantic and statistical methods to enable content and context-based filtering.

Keywords. Recommender System, Adverse Childhood Experiences, Semantic Technologies

1. Introduction

Adverse Childhood Experiences (ACEs) are negative events or situations that a child may encounter. They include a wide range of conditions such as neglect, abuse and some challenging family situations (incarceration, mental illness, and so on). Systematic studies of ACEs began more than twenty years ago [1]. Over the years, their consequences in terms of social and health outcomes and behavior have been investigated and the results paint a dire picture. The U.S. Center for Disease Control and Prevention (CDC) has shown that ACEs are one of the root causes of several physical, social, cognitive and emotional troubles [2]. Almost half of U.S. children have suffered from at least one ACE [3]. However, many questions remain concerning the causal pathways as well as the best methods to detect, prevent and handle ACEs. In particular, historical information is difficult to obtain. Most early studies focused on adults, years after the occurrence of ACEs, and presented a retrospective picture of the situation [4], while contemporaneous, longitudinal studies of children are beginning to provide enlightening results. In a similar way, it is difficult to evaluate the effectiveness of the relevant interventions and no current guideline exists to decide what intervention is the most appropriate for a given situation or decide between medical versus community-based approaches [5].

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Herein, we will present a recommender system in the context of a clinical visit by the parent of a young child, similar to a current study under the Family Resilience Initiative at Le Bonheur Children Hospital in Memphis, TN [6]. One of the goals of the Le Bonheur study is to gather information about ACEs in order to improve the state of the art of surveillance, however, the primary objective is to improve the quality of life for visiting families and to help them overcome their relevant problems. During a typical clinic visit (e.g. regular pediatric care), parents are offered the option to participate in the study by answering questions on the ACEs that their children may have been subjected to, on their social situation and on the emotional and social development of the children. The parents also describe what their main concern is. Depending on the answers, and the experience of the interviewer, the families are directed towards the resources expected to offer the most appropriate interventions. After the visit, the interviewers follow up to see if the problems have been addressed in a satisfactory manner and if new issues have surfaced.

We will discuss the architecture, application and expected issues for an ACEs recommender system. In *Methods,* we describe the sources of data and causal relationships used by the recommender system. In *Application,* we use examples to illustrate the recommender system's functioning. Finally, we discuss our future work and conclude in the *Discussion*.

2. Methods

To find the most appropriate intervention, the interviewers need to have knowledge about the families themselves, the family's neighborhood, the children's ACEs and their health consequences, available resources, etc. While the interview provides information pertaining to the families, the rest of the information is distributed through various medical, non-governmental and governmental data sources that use different formats and vocabularies and work at different granularities. For instance, in the hospital (medical data) a person is likely to be described as a 'patient' and their associated information will include basic demographic information in addition to diagnoses and treatments, while in a court document (government data) they might be a 'defendant' and only have basic demographic information. In order to use all this data in a coherent way a tool to integrate every data source into a uniform knowledge base is needed. We developed the ACEs ontology for this purpose [7, 8]. An ontology defines a lexicon to describe entities (e.g., a person, a clinic, abuse), the relationship between entities (e.g., Alice is the parent of Bob, Charles suffers from Emotional Neglect), and axioms describing the logical connections between concepts (e.g., physical abuse is a kind of abuse, someone's sister is their female sibling). The ontology can express every piece of knowledge coming from the various data sources in a common framework independent of its origin.

As our ultimate goal for the recommender system is to help make intervention decisions, a way to reason about causes and consequences is required. For this purpose, the recommender system needs access to some kind of causal knowledge [9]. The causal knowledge will be used to make inferences from established data to make recommendations. Causal knowledge should represent commonly agreed upon causal relations and thus are interpreted through the ontology. They may also be modified by the recommender system depending on the data that is received.

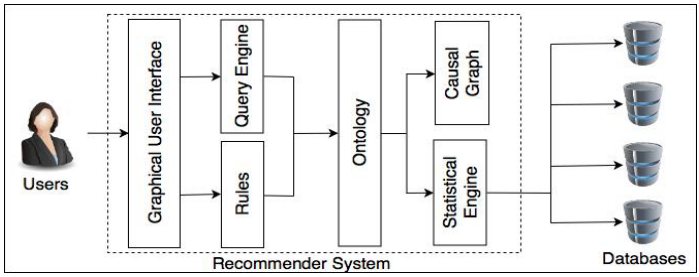

Figure 1. The architecture of the recommender system.

3. Application

In our recommender system (Figure 1), interviewers ask questions of parents to gather relevant ACEs data. Currently, in the clinical setting, the questions are fixed for a uniform data set. However, part of the task of the recommender system is to help choose which questions to ask. The recommender system will use causal paths to help direct the exchange. For instance, if there is a direct path from "Feeling that the neighborhood you live in is unsafe" to "Risk of the child being a witness of a violent crime", the answer to the question "Do you think your neighborhood is safe?" will prompt different follow-up questions. These causal paths can be used to generate rules on which questions to ask, how and when. For instance, the question "Is your child bullied at school?" is skipped when dealing with children that are not school-aged. The rules used by the recommender system, as well as the causal knowledge that some rely upon, will be updated during the execution of the recommender system. Interviews and new studies will provide new information and modify the knowledge base. Additionally, when new data is added, statistical methods can be used to learn new causal relations between concepts. The ontology also plays a role as it can propose to extend the causality relation to a more general concept, e.g., knowing that "Living with someone with a drug abuse problem" is connected to the risk of "Physical Abuse" one may want to try to see if it is connected to "Abuse" in general; or restricting it to a more specific concept, e.g., knowing that there is a link between "Neglect" and "Suicidal Ideation", one may want to see if the link is similar for all types of neglect. The recommender system can update the rules automatically when new data is added, when it is prompted to test a theory by the user or when a choice of questions seems to indicate that such a theory exists in the mind of the user.

The recommender system is also tasked with helping decide how to intervene. Here the ontology can be used to classify the issues and the available resources. By incorporating the results of follow-up interviews and meetings, it is also possible to evaluate the effectiveness of each intervention and thus to optimize the response.

4. Discussion

We have presented a recommender system that is tasked with helping ACEs surveillance experts. It uses rules built from semantic knowledge, extracted from an ontology, and previously acquired causal paths to help gather, access and reason on the data. Furthermore, by using statistical methods, it also updates the causal knowledge

and the rules in order to better represent the knowledge when new information is acquired. Our recommender system is based on an intervention currently taking place where issues that the recommender system is trying to address are raised.

Yet, our recommender system is still work-in-progress and there are significant theoretical and practical difficulties that need to be overcome. First, the idea of using intertwined semantic and statistical reasoning is quite new and will require further work to make it efficient and trustworthy. Second, the specific qualities of the data that need to be considered in the context of ACEs add complexity, e.g. medical and certain social (i.e., criminal history) data need to be protected. This means that recommender systems need to work with information at various granularities with as little loss of precision as possible. Finally, ACEs are a sensitive subject. In order to obtain straight and truthful answers, the interviewers need to build a rapport with the families. The order of the questions, their number and the way they are asked have a tremendous impact. While this seems to be a clear indication that a recommender system would be a valuable tool to optimize these interactions, interviewers have said that using a computer to note interview answers, instead of relying on their memories or even taking notes on paper, feels less personal and tends to yield inferior results. Thus, significant work on the user interface is needed to improve the interview experience.

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Applied Network Science for Relational Chronic Disease Surveillance

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Abstract. Chronic diseases and conditions are the leading cause of death and disability in the United States. The number of people living with two or more chronic conditions has increased in the last decades and is expected to continue to rise over the upcoming years. Yet, traditional chronic disease surveillance practices have been specialized for a specific symptom or a single health condition. To better understand the complication and complexity of multimorbidity in chronic diseases, this paper suggests the use of network science for multimorbidity network surveillance (MNS). We discuss why the relational perspective in surveillance is critical and how network science can help and be integrated into surveillance and public health practice.

Keywords. Applied Network Science, Relational Chronic disease Surveillance, Multimorbidities, Population Health, Health Informatics.

1. Introduction

The global prevalence of chronic diseases, especially in developing countries, is increasing. Chronic diseases and conditions are the leading causes of death worldwide [1] and in the United States. 31.5% of the population in the U.S. experience multiple long-term disorders [2, 3]. The number of people who has two and more chronic disease has grown in the last decades worldwide [4-6]. As with population aging, the prevalence of multiple chronic conditions becomes more pronounced and increased and in the population of 65 years and older, 27.6% have two chronic conditions and 33.2% have three or more chronic conditions [5]. Certainly, having multiple chronic conditions is qualitatively different in nature from living with one chronic condition [7] and the outcomes of co-existing diseases vary not only in their mortality consequences but also in life quality of patients, their health plans and health care [8]. Multimorbidities are associated with a wide range of disadvantages; e.g. elderly populations with multiple chronic conditions have a shorter life expectancy than their peers with a single disease [8, 9]. Traditional disease surveillance systems have been specialized for specific symptoms or a single health condition. Therefore, they might underestimate, if not neglect, the complications, and the co-prevalence of multiple chronic conditions. This approach particularly can be problematic given the fact that chronic conditions are often long-lasting or permanent. Therefore, whether tentative or persistent, a chronic condition inevitably co-occupies with other diseases or symptoms. To avoid this pitfall, it is

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advised to widen the scope of surveillance systems to include a broader range of chronic diseases and health outcomes in our studies.

There is a kin affinity of the two fields, network science, and health surveillance, which seems to have been unduly ignored and under-labored particularly in laying out the basic benefits of merging the two. This paper articulates the fundamental benefits of merging network science and chronic disease surveillance by discussing why relational perspective is critical when it comes to public health surveillance and how network science can help.

2. Applied Network Science in Medicine and Healthcare

One of the most distinctive aspects of network science is the ability to measure the relational composition of the objects in a network. Unlike an individualistic approach, the network analysis takes relational characteristics at its core focus. For example, not only it investigates one specific symptoms or disease prevalence or progress, but also it enables us to consider other symptoms and diseases together, i.e. overall configurational changes such as density and centrality of each disease or morphological changes of the organic whole. If we treat disease as a single independent entity, we are at peril of ignoring the underlying organism. Human metabolism is interconnected and the underlying metabolic connections yield a distinctive network typology among disease comorbidity [9]. The network science approach help to understand and study not just a single disease in isolation but the organic network of diseasome [8].

The application of network science to medicine and healthcare can be seen at the individual and population levels. For example, multimorbidity network surveillance helps us to study a disease, with its underlying complex mechanism, in a population (for public health surveillance) or in an individual (for personalized medicine). Over the last decade, there has been a growing interest in this area resulting in several multidisciplinary research efforts [8, 10-12]. Links (relationships) can be induced between two or more concurring diseases present in one biological unit, human being, or a geographical unit. Two mode network analysis is a heuristic tool converting ego-level information to the object-oriented overall network, as shown in Figure 1.

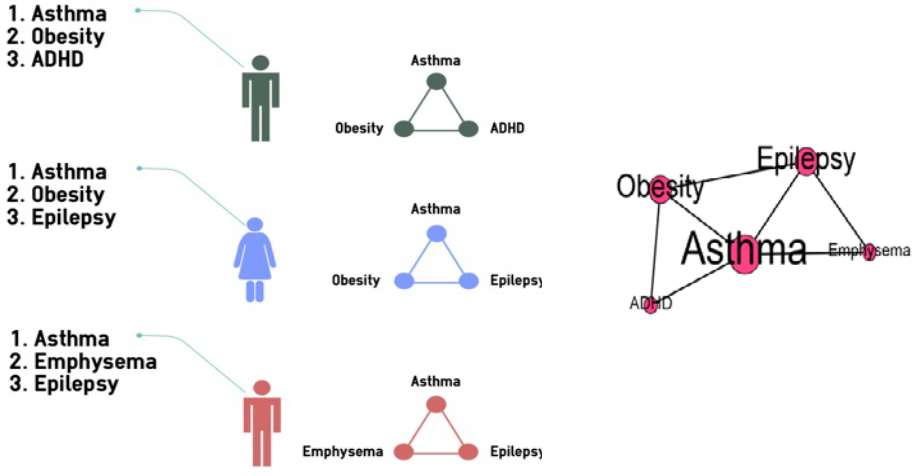

Figure 1. Extracting a symptom network from three patient data.

Nodes in the graphs represent different diseases or symptoms. The lines between nodes indicate the co-observation of the two diseases in a patient. On the left-hand side, in the ego level multimorbidity network, the colors represent different individuals at the micro level comorbidity network. On the right-hand side, the relational configuration extracted from the three individuals is shown among different diseases. The sizes of the nodes in the comorbidity network are calculated by each disease's relative connectedness and the centrality of the disease in the macro network. Given the actual number of diseases and ever-growing patient population, multimorbidity network surveillance (MNS) can be computationally challenging, yielding high dimensional network spaces. However, with increased computational power, processing speed, and storage capacity nowadays the real-time analysis of multimorbidity networks of general populations have become feasible.

Using the MNS method one can first trace how commonly certain chronic conditions/symptoms are observed in a group of people or in one geographical unit simultaneously and longitudinally. This helps to better understand the relations between different diseases and conditions in a population and check if there is an affinity between the diseases and whether those affinities are unique to a certain population/region. Second, once the overall multimorbidity networks, aggregated from the general population, were constructed, one can identify where a patient stands within the general multimorbidity network distribution. This information then will be used to suggest a better-designed management plan and medication options depending on the specific multimorbidity pattern of the patient. Furthermore, if we observe an extremely unique multimorbidity pattern from newly admitted patients, this can help medical practitioners to detect epidemic outbreaks from the early onset. Also, tracking the dynamics of connections helps to understand the influence of these relational patterns on other subsequent health outcomes.

3. Toward Relational Chronic Disease Surveillance

Chronic disease surveillance aims "to recognize clusters of cases to trigger interventions to prevent transmission or reduce morbidity and mortality [13]". Therefore, by its nature, chronic disease surveillance, using both data collection and information distribution networks, has a strong relational dimension.

Understanding the interconnection between different chronic diseases is a first step towards designing, implementing and delivering efficient health interventions. Chronic health surveillance can be further benefitted from the relational perspective with geo-parsed comorbidity networks [14]. Specificity can be further articulated with the assistance of network analysis and thus induce localized interventions. For example, if a population has been detected to have a sudden increase in the complication of obesity, arthritis, and asthma, further investigations might be required to check the presence of hazardous environmental factors in their neighborhood.

4. Conclusion

The increased multiple chronic disease prevalence is quite alerting. The distribution of multiple comorbidities is closely related to socio-economic deprivation and geospatial characteristics [15]. Prevalence of chronic disease and multimorbidity are not only a

heavy burden for the suffering individuals but also cumbersome burden for the government and society as well. In addition to losing human capitals in society, there is an unavoidable financial cost associated with them. Hence health care system has to accommodate the changing scene relational chronic disease surveillance can help us to properly prevent the calamity, rather than fixing them *a posteriori*.

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Improving Patient Safety by Reducing Falls in Hospitals Among the Elderly: A Review of Successful Strategies

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Abstract. Patient safety is a main dimension of healthcare quality, considering minimizing, reporting, and analyzing incidents that often lead to avoidable adverse effects. Patient falls among the elderly is a common challenge. To explore strategies for preventing patient falls, a review of literature and a qualitative analysis was conducted. Five strategies were identified: Patient and Staff Education; about risk factors and best practices, Patient Exercise; strengthening body muscles and improving balance, Diagnosis and Treatment of Medical Conditions; vision and balance, Enhancing Surrounding Environment; beds, flooring, rails, and passageways, and Using Information Technology; monitor, alarm, and give feedback on falls and risk situations. Many of the multicomponent programs proved to be cost-effective, considering the extended stays, increased complications, and higher costs of caring for injured patients. The utilization of innovative approaches of big data mining to explore reasons, circumstances of falls, and ways of reducing them are recommended through further research.

Keywords. Patient Safety, Patient Falls, Elderly Patients, Strategies, Hospitals.

1. Introduction

Among the most commonly encountered patient safety challenges is patient falls, especially in the elderly, leading to chronic pain, functional deterioration, physical disability, and death. A patient fall is defined as an unplanned descent to the floor with or without injury to the patient [1]. Hospitalization increases the risk of patient fall because of unfamiliar environment, diseases, and treatments. Elderly patients are three times more likely to fall in the hospital and when this happen, they are over ten times more likely to suffer an injury [2]. Almost 45% of patient falls among elderly lead to some sort of injury and 10% of these lead to serious injuries that end up with a mortality. Falls usually increases the patient's length of stay in the hospital, increases the discharge to a long-term nursing institute, and significantly increases the costs of the healthcare. The operational costs for falling elderly patients, with serious injuries, are US$13,500 more than regular patients and they stayed 6.3 days longer. In addition to the physical harm and costs, falls may also contribute to emotional injury and decreased quality of life [3]. There are two main measures for monitoring and reporting patient falls; the rate of the total patients falls, and the rate of injurious patients falls per

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1000 inpatient days [1]. Falls input measures include fall incidents, characteristics of falling patients, falls circumstances, and categories of falls [4]. Process measures include the utilization of incidents reporting systems and their usability, acceptance and compliance [5]. Outcome measures include indicators of serious events after falls, such as fractures, delayed patient discharge or patient's length of stay, estimated costs of patient falls, in addition to measures quality of life following falls [6]. The main objective of this study is to explore effective methods that could form successful strategies for preventing patient falls in hospitals among the elderly.

2. Methods

A review of literature was conducted through searching MEDLINE, EMBASE, CINAHL and Google Scholar for studies including the concepts of Improving, Patient Safety, Preventing, Patient Falls, Elderly. Studies published in English over the last ten years reporting patients 65 years and older were retrieved. Out of 381 identified studies, 34 found to be eligible for review, after screening titles and abstracts for relevance and excluding non-eligible studies by examining full text of the retrieved studies. Inclusion criteria focused on studies describing specific strategies and recommendations for preventing and reducing patient falls among the elderly. Qualitative analysis was used to classify the main strategies of preventing and reducing patient falls.

3. Results

We identified five main strategies for preventing and reducing patient falls among the elderly. 1) Patient and Staff Education; using various approaches and methods to improve awareness of risk factors and follow best practices, 2) Patient Training and Exercise; to strengthen the body muscles, improve balance, and minimize the risk of fall, 3) Diagnosis and Treatment of Predisposing Medical Conditions; which could interfere with vision or vestibular balance function, 4) Enhancing the Surrounding Environment; such as beds, flooring, rails, and passageways, and 5) Using Information Technology; to monitor, alarm, and give feedback on falls and risk situations. Figure 1 shows summary of the strategies for preventing and reducing patient falls.

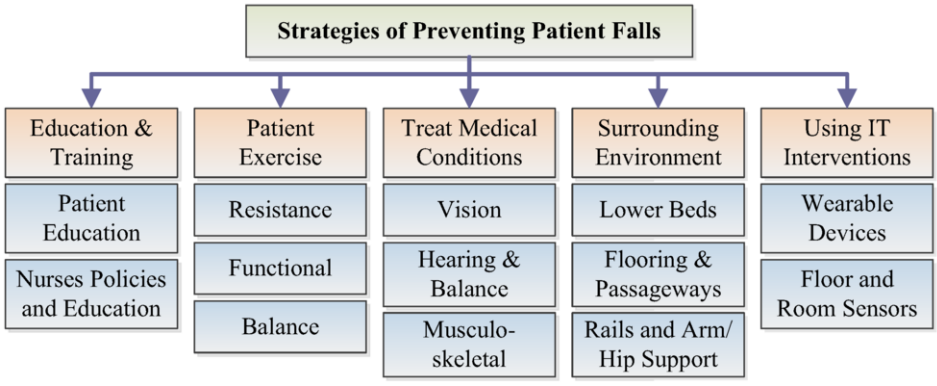

Figure 1. Summary of Strategies for Preventing Patient Falls

4. Discussion and Conclusion

First Strategy: Patient and Staff Education. Education is a fundamental part of falls prevention. In two Australian hospitals, the use of written and video-based educational material in addition to a follow-up by a healthcare professional, e.g. a physiotherapist, to provide information and directions at the patient's bedside proved to be significantly more effective than providing the patient with the educational material only [7]. The conduction of patient education on falls prevention becomes more crucial and effective in the preoperative phase, especially with orthopedic interventions of the elderly [8]. In many hospitals, such educational programs have been proved to be cost-effective, considering the extended stays, increased complications, and high costs of healthcare services provided for patients following falls [9]. Nurses attitude and behavior can significantly influence the success of patient falls prevention programs. Nurses needed to learn about risks of falls, how to educate patients, and what methods of falls prevention are available at their local settings and how they could best use them [10].

Second Strategy: Patient Exercise. Progressive resistance and functional training are safe and effective methods of improving the strength and muscular activity and minimizing fall related behavioral and emotional limitations in elderly patients. Patient exercise, as a single intervention, can prevent falls. Programs that contained balance training and a large amount of exercise for elderly patients had the largest effects on reducing falls. It is recommended that such falls prevention exercise should be taken by patients for at least two hours every week and should target both the general aged population as well as higher risk patients, except for those prescribed less mobility [11].

Third Strategy: Diagnosis and Treatment of Predisposing Medical Conditions. The ability to move and walk safely depends largely on the coordination of motor and sensory functions, such as the vision, vestibular balance, proprioception, and musculoskeletal functions. Therefore, it is important, as a long-term strategy of preventing falls among elderly patients, to diagnose and treat medical conditions that might affect this kind of balance and increase the incidence of falling. These medical conditions include impaired vision due to cataract, vestibular disorders affecting balance, and osteoarthritis [12]. Some older patients may experience higher incidents of falls when they are on sedatives, as these may cause reduced sensorium and impair balance. This brings to the attention the importance of reducing the dose and the close monitoring of these patients [13].

Fourth Strategy: Enhancing the Surrounding Environment. There has been a significant reduction of bed falls as well as injuries from falls after reducing bed heights in geriatric patient wards. Using arm support, rails, and padding of the floors with rubber materials to minimize slipping, in addition to lower beds, can significantly reduce the incidence of falls and the severity of the associated injuries [14].

Fifth Strategy: Using Information Technology Interventions. Wearable sensors have proved to be very useful in monitoring and analyzing the stability of patients. Accelerometers and gyroscopes are the most widespread technologies used to detect stability and balance problems. Such sensors can be placed on the trunk to evaluate both static and dynamic stability [15]. Information technology can also serve the function of analyzing the data of the falls and the associated circumstances to explore the associations between different factors. Some smart phone applications, using their built-in accelerometer and movement detection functions, enable detecting falls, outside the hospital, and starting alarms to reduce their effect. Such applications can also send data, incidents and alarms to healthcare providers instantaneously [16].

As a conclusion; many of the suggested multicomponent programs, of preventing patient falls among the elderly, proved to be cost-effective, comparing the extended stays, increased complications, and the higher costs of caring for the injured patients to the costs of caring for regular non-falling patients. However, the utilization of new approaches of big data mining and the continuous innovation of new methods for exploring the reasons of falls, circumstances and criteria of falls, criteria of the falling patients, and new ways of reducing falls are recommended through further research.

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Clinical Decision Support Systems: From the Perspective of Small and Imbalanced Data Set

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Abstract. Clinical decision support systems are data analysis software that supports health professionals' decision – making the process to reach their ultimate outcome, taking into account patient information. However, the need for decision support systems cannot be denied because of most activities in the field of health care within the decision-making process. Decision support systems used for diagnosis are designed based on disease due to the complexity of diseases, symptoms, and disease-symptoms relationships. In the design and implementation of clinical decision support systems, mathematical modeling, pattern recognition and statistical analysis techniques of large databases and data mining techniques such as classification are also widely used. Classification of data is difficult in case of the small and /or imbalanced data set and this problem directly affects the classification performance. Small and/or imbalance dataset has become a major problem in data mining because classification algorithms are developed based on the assumption that the data sets are balanced and large enough. Most of the algorithms ignore or misclassify examples of the minority class, focus on the majority class. Most health data are small and imbalanced by nature. Learning from imbalanced and small data sets is an important and unsettled problem. Within the scope of the study, the publicly accessible data set, hepatitis was oversampled by distance-based data generation methods. The oversampled data sets were classified by using four different machine learning algorithms. Considering the classification scores of four different machine learning algorithms (Artificial Neural Networks, Support Vector Machines, Naive Bayes and Decision Tree), optimal synthetic data generation rate is recommended.

Keywords. Clinical decision support system, machine learning, small data set, imbalanced data set, oversampling methods.

1. Introduction

A large part of all health-related activities is related to decision-making. Complaints and anamnesis data, physical examination findings and simple measurement values are collected during the first visit of patient. These medical data are input for the clinical decision support systems which are computer systems designed to impact clinician decision making about individual patients at the point in time that these decisions are made [1]. Data mining is well suited to provide decision support in the healthcare setting

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[2]. Usage of data mining in the field of health has created a new perspective in many respects and has also begun to accelerate decision-making processes. The main objective of data mining is to explore the correlations that are thought to contribute to the future through data masses. In other words, data mining is the creation of qualitative models that are hidden in the data, which are not very clear, previously unknown, but which are potentially effective. Qualitative models are used effectively in decision making. Establish of disease prediction models is the subject of many studies. The sample data set is expected to be large enough and balanced to obtain an accurate prediction model. Otherwise, the established model is considered to be unreliable. By the nature, many data in the medical field are small and imbalanced, so there is great difficulty in designing a clinical decision support system.

2. Small and Imbalanced Data Set

The majority class is having the highest frequency in the class distribution. The minority class is having the lowest frequency in the class distribution. Less than 10 occurrences per predictor variable is the condition of the small dataset [3]. It can be said that in a data set with two class variables, if the number of observations in the minority class is below 10, there is a small data set problem.

Small dataset learning problem is especially interesting in medical science, since the number of samples in a medical study may be very limited because of the sparseness and costs of the samples [4]. The small data set is often accompanied by an imbalanced data set problem resulting from the imbalanced distribution of observations in the class. Some problems that arise in data mining can be increased because the size of the sample data is small and imbalanced. These kinds of data sets usually generate biased results [5]. This situation is the most evident in the case of ignoring or misclassifying of minority class, focusing on the majority class.

2.1. The Solution for Small / Imbalanced Data – Distance Based Oversampling

Oversampling is a kind of synthetic data generation to increase the number of samples in the minority class [6]. In distance based oversampling methods, synthetic samples are generated by taking into consideration the k- nearest neighbor for each sample in the minority class. Synthetic data are generated throughout the continuous vectors between the nearest neighbors. Although the information gaps in the minority class are filled with synthetic data, synthetic data are distributed within the real data examples in the minority class [7].Thus, the minority class is over-sampled.

The main advantage of distance based oversampling is the production of synthetic samples considering the close neighbors instead of replicating the samples in the minority class. Methods such as ROSE, ADASYN, SMOTE, DBS, RSLS and SLS are frequently used as oversampling method in literature.

2.2. Experimental Study

The oversampling methods mentioned in 2.1 were used in the experiment. Over sampled data were classified by SVM, ANN, NB and C4.5 algorithms. The precision scores were compared for the minority class because obtaining high classification accuracy score was not very meaningful in small and imbalanced data sets.

From the UCI database, the open-access hepatitis data set was used in the experiment [7].

The general characteristics of the original data set are shown in Table 1.

Table 1. The General Characteristic of the data set

Data Set Name	Hepatitis
Number of observations	155
Number of Attributes	19
Number of Classes	2
Class Distribution	32 - 123
Benchmark Accuracy	Max. 83%

3. Experimental Setup

Original data has been rendered small and imbalanced.

1) 3 different data subsets that contained 12 observations in minority class were established. The sample dataset is referred to as DS-0.
2) In-class precision scores were calculated by running the 4 different classification algorithms (Artificial Neural Network, Support Vector Machine, Naive Bayes, Decision Tree) on 3 different data sub- sets.
3) For each data subsets, the observations of the minority class were oversampled by default values of the distance based oversampling .The oversampled dataset is referred to as DS-0'.
4) In-class precision scores were calculated by running the 4 different classification algorithms on 18 different oversampled data subsets.
5) For each data subsets (DS-0), the observations of the minority class were oversampled by 2, 3, and 4 times of the minority class in the training data set with the same distance based oversampling methods.
   The sample dataset with extra 6 synthetic data is referred to as DS-0'X2.
   The sample dataset with extra 12 synthetic data is referred to as DS-0'X3.
   The sample dataset with extra 18 synthetic data is referred to as DS-0'X4.
6) In-class precision scores were calculated by running the 4 different classification algorithms on oversampled 18 different data subsets (Refer to item 5th).

4. Experiment Result

The data set, which is formed as 12 observations in minority class, is classified by ANN, SVM, NB and C4.5 algorithms. The in-class precision scores of the minority classes of the datasets created as described in the previous section (DS-0) are presented in Table 2. Because high accuracy scores are not significant, the precision scores for the minority class are taken into account.

Table 2. In-class precision scores of the minority classes of DS-0

Classification Algorithm	**Score**
ANN	0.1904
SVM	0.0000
NB	0.3957
C4.5	0.2394

According to the results, the data set which was oversampled with SMOTE method gave the highest minority class precision in the NB algorithm, while the data set which was oversampled with SLS method gave 0 minority class precision in the SVM algorithm.

Oversampled training data sets with default values were observed to be between 3 and 10 times of the number of minority class observations. Increasing the number of the minority class by 3 to 10 was found high. For this reason, the minority class in the training data of DS-0 was oversampled 2, 3 and 4 times. The dataset with limitation of 2 times, 3 times and 4 times of the minority class observations are called DS0'-2X, DS0'-3X and DS0'-4X respectively (Refer to 5th). The experiments were repeated for those oversampled data (Refer to 6th).

When the number of observations in the minority class is increased by 2, 3 and 4 times, ROSE and SMOTE oversampling methods gave the highest in-class precision due to under sampling with oversampling in NB. Adasyn and DBS methods provide the highest in-class precision in the NB algorithm when it is desired to perform pure oversampling when the number of observations in the Minority class is increased to 2, 3 and 4 times.

5. Conclusion

When classifying a small and imbalanced data set, the minority class is often misclassified because of classification accuracy is biased in favor of the majority class. The main purpose of oversampling is to eliminate the imbalance between the classes.

With the scope of the study, the original data set was minimized and imbalanced. Distance-based oversampling methods were applied to the datasets. Number of the observations of the minority class in training data set were increased to 2, 3 and 4 times then in-class classification scores were compared.

Two of the classification algorithms, SVM and C4.5, is unstable in the small and imbalanced data set. ADASYN and DBS have the best classification scores in the oversampled small and imbalanced data sets. For the oversampling methods the most convenient rate for number of observations in the minority class is 3 to 4 times.

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Using PubMed to Generate Email Lists of Participants for Healthcare Survey Research: A Simple and Practical Approach

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Abstract. Survey research is one of the most essential domains of evaluation and measurement in healthcare and social sciences. Online surveys are considered the most economical of the three main data collection methods, followed by telephone interviewing, while face-to-face interviewing is the most expensive. Even though they have many advantages, online surveys have very low response rates. The objective of this paper is to demonstrate a practical and simply replicable approach for using PubMed to generate large email lists of potential participants for healthcare survey research. In addition to personalizing each email, researchers can use a range of strategies to improve the response rate, including sending reminders, adding the updated response rate to the reminders, and stating the average time it would take participants to complete the survey. Moreover, acknowledging participants, using financial and non-financial incentives and contacting participants through their affiliated organization, can significantly improve participants response rate.

Keywords. Healthcare, Survey Research, Participants Emails, Questionnaires.

1. Introduction

Survey research is one of the most essential domains of evaluation and measurement in healthcare and social sciences. This wide domain includes evaluation interventions through asking questions of participants. A survey can take a wide range of types, starting from the simplest paper-based feedback forms to the most intensive one-on-one in-depth interviews [1]. Online questionnaires have been considered the most economical of the three main data collection methods, followed by telephone interviewing, while face-to-face interviewing is the most expensive [2]. Questionnaires can support both quantitative and qualitative research methods. In addition to answering quantitative questions, respondents could provide rich, free text feedback [3]. Online questionnaires have many advantages. They are inexpensive, practical, provide a quick way to get results, scalable, provide comparability with easy analysis and visualization, offer actionable data while keeping respondent anonymity, have no time constraints, and can cover every aspect of a topic. Disadvantages include providing dishonest answers or leaving unanswered questions. Questionnaires cannot convey feelings and emotions, there is lack of personalization, unconscientious responses, in

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addition to the questionnaire or survey fatigue problem [4]. The lower response rate of online surveys has been a major concern for survey researchers. There is a wide variety of factors that can affect response rates, such as the content and presentation, sampling methods, contact delivery modes, invitation design, using reminders and incentives [5]. One way of overcoming the low response rate of online survey is to contact a larger sample of participants [6]. Compared to other healthcare databases, PubMed includes the largest number of publications and offers an optimal update frequency. PubMed remains the best tool in biomedical electronic research [7]. The objective of this paper is to demonstrate a practical and simply replicable approach for using PubMed to generate large email lists of potential participants for healthcare survey research.

2. Methods

In simple and replicable five steps, and as an example, we will generate an email list of emergency department clinicians and researchers who published at least one PubMed indexed paper, over the last five years. Step one includes using the advanced search function of the PubMed (https://www.ncbi.nlm.nih.gov/pubmed/advanced) to search for papers. We will use the search key words: Emergency Medicine OR Emergency Department OR Emergency Departments OR Emergency Service OR Emergency Services in the [Title/Abstract] AND the same search key words in the [Affiliation], to make sure retrieved papers not only are about emergency medicine, but also have been conducted by clinicians and researchers who belong to the emergency medicine or emergency department at their organizations. Step two includes retrieving the results from the PubMed, in the MEDLINE format, to a text file to be saved on the computer. Step three includes extracting the emails listed in the MEDLINE results text file, using a free online email extraction website, specialized in extracting emails from text files (http://convertcsv.com/email-extractor.htm). Step four includes preparing a MS Excel sheet with the extracted emails. Step five includes using the mail merge function of the MS Office, through MS Excel, Word, and Outlook, to send emails to the identified participants of the survey research. Figure 1 shows the five steps approach of identifying publications, retrieving and extracting emails of their authors.

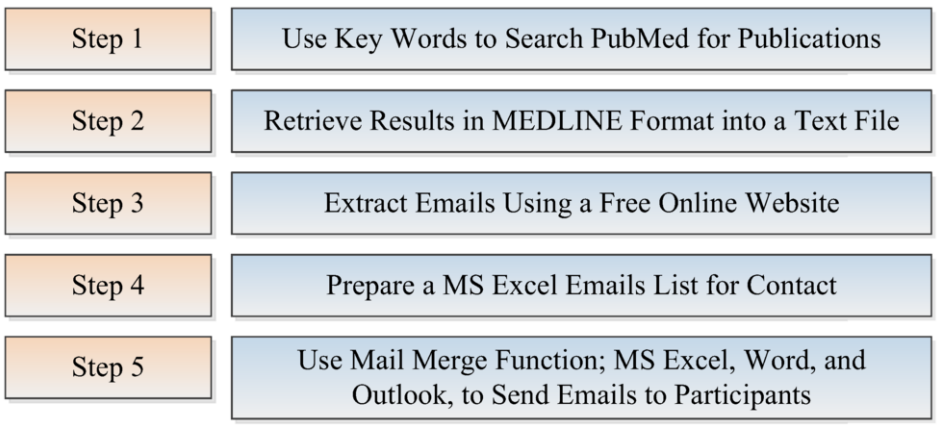

Figure 1. Five steps approach of identifying publications, retrieving and extracting emails of their authors

3. Results

The results of the search on the PubMed retrieved 13,608 identified papers published in the area of emergency medicine or emergency department by emergency medicine clinicians and researchers over the last five years. Retrieving the MEDLINE format results into a text file generated a 55 Mega Byte data text file containing the titles, abstracts, author information, and other relevant information of the retrieved publications. The extraction of authors' emails generated 5,817 unique emails.

4. Discussion and Conclusion

We have described in detail a simple method to generate a large emails list of emergency medicine clinicians and researchers through using the advanced search function of the PubMed. PubMed is one of the best resources for biomedical published research. The keywords and the search fields used ensure that the identified papers are relevant to the emergency medicine. Using the last five years as a timeframe, ensures that a large percentage of the emails are still valid and attended by their owners. This method generates emails without names, which might lower the response rate. It is reported that decreasing costs associated with designing and administering online surveys would make survey fatigue more prevalent [8]. On the other hand, it is discussed by many researchers that personalizing the email invitations significantly improves the response rate of participants as it gives the impression of focused message and targeted audience [9]. However, using the mail merge function enables researchers to send a separate email directly to each participant, which is better than sending bulk emails using the blind carbon copy function. Bulk emails are sometimes identified by email agents, such as MS Outlook and Gmail, as spam and are automatically sent to the trash, or simply are overlooked by the recipients considering them as commercial, low priority or less relevant communications [10]. Sending survey invitation emails anonymously could generate a response rate between 1 to 5%, while sending personalized salutation emails could raise this rate up to 10 to 15% [11]. Alternately, the names of the researchers still can be extracted, from the MEDLINE format results file that we downloaded earlier, through checking the Affiliation (AD) field which comes after the Author (AU) field in the MEDLINE format text file. However, if this process is done manually it will take quite a long time, 30 seconds on average for each email, which makes the total time needed to extract the names for the 5,817 emails identified earlier about 48 hours of work. This time can be much reduced if a programming code was written for this task, which is out of the cope of this paper.

In addition to personalizing each email by including the correct salutation and last name of the recipient, researchers can use a range of strategies to improve response rate of online surveys. These strategies include sending up to three reminders two weeks apart, adding the updated response rate to the reminder emails to encourage others to participate when they see the study is progressing, and stating the average time it would take a participant to complete the survey in the text of the invitation email [12]. Providing the participants with the option to request to be acknowledged in the publication of the study could also provide a good incentive to improve their response rate, especially when they are active researchers [13]. Moreover, financial and non-financial incentives of participants proved to have a significantly positive influence on improving their response rate [14]. Studies show that online survey response rates can

be increased by low to no cost incentive and text appeal strategies. There is a robust evidence that both low-cost cash prize lottery incentives and cost-free text appeal interventions targeting an individual's egotistic need for approval may increase the survey response rate [15]. It is also suggested that contacting participants through their affiliated organizations, such as professional bodies, associations, and colleges, can significantly improve their response rate to the online survey. Because this would enhance the credibility of the survey study, increase the trust of participants and their commitment towards completing the survey. However, this necessitates more efforts, resources and time to organize [16]. As a conclusion, the recently developing easiness of contacting a larger number of participants for survey research is associated with a lower response rate due to many reasons. However, we still can overcome this challenge by either generating larger participants' lists or using strategies to improve their response rates. It is true that the retrieved emails are publicly available through online publications, however, it is essential to consider different data protection and privacy regulations. It is advised that such lists should not be used for purposes other than research and that contacting each researcher should be accompanied by an explanation of how we got their emails and why we are contacting them.

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Self-Management and Diabetes Mellitus mHealth, a Glance at the Present and a Glimpse into the Future

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Abstract: mHealth is new technology that can help in the self-management of diabetes mellitus (DM), a highly prevalent metabolic disease. mHealth applications can enhance patient–provider communication, and improve health data capture and monitoring, patient education, and the provision of feedback. However, aspects related to the functions and content required in the application, as well as privacy, accuracy and the safety of patient data, should be managed. The use of mHealth in DM self-management can be optimized by overcoming technical, societal, and business barriers. Using appropriate behavioral change theories, the short and long-term effects of mHealth should be targeted. Providing interactive feedback is an important feature of any mHealth strategy, so as to ensure a closed-loop in DM management. Accuracy and validity of information included in the mHealth application is vital; therefore quality and appropriateness of the information should be assessed, and enhanced where necessary. Consideration for the perspectives of end-users is at the core of mHealth care. The effects of mHealth should be assessed in a real-world setting, rather than the current clinic-based studies. In conclusion, mHealth is a tool that provides an opportunity for integrated and coordinated DM care.

Keywords: Self-Management, Diabetes Mellitus, mHealth

1. Introduction

Diabetes mellitus (DM) is a multisystem, metabolic disease characterized by increased blood glucose level. DM is associated with many cardiovascular and non-cardiovascular diseases, such as coronary artery disease, heart failure, renal disorders, liver disease and dementia. Diabetes is prevalent worldwide and is increasing every year, as 415 million were reported diabetics in 2015 [1]. The health and economic burden of diabetes necessitate the introduction of multilevel and multidisciplinary approaches for coordinated diabetes care [2]. Since diabetes affects individuals' lifestyles, diets and daily activities, self-management is considered to be at the core of diabetes care. The aim of DM self-management is for individuals to play an active role in effectively containing their diabetes and its complications through coordinated care. It incorporates checking one's own blood glucose levels, tracking lifestyle and daily

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activities (e.g., smart dieting, physical activitiy, smoking cessation, weight control, and stress management), taking medications, and other measures (including, for example, foot care, eye screening, vaccinations, etc.) [3].

One the used approach to enhance self-management of chronic diseases is through the use of mobile applications. Wide and increasing use of smart mobile phones and the Internet has led to the widespread adoption of health-related mobile applications. mHealth is concerned with the use of mobile applications in the healthcare arena. In particular, mHealth applications can be used to track wellness; for diet control; or to monitor individuals' fitness and compliance with medications and other treatment plans. mHealth may also be used for early diagnosis, disease management and prevention, and for educational purposes [4]. Furthermore, data generated through mobile application can be compiled in a patient Portal at the hospital side and a Clinician Monitoring Station can help in providing a closed-loop diabetic care.

2. Method

A search was conducted on PubMed, Google Scholar; Cochrane and other health databases. The search was to identify studies that have Self-Management, Diabetes Mellitus, mHealth, and Self-containment on the title. We limited the search to studies published in full text in English language. Abstracts of potentially eligible articles were retrieved for review and only relevant articles were included.

3. Results

3.1. Mobile Applications and its impacts on Diabetes Mellitus Self-management

mHealth has positive effects on individuals with diabetes. One meta-analysis revealed that mobile applications can help patients to control hemoglobin A1c (HbA1c) levels, thus they should be considered as an adjuvant tool to standard type 2 diabetes self-management [5]. Many studies have reported positive outcomes on consumption of a healthy diet, increased physical activity, and patients' tendency to test their blood sugar levels more frequently [6, 7]. A recent review reported improvements in HbA1c levels in four ways: through improved patient–provider communication, better health data capture and monitoring, improved patient education, and better provision of feedback. However, the studies included in this systematic review study lacked homogeneity in terms of the technology and applications used, and found discrepancy in the rates of HbA1c control. This discrepancy was aggravated by factors such as sample size, baseline characteristics, patient level factors, and variations in the features of the applications used. Also varied was the extent to which individuals with diabetes introduced lifestyle changes, such as consuming healthy food, performing physical exercises, undertaking continuous checks and monitoring, complying with treatment, managing stress, and enhancing health literacy [7]. Some studies have acknowledged drawbacks of mHealth applications. These drawbacks include the inability of most mobile applications to differentiate between types of the diabetes, the lack of an educational component, the content, and issues related to privacy, accuracy and safety of patient data [6, 8].

3.2. The promises of having a closed loop Diabetic care

In the integrated DM management model, the mobile application is connected to a patient portal on the providers' side, and the clinician monitoring station (CMS). The mobile application feeds patient-reported data, such as their blood glucose levels and other necessary information, into the portal. The portal compiles this data into one place, allowing clinicians to review and interfere (if necessary) by scheduling appointments, or by introducing or modifying treatment regimens. The CMS is equipped with different devices (audiovisual, telemedicine, etc.) to allow care providers to communicate with patients, as well as to collaborate with other care providers to provide coordinated care.

3.3. The barriers to optimal use of mhealth in Diabetes Mellitus Self-management

There are several challenges to the optimal use of mobile mHealth applications in DM self-management and patient care. These challenges can be categorized as technical, societal, or business in nature. Technical barriers are related to difficulties in establishing interoperable components that can work together in harmony. Overcoming these technical barriers requires consumers to attain new information technology skills, with regards to installation, configuration, maintenance, and adopting change [9].

Overcoming societal barriers to the adoption of mHealth requires continual assessment and improvements in the adaptability and usability of mHealth technology, along with the other components in the model. Privacy and confidentiality of collected and used data must be maintained and assured. Health organizations must also be committed to the new process so as to anticipate the benefits of using mHealth in DM patient care.

Business barriers are related to the allocation of resources to initially invest in and maintain the proposed model. The current billing system rewards healthcare providers for treating sick patients, not for keeping patients healthy. Therefore, the reimbursement of care services delivered through mHealth applications is one of the biggest hurdles to wider adoption of the integrated and coordinated care that mHealth promises in DM patient care [10].

4. Discussion

Numerous applications are now available to help individuals with DM. Together with the viability of telemedicine and the wellbeing framework, patients are able to overcome geographical boundaries and use newly developed and regularly updated mHealth technologies. Nevertheless, debate remains as to the utility of portable applications for overseeing one's own diabetes. Most of the studies reviewed here recommended that:

- mHealth applications should be designed with the aim to change behavior, focusing on improving individuals' health over time, and targeting both the short and long-term effects, utilizing appropriate theories of behavioral change
- It should include an interactive feedback function, so as to ensure closed-loop DM care

- The quality and appropriateness of the information should be assessed and enhanced
- End-users should be involved in the development of mHealth applications because their perspectives are at the core of mHealth care
- The impact of the mHealth application should be assessed in a real-world setting, unlike in current clinic-based studies, and should include a diverse study population, including – for example – indigenous, elderly, and rural residents.

In conclusion, mHealth applications – if designed and utilized properly – provide an opportunity for integrated and coordinated DM care. With advancements in connectivity, mHealth has the potential to provide DM patients with real-time monitoring and round-the-clock care, both in terms of treating their disease and promoting their health.

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Utilizing Big Data in Healthcare, How to Maximize Its Value

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Abstract. Big data has been applied in a variety of ways in healthcare. It can be considered as a tool for data collection. And hence, there are certain criteria needed in this tool to be of value. Optimists have exaggerated the benefits of big data, while pessimists reported negative aspects. Big data remains a reality that healthcare must face and maximize its value. The authors identified few guiding principles for scientific utilization of big data in healthcare. These include: generate evidence by scientific methods, assure validity and significance, use multi-step analysis, and lastly consider sensitivity, and specificity.

Keywords. Big data, healthcare, prevention, Bradford Hill criteria

1. Introduction

As technology matures in its life cycle, Gartner "hype cycle" describes the changes in expectation overtime. Shortly after the technology triggers publicity and reaches the peak of exaggerated expectation, a trough of disillusionment follows. Then realistic enlightenment and plateau of productivity are reached. This has probably already happened in "Big Data" [1].

Big data is an indispensable reality, not an option anymore. It is an opportunity and challenge to healthcare. In a typical description of big data, it consists of five "V's": Velocity, Volume, Value, Variety, and Veracity. So, big data is a collection of huge volume of trustworthy data, accumulating in high velocity, and coming from variety of sources, not only medical records. Veracity means the quality of data, and variability highlights the inconsistency of its format [2]. It is worth to consider the value, and the validity, as well. Big data is naturally collected and aggregated. To some extent, healthcare organizations do not realize that they are collecting big data by the second. Worth to mention, there is no collection bias. However, there is participation (non-response) bias. Big data spans from molecular level, individual level, and up to population and global levels. It tends to be holistic, yet mostly in unstructured format. In healthcare, big data is recently applied in many aspects such as clinical research, patient

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care, and operation of healthcare. Useful applications have been reported. However, disappointing outcomes have been also noticed [3].

This paper investigates how big data can be best utilized in healthcare. Keeping in mind, the positive and negative aspects of big data, the authors investigate to identify the guiding principles for utilizing big data to create "value" for healthcare.

2. Methods

A search for all related articles was conducted in PubMed, Google Scholar, and the World Wide Web (reports, blogs, news). The following keywords were searched: big data, health, healthcare, disease prevention, data mining, machine learning, and simulation. The search results were limited to articles published in the last five years (2014-2018) and written in English. Articles related to the investigators question are read and analyzed.

3. Results

The search revealed 73 article and reports with relevant titles to big data in health care that could be fully accessed. Abstracts were read, and 10 articles were selected according to relevance to the topic with opinion of two experts in the field. The focus of the paper is on identifying guiding principles to improve the utilization of big data in healthcare. For big data to be of value, the investigators identified the following guiding principles:

3.1. Generate Evidence by Scientific Methods:

For decades, the practice of medicine has been described as "evidence-based". Dr. David Sackett had shaped research methodology in clinical epidemiology. Now, it is mandated to justify all decisions in healthcare by evidence. The use of big data is not an exception to this rule. One of the common uses of big data is to identify relationships between different variables, such as correlation between social media posts and the mood of an individual. This use needs to follow scientific methods. It should demonstrate acceptable methodology to generate sound evidence. "Bradford Hill criteria" for causation of disease were originally created to ensure correct methodology in epidemiological studies [4]. These criteria are still valid today. Accordingly, when big data is used, the methods need to demonstrate Bradford Hill criteria.

So, even with big data, to determine cause-effect relationship, the methods need to estimate the strength of the relationship. This is done statistically by calculating the odds ratio, or the relative risk depending on the design of the study and the analysis. Consistency in the relationship needs to be measured. Specificity of the relationship is another criterion that needs to be considered since big data might be vague and not precise. Temporal relation between the cause and the effect is needed. Big data provides high velocity flow. However, the temporal relationship should not be neglected. Big data would allow broader interval of years and decades, since big data is naturally occurring and collected overtime. Dose-response gradient should also be drawn. A typical example is increase in drug toxicity as the dose of the drug increases. No evidence is accepted until it can be biologically plausible and explained. If the current knowledge does not

support the relationship under study, the results remain irrelevant and clinically not significant [5]. Big data is not an evidence in itself, it is rather a tool to generate evidence.

3.2. Ensure Validity and Significance:

There are different types of validity: content validity, process validity and conclusion validity. In healthcare, what matters is validity of conclusions. This depends on the purpose for which the data is collected. Yet, the method of data collection in big data is frequently not oriented to a specific purpose. Instead, data is collected as they occur naturally and spontaneously, such as recording geographical location and movement of individuals in a population [6].

When big data is analyzed, results and findings need to be relevant and significant. There are two types of significance in this discussion, statistical significance and clinical significance. Big data, by definition, is huge in volume. It may magnify minor relations or differences between variables. Furthermore, big data may easily give statistically significant results. Unfortunately, statistical significance does not always mean providing a plausible outcome clinically. Big data in genomics may identify unusual gene mutation or DNA defect; however, this finding remains irrelevant if the individual is clinically healthy. So, the use of big data may predict health problems. But this prediction should be further investigated for its validity and significance [6].

3.3. Use Multi-Step Analysis:

In spite of the high velocity of data collection and aggregation in big data, creating value and critical decisions need a multi-step analysis. It is estimated that the majority of data in healthcare are unstructured. This includes, narrative text, and hard-to-process images. [7]. To achieve accurate results and sound decisions in the healthcare field, one must follow the proper steps for data analytics. Collecting data from variety of big data sources must ensure quality of data. Then, data should be cleansed from noise. This is followed by transforming data through mathematical and compression algorithms to draw descriptive analysis. Finally, one may draw conclusion and predict future outcomes [8].

Data Mining is done by a set of tools aiming to find important information to generate meaning. Data mining methods have been criticized due to uncertain reliability and lack of data modeling [9]. However, if data mining is applied within a multi-step process, a reasonable reliability and validity can be achieved. Machine learning is another tool with high potential. It successfully uses algorithm for prediction of early disease risk [10]. There is certainly a need for careful design of a multi-step analysis of big data.

3.4. Consider Sensitivity and Specificity:

The application of Big data can be considered as a testing device, with a sensitivity and specificity that can be measured as compared to a “gold standard” reference. The failing project of Google Flu Trends should have been studied to determine its characteristics, such as sensitivity, specificity, positive predictive value, negative predictive value and overall accuracy. Failure to apply big data in the correct context has led to disappointing results.

4. Discussion and Conclusion:

Certainty is a myth. In healthcare, no method or tool is perfect. Big data may give a comprehensive view, from molecular level, such as genetics, epigenetics, proteomics, and metabolomics, to individual level, such as electronic health record (EHR), to population level, such as environmental factors. However, big data remains a tool that needs to be utilized wisely to maximize its value. We discussed few guiding principles to improve the outcome of big data in healthcare. More research is required to construct robust models and guidelines for the use of big data in healthcare.

There is a gap between information technology and computer science from one side, and healthcare from the other side. We strongly recommend a multidisciplinary approach with expertise in health informatics to tighten this gap by constructing models to manage big data in a scientific approach. A multidisciplinary team consisting of clinician, data scientists, clinical performance metrics specialists should work toward better utilization of big data technology.

The review has a few limitations. Firstly, the literature search was biased towards finding positive results related to big data in the field of medicine. Furthermore, the results of this study cannot be generalized for fields other than healthcare. Also, many information sources could have been missed or not included in the study. Future studies should be based on research validations of the impact of big data in healthcare.

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Lifestyle Intervention for Young Adults with MS: A Design Study

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Abstract. This paper presents a mid-fidelity prototype of a mobile application for self-management of the chronic disease Multiple Sclerosis (MS). The study focuses on newly diagnosed young Norwegians with MS and wants to deliver IT solutions for a healthier lifestyle. An analysis of a social media platform, interview with medical staff, a social media focus group interview and one case study where utilized to gather data alongside with design iterations. A high-fidelity prototype is being implemented with main functionalities: health, training, patient notes for next medical appointment, disease related life and work issues, and a reward point system.

Keywords. Multiple Sclerosis (MS), young adults, self-management, application.

1. Introduction

Multiple Sclerosis (MS) is a chronic disease that attacks the central nervous system. It can occur at any age, and at the early stages, it is common to have occasional attacks. A minority of patients will see a worsening of the disease after a few years [1]. There is no disease specific test, meaning MS can be hard to diagnose [2]. Medical attention mainly goes to those who suffered with MS for a longer time which in turn often leaves newly diagnosed with less attention and fewer follows-ups during asymptomatic periods. When creating a lifestyle application for young adults one should use technologies to promote wellbeing, connect people and guide them to best available help [3]. Another important issue is to assess the effectiveness of the intervention with measurable means [4]. The aim of this study is to design a prototype with highly relevant content for young adults with MS. Effectiveness could be realised through rewarding good lifestyle choices and collecting data for users' self-management and possibly for sharing with medical staff.

2. Method

The content analysis was carried out for a MS social media platform and thereafter the resulting data was evaluated by experts at the Norwegian Multiple Sclerosis Competence Centre at Haukeland University Hospital. A focus group with five young adults between 20-30 years of age was interviewed. Consequently, a mid-fidelity prototype was designed using the acquired data and evaluated in a case study with two participants.

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3. Results

3.1 Social Media Analyses

Displayed in Figure 1a-c are some of the data categories regarding the concerns and frequently asked questions at the MS social media platform [5] by the users during the last four years. Proving information are sought out at more places than the doctor's office. The results from the analysis were used to help establish user requirements.

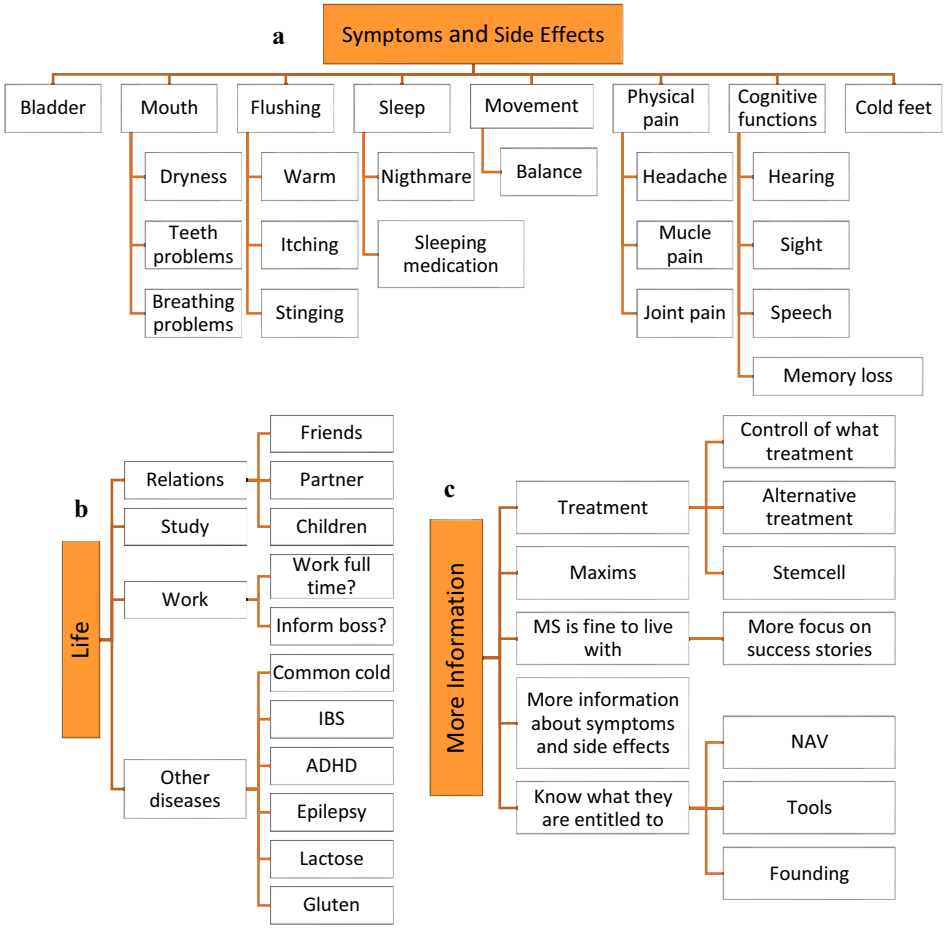

Figure 1a, b and c. Frequently asked questions concerning the MS diagnosis.

3.2 Expert Evaluation

The medical expert evaluation looked at the categories from the Figure 1, as well as some other figures not presented in this paper. After the evaluation, some categories were excluded from the requirements that were not specific for this group (e.g. food functions).

3.3 Interview with Social Media Focus Group

The focus group had a clear and mostly uniform opinion regarding their design and content preferences. All of them had struggled to find a Norwegian app for handling MS. They did use apps with dark backgrounds such as Spotify, but they did not spend much time scrolling on it and agreed that a light background with dark text and a dash of colour was the best option. The group was presented with a list of functions (*calendar, workout, notes, health, frequently asked questions)* resulting from the analysis of the social media platform and expert evaluation. They wished for a list of available MS-nurses per geographic location. They suggested there should be a place with information on MS for family, friends, and work colleagues, especially bosses. They seek more information about treatment including medicine. One in the focus group would appreciate a calorie counter alongside with healthy recipes. A few would like to have a forum to discuss MS. The majority have found the calendar function redundant. All these results concerning design choices and content were used in the next design iteration.

3.4 Case Study

There were two participants in the case study who evaluated separately. Firstly, there was a 26-year-old female, finishing a master's degree, diagnosed in 2016. The second was a 29-year-old male, with a master's degree, working full time; his diagnosis was established in 2018.

Both liked the colour orange for the applications since it is the MS colour. The font size was good, but the font family was not satisfactory. One meant that there could never be enough content, whilst the other meant too much information could make it hard to navigate through. Suggested improvements were to change the position of the menu and adding a MS-dictionary. In addition, shorter workouts where requested. Information on the medical exams could be compressed when appropriate (e.g. "read more"-button). One felt food recipes were unnecessary whilst the other wanted easy and quick recipes due to fatigue. They both disliked push notifications. Figure 2 displays the landing page and not additional content; the first version of the prototype was created based on the focus group findings, and the second version was implemented after the case study.

Figure 2. The entry menu and the landing page before and after the case study.

4. Discussion

To really understand the needs of young adults, we have joined a Norwegian social media group for people with MS. In direct contacts we have identified main concerns and needs from which a dynamic picture appeared (Figure 1a-c). Important life and quality of life related questions that were discussed. Information often exchanged amongst peers is usually not addressed during regular medical visits, hence the information needs.

The medical experts from Haukeland University Hospital have also appreciated the data coming from this research (Figure 1a-c). Based on such positive feedback, we have designed a prototype to suit young adults and keep them interested in a healthy lifestyle instead of reminding them on the worrisome side of the MS. There are situations such as acute attacks that are demanding on patients and surroundings, but all other times the quality of life remains good. Ideally, they could manage their lives on their own and contact medical professionals when absolutely needed. An app would thus be helpful.

We have also used a case study to gain more information about the conditions of living with MS and to evaluate the prototype. The detailed feedback provided some reassurance that this kind of lifestyle tool would be a good addition to the already exiting information [6]. Evaluation by the IT experts and the social media group will be important for refinement of the current design solutions.

5. Conclusion

The design for young adults with MS is the first in Norway, tested by a mini social media focus group and participants of a case study. Their suggestions have influenced the content and design. The results were satisfying but could be further improved regarding the medication, an MS dictionary, information on the medical exams, as well as suggestions for short, straightforward physical exercise and easy to make recipes. All these should help young adults with MS to maintain a conscious and healthy lifestyle.

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An Edge Computing Method for Extracting Pathological Information from Phonocardiogram

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Abstract. This paper presents a structure of decision support system for pediatric cardiac disease, based on an Internet of Things (IoT) framework. The structure performs the intelligent decision making at its edge processing level, which classifies the heart sound signal, to three classes of cardiac conditions, normal, mild disease, and critical disease. Three types of the errors are introduced to evaluate the performance of the processing method, Type 1, 2 and 3, defined as the incorrect classification from the critical disease, mild, and normal, respectively. The method is validated using 140 real data patient records collected from the hospital referrals. The estimated negative errors for the Type 1, and 2, are calculated to be 0% and 4.8%, against the positive errors which are 6.3% and 13.3%, respectively. The Type 3, is calculated to be 16.7%, showing a high sensitivity of the method to be used in an IoT healthcare framework.

Keywords. Time growing neural network, edge processing, internet of things.

1. Introduction

There is a new era of Internet of Things (IoT) thanks to the ever more capable mobile devices, ubiquitous internet, and cloud computing. The concept of Internet-of-things (IoT) provides a solid framework for interconnecting edge computing devices based on the data from mobile technology with its architectural components and their potential to provide person-centered healthcare [1].Actualization of such devices has already been addressed in various studies in the sense of the communication infrastructures and needs for the implementation [2, 3]. Although application of machine learning methods has be investigated in different studies [4, 5], a research gap still exists in monitoring children with heart disease. The main part of such a system is the machine learning algorithm which is installed in a level closed to the sensor to process heart sound signals, so called edge processor that is capable to extract medical information from the signals for the classification purposes. Phonocardiogram (PCG), known as a recording of mechanical activity of heart, has been investigated in light of finding machine learning methods to extract specific information about certain heart disease [6-9]. However, finding a robust algorithm deployable at the edge processing level for

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symptom detection of PCG is yet regarded as a challengeable task, even though artificial intelligence-based methods have been extensively reported in the previous studies [10, 11]. Our recent studies proposed different machine learning methods for detecting certain anomalies from PCG signal, as well as methods for validating structural risk of any machine learning method [12-14]. In this paper, a decision tree-based algorithm is presented to detect pathological systolic murmurs and classify them in terms of the disease severity through a hierarchical architecture. Such an algorithm can be easily incorporated into the FOG level of an IoT framework to serve as an efficient decision support system, by extracting important medical information from PCG. Results show that the obtained system is capable to help the practitioners to prioritize pediatric patients according to the detected pathology.

2. Materials and Methods

The referrals to the Children Medical Center of Tehran, Tehran University, were invited to participate in the study. The informed consent was obtained from the referrals or their legal guardians. All the referrals underwent echocardiography and complementary clinical examinations. We used a portable computer and an electronic stethoscope of WelchAllyn Meditron Analyzer for signal acquisition. Table 1, lists the patient population along with the corresponding cardiac condition.

Table 1. The study population

Heart Condition	Age Range (years)	Number of Referrals	Critical Cases
Aortic Stenosis	1 - 8	20	7
Atrial Spetal Defect	5 - 15	10	2
Mitral Regurgitation	4 - 18	15	0
Normal Heart Condition	4-15	30	0
Patent Ductus Arteriosus	0 - 5	20	3
Pulmonary Stenosis	1 - 10	15	5
Ventricular Septal Defect	2 - 5	30	30

The method is sophisticated to be implemented at the FOG layer of an IoT structure as shown in the Figure 1. The edge processing performed at the FOG layer, involves sub-classifications using the medical information which are stored at the cloud. Performing such a sub-classification, substantially reduces excessive processing load from the cloud layer, where the patient records are stored and for which a fast retrieval is important. Time Growing Neural Network (TGNN) is employed for extracting the pathological features, including ejection click, ejection murmur, regurgitation murmur, ventricular septal defect and patent ductus arteriosus. TGNN is based on characterizing signal using spectral energies extracted from the temporal windows with the identical initial point, but by growing length until the whole signal is covered. The extracted spectral energies from the growing windows are classified using a multilayer perceptron neural network. Mathematical details can be found in the citations. In brief here, more than 30% of the children with heart pathology suffer from ventricular septal defect, and our previous studies suggested an efficient method to screen such patients [15]. The rest of the cardiac diseases, are dominantly comprised of aortic or pulmonary heart disease, both producing ejection murmur which is sometime concomitant with ejection click. Time growing neural network has already been employed to screen such the pathological symptoms that can effectively help decision making [16, 17].

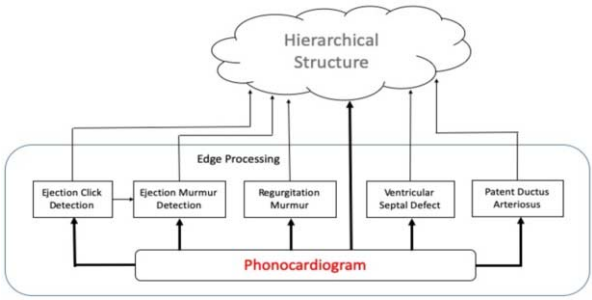

Figure 1. The edge processing architecture for extracting medical information at FOG level.

Detecting ejection murmur from the regurgitation murmur, is performed by using a sophisticated TGNN [4, 18, 19]. The main idea of using such the hierarchical structure is to find the children suffering from severe cardiac diseases to be immediately hospitalized and treated as emergencies, whilst keeping the mild pathologies in the lower priority for a continued monitoring. The first processing level of the hierarchy involves the processing methods for detecting pathological murmurs, in conjunction with the ejection click. The pathological murmurs can be created by harsh conditions like ventricular septal defect, or severe aortic stenosis, or paten ductus arteriosus. Trivial aortic or pulmonary stenosis initiate ejection click together with the ejection murmur, and can be classified as no urgent condition.

3. Results and Discussion

In order to evaluate performance of the method, we defined three types of errors. The Type 1 error takes both negative and positive value, corresponding to the patients with critical heart condition classified as normal and vice versa. The negative Type 2 error corresponds to the patients from the critically diseased group, classified as mild cases, whereas the positive Type 2 error is the percentage of the mild case classified as the normal and critically diseased cases, respectively. The Type 3 error is all positive error, corresponding to the normal patients classified as abnormal. The number of the misclassified patients from the critically and mild diseased were 0 whilst there were 7 patients out of 47 and 63 subjects, respectively. The 7 misclassifications correspond to 3 negative and 4 positive errors. From the 30 normal subjects, 4 subjects were classified as having mild disease and 1 as the critically diseased, yielding a positive error of 16.6%. Therefore, the negative error is estimated to be 0% and 4.8% for the Type 1 and 2, respectively. The positive errors are calculated to be 6.3% and 13.3% for the Type 1 and 2, respectively. Although study on PCG signal is considered as a relatively old domain, such the structural processing along with the error definition, incorporated into a, IoT structure is innovative.

4. Conclusions

The paper suggested an IoT structure for intelligent processing of heart sound signals towards development of a decision support system for cardiac disease. Results show

that the presented method can provide sufficiently accurate methods to be employed by the health providers like primary healthcare centres or family doctors to screen critically diseased and even mild diseased patients in the IOT healthcare framework.

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Hiding Decision Tree Rules in Medical Data: A Case Study

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Abstract. Data sharing among health organizations has become an increasingly common process, but any organization will most likely try to hide some sensitive patterns before it shares its data with others. This article focuses on the protection of sensitive patterns when we assume that decision trees will be the models to be induced. We apply a heuristic approach to hide any arbitrary rule from the derivation of a binary decision tree. The proposed hiding method is preferred over other heuristic solutions such as output disturbance or encryption methods that limit data usability, as the raw data itself can then more easily be offered for access by any third parties.

Keywords. Decision trees; privacy preserving; hiding decision tree rules; medical data; data sharing

1. Introduction and background

In health informatics, data privacy is essential, especially when it comes to analyzing vast amounts of data collected from different sources including health care providers, insurance companies, pharmacies, and research institutions. Information in health care is considered sensitive, and its privacy is a major concern when analyzing for research purposes the personal health care data of the patient. Privacy-protecting data mining [1,2] is a research field that aims to alleviate issues arising from the use of data mining on data collection, information or knowledge contained in data collections, and the confidentiality of subjects recorded in them. Agrawal and Srikant [3] were the first to consider inducing decision-making trees from anonymized data that were adequately noise-driven. For example, the general strand of knowledge-hiding research [4] has resulted in specific algorithms adding noise through a process of data swap [5]. The purpose of this article is to present an application of LDH (Local Distortion Hiding) algorithm [6] in order to protect sensitive patterns that result from the use of data mining techniques. All approaches to privacy conservation are designed to maintain the quality of data. In our previously published articles [7,8], we proposed a series of techniques to adequately protect against the disclosure of sensitive knowledge patterns in mining classification rules. We aim to hide sensitive rules without compromising the information value of the entire data set. After an expert selects the sensitive rules to eliminate the gain achieved by the information metric causing the split, the class labels at the tree node corresponding to the tail of the sensitive pattern are modified. In the articles [9,10], we

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extend the aforementioned work by formulating a generic look ahead technique that takes into account the decision tree structure from an affected leaf to the root. This paper aims to enable the original medical data set to be published or shared by hiding the critical rules produced by creating the corresponding decision tree and thus preserving to the maximum extent possible the privacy of the data that led to the appearance of these critical rules. In this article, we present an application of our technique in a medical dataset that does not, as our previous techniques do, affect the class labels of sensitive instances, but rather modifies the values of the attributes of these specific instances. In the proposed method, we first identify the instances that contribute to the creation of a specific rule and then successfully hide this rule with minimal impact to the rest of the decision tree by changing attribute values appropriately.

2. Applying Local Distortion Hashing for Leaf Hiding

To hide by changing the original data set minimally, we can interpret "minimal" changes in data sets by judging whether the sanitized decision tree generated through hiding is syntactically close to the original with minimum modification of the initial data set. Measuring how decision trees change has also been examined in the context of heuristics which attempt to approximate the structural effects of such changes [11,12,13]. In our example, we use the kappa statistic to compare the efficiency of the deduced decision tree after the proposed modification with the original one. The information gain metric is used to select the test attribute at each node of the decision tree, just like ID3, one of the earliest decision tree induction algorithms [14], whereas its successor, C4.5 [15], uses the gain ratio metric, an improvement of the information gain. The attribute with the highest gain ratio is selected as the splitting attribute. Therefore, if we would like to suppress a particular attribute test at a node, a reasonable heuristic would be to try to modify the values (for that attribute) of the instances which would arrive at that node. By this modification, the resulting information gain due to that attribute would be reduced, becoming equal to zero if possible. The algorithm LDH locates the parent node of the leaf to be hidden and ensures that the attribute tested at that node will not generate a splitting which would allow that leaf to re-emerge.

3. Applying LDH to a medical data set

We show an example in this section regarding a binary medical dataset from the UCI—Machine Learning Repository [16] (SPECT). The SPECT Heart [17] training data set is based on data from cardiac Single Proton Emission Computed Tomography (SPECT) images. Each patient is classified into one of two categories: normal and abnormal. SPECT is a good data set for testing ML algorithms; it has 187 instances that are described by 23 binary attributes (A1–A22, Class). The binary values for the attributes (A1–A22) are true (t) or false (f), and the corresponding values for the Class are positive (p) or negative (n).

The WEKA—Data Mining Software in Java [18] workbench is a collection of machine learning algorithms and data preprocessing tools. We chose for our experiments to use the classification algorithm J48 which is the implementation of the Quinlan C4.5 algorithm. C4.5 can be referred to as the statistic Classifier. This algorithm uses the gain ratio for feature selection and to construct the decision tree. It handles both continuous

and discrete features. The C4.5 algorithm is widely used because of its quick classification and high precision. The C4.5 algorithm for building decision trees is implemented in Weka as a classifier called J48.

In our example in the SPECT data set, we try to conceal the terminal internal node *attr15* which is shown in the figure below (Figure 1). In this way, we have succeeded in eliminating the contribution of the node *attr15* below its parent *attr5*, and the result is shown in Figure 2. Since the size of the above decision tree is too large to fit into one page, only the tree section around the critical node is presented. The reader can find all the data set files (.arff) on the website [19] before and after our distortion method has been applied. In addition to the data sets, all decision trees are also available in full-scale deployment as extracted from WEKA and visualized by Graphviz [20]. The kappa statistic adjusts precision by taking into account by chance alone the possibility of a correct prediction.

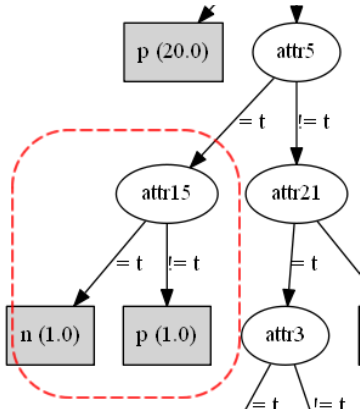

Figure 1. Original decision tree with the node attr15.

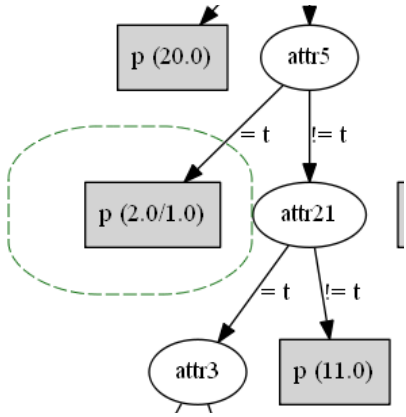

Figure 2. Final decision tree without the node attr15.

The kappa statistic values corresponding to the original and modified data sets are 0.834 and 0.795 respectively. We can also conclude from all other WEKA statistics presented in Table 1 below that the node *attr15* has been successfully hidden without significantly affecting the effectiveness of the decision tree. The decision tree induced by the modified dataset produced by LDH algorithm is the same as the original one without the existence of node *attr15*.

Table 1. Weka output for the original and modified data sets.

	Original	**Modified**
Correctly Classified Instances	182	181
Incorrectly Classified Instances	5	6
Kappa statistic	0.834	0.795
Mean absolute error	0.0352	0.0406
Root-mean-squared error	0.1328	0.1425
Relative absolute error	29.2968%	26.8315%
Root relative squared error	48.8664%	52.4427%

4. Conclusion

Our new methodology enables one to specify which decision tree leaves in the original data set should be hidden and then to judiciously change certain attribute values in specific instances. This technique could be extensively used in sharing medical data by helping to hide only the sensitive patterns without affecting all the remaining valuable information. The short-term development objective is to have the technique proposed as a standard data engineering service to address hiding requests.

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Establishing User Requirements for a Norwegian IBD Mobile Application

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Abstract. Six people with Inflammatory Bowel Disease (IBD) were interviewed in a natural setting with the purpose of defining requirements for a new IBD mobile application. The first part of the interview had open disease related questions, and the second part involved evaluating three publically available IBD applications. Results suggest that the most important user requirements could be met by implementing the following functionalities; registration of general well-being, bowel movements, and pain. All the study subjects believed in simple graphical solutions to register data and to represent the course of the disease in a satisfactory manner. It should be possible for a user to modify information and enter notes regarding changes of medication, diet, operations. The main features must meet the most general needs, while allowing users to enter unique information. This could serve as a practical guideline for developers.

Keywords. Inflammatory bowel disease, self-management application, user requirements, prototype.

1. Introduction

Inflammatory Bowel Disease (IBD) is an umbrella term used to describe disorders that involve chronic inflammation of the digestive tract. The term include two types: Ulcerative colitis (UC) and Crohn's disease (CD) [1]. An increase in the prevalence of IBD over the past ten years has led to an increased use of health services and longer waiting lists for people with IBD. Self-management is thus an important tool for people with IBD when dealing with the various symptoms that can arise in everyday life.

When developing a mobile application for self-management, it is important to consider perspectives from both patients and medical personnel [2]. The main motivation for designing an IBD application is to meet the user needs of persons living with the disease in Norway. A well-informed design is likely to be both relevant and competent for Norwegian users. Six people living with IBD were interviewed to establish user requirements for a new IBD mobile application.

Principally, there are functional requirements to consider; users should be able to register symptoms and follow the disease course for their own sake, but also to share it with doctors during consultations. Ideally, the application would use the registered data to inform the users when they should contact medical personnel. Of the non-functional requirements, the application should encourage user friendly and regular entries to fulfil

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its monitoring and self-management purpose. The paper focuses on establishing user requirements as a part of designing a prototype of an IBD application.

2. Method

Six people with IBD were interviewed in a natural setting in Bergen, Norway, during the spring of 2018, with the purpose of defining requirements for a new IBD application. The interview consisted of two parts. The first part with open disease related questions, and the second part involved evaluating three publically available IBD applications, "Bowelle" [3], "IBD-app" [4], and "myIBD" [5].

Study subjects were recruited via a patient organization called "The National Organization for Digestive Diseases", which is a Norwegian organization for people with IBD. There were three males and three females, aged between 20 and 60 years. Three of the participants had a CD, and three had UC. Experience with the disease varied in degree, both in terms of how long they had lived with it, and how the disease affected them in everyday life. Three people reported that they were in remission, while three people had been through operations and/or felt the disease negatively affected them in terms of pain and other challenges.

The purpose of the first part of the interview was to get information about the subjects' experiences with the disease and with technology. For example, on handling symptoms, patient-doctor consultation, and their experience with IBD mobile applications. During the second part of the interview the subjects were asked to evaluate three IBD applications. For this purpose, we used a Likert Scale [6] to identify the most preferable functionalities in already available IBD applications. In addition, we conducted an in-depth case study with a person who had lived with UC for six year with the objective to find the most suitable functionalities and design features.

3. Results

Five of the participants thought their IT skills could be described as average. An average user would use a PC and mobile telephone daily and is capable of trying different programs. One of the subjects classified as well above the average in terms of IT skills, due to his current profession in the IT industry. Regarding the functionalities, four had not used a similar application earlier and had no concrete examples of functionality, but rather general remarks on how it could work. They thought the key was that an application should be simple and quick to use, and it should not be associated with any stress. It should also follow the course of the disease and present it in an understandable manner. One subject had occasionally used the application IBD-app earlier, but stopped using it because it crashed several times.

One of the subjects' actively used the IBD-app and had specific suggestions regarding functionality. The subject considered registration of pain and toilet visits as the most useful features, and pointed out that it should be possible to register multiple toilet visits during the day. The subject also thought that if the results were to be presented as a graph, it should be possible to get more information out of the graph, such as high activity points through use of colors. There were also suggestions regarding design features, i.e. to use simple icons such as rolls of toilet paper and smileys that could simplify daily registrations.

In the second part of the interview three applications were evaluated. The focus group believed that the application “Bowelle” was the most simple and straightforward to use. All the applications had functionality for registering intestinal activity, and all six subjects’ believed that “Bowelle” was the best. “IBD-app” and “myIBD” had also functionality for registering pain with “myIBD” as the preferred solution. Four of the subjects mentioned that pain scale from 0-10 used in “myIBD” was a good choice since the same scale is also used by doctors. All subjects preferred results presented in graphs, but would add type and cause of pain. The group feedback resulted in three main functionalities, namely; registration of “General well-being”, registration of “Bowel movement” and registration of “Pain”. It was also suggested that a collection of the registered data should be presented in a graph. A low to mixed-fidelity prototype was developed (Figure 1) to visualize the concept and functionalities.

Figure 1 illustrates "General well-being", "Bowel movement", and "Pain" wireframes. It should be possible to press each of them to register more information, for example adding a bowel movement or register pain from 1-10. At the top of the application, users can follow the course of the disease, where each point on the graph represents a day. In the menu at the top right, users can enter medication, reminders, and see a report showing historical data they have entered.

Figure 1. A low to mixed-fidelity prototype based on feedback from the focus group.

4. Discussion

According to Nielsen and Levy [7] “one has a reasonably large chance of success if one chooses between interfaces based solely on users’ opinions”. The method in this study could be considered as a user-centered approach, which is the recommended method to use in the medical domain because it enables and actively encourages understanding into user needs and requirements [8]. It would have been beneficial to include more study subjects which is something to consider in future development.

It was commonly understood by the group that a new application should be simple and straightforward to allow frequent use. Three most relevant functionalities were;

"Register general well-being", "Register bowel movement", and "Register pain". However, there was a wish to have individual possibilities to register unique information which would put demands to design customizable solutions. For example, register information about change of medication or sudden weight loss could be beneficial.

During the interviews, it became clear that all the study subjects believed that a graph in itself did not represent the course of the disease in a completely satisfactory manner.

Therefore, it should be possible for a user to modify information and enter notes regarding change of medication, diet, operations. One of the subject said during the interview that alcohol could lead to pain. This too would be unique information for this user that could be entered as a note in the application.

Because IBD is considered to be an unpredictable disease that requires individual adaptation, it becomes difficult to create an application that meets every need of each patient. The main features must then meet the most general needs, while allowing users to enter unique information. This could serve as a practical guideline for the developers.

5. Conclusion

Results from interviews with persons living with IBD led to low- and mixed-fidelity prototypes of a self-management mobile application. The most important user requirements are met through the following functionalities; *registration of general well-being, bowel movements, and pain*. Certain features should be personalized when needed; graphs and standardized pain scale are preferable. Future work includes heuristic evaluation of the new application and multiple evaluations with patients and medical experts using System Usability Scale (SUS) to measure perceived usability. In addition, a clinical trial should be conducted with a larger number of study subjects to understand the clinical value of an IBD application.

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Confocal Laser Endomicroscopy for Intraoperative Tumor Assessment: Development of a Conceptual Model for an Evaluation Study

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Abstract. Brain tumor surgery is a complex medical procedure. The extent of tumor resection is essential for postoperative recovery and survival. The neurosurgeon needs to regularly check the borderline between healthy and cancerous tissue. Currently, tissue samples are extracted via instantaneous sections and sent to a neuropathologist for examination. This process takes time and requires extensive human resources. Confocal laser endomicroscopy (CLE) allows visualization of cellular structures in vivo without the need for sample extraction. This paper presents a conceptual model which serves as the hypothetical basis for a planned intervention study to evaluate CLE with the case example of brain tumor surgery. Using current literature and expert interviews, the model has been tested. The expected improvement of the medical outcome could be confirmed. Regarding the socioeconomic impact of CLE, the literature is scarce. Expert interviews confirmed the hypotheses that costs and the workload for clinical staff might increase.

Keywords. Confocal endomicroscopy, digital biopsy, neuropathology

1. Introduction

Brain tumor surgery is a complex procedure. The extent of tumor resection is essential for postoperative recovery and survival [1-3]. The neurosurgeon needs to regularly check the borderline between healthy and cancerous tissue. Depending on tumor type and penetration, it can be difficult to impossible to determine the border intraoperatively [4; 5]. Currently, tissue samples are extracted via instantaneous sections and sent to a neuropathologist for micro- and macroscopic assessment. Transport, examination and redelivery of results prolong the surgery. According to scientists it is not uncommon for the surgeon to wait up to 45 minutes before continuing with the operation [3].

Digital technologies are considered to be an essential stimulus for improved processes in medicine. Telemedicine, remote diagnosis or therapy with information and

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communication technologies, is especially promising [6]. Confocal laser endomicroscopy (CLE) digitalizes the biopsy process and has the potential to accelerate intraoperative decision-making and improve patient outcome. This article describes a project aiming to evaluate CLE using the tool CONVIVO (Carl Zeiss AG, Figure 1). CONVIVO is equipped with a confocal microscope located in a handheld scanner probe which can be placed on the tissue surface. Cellular tissue structures can be visualized in vivo during surgery and are shown on a monitor. There is no need for sample resection.

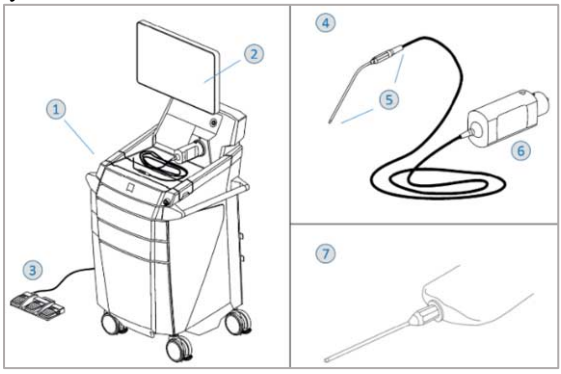

Figure 1: Main components of CONVIVO including sterile sheath. (1) Cart, (2) touchscreen monitor, (3) foot control panel, (4) scanner unit, (5) scanner probe, (6) coupler unit, (7) sterile sheath [7]

2. Methods

The increasing availability of digital devices in health care, rises the need for assessment studies. The planned pilot study (funded by the Bavarian Ministry for Science and Arts) aims to test CONVIVO at the Technical University of Munich Hospital using the case example of brain tumor surgery. The device will be connected to the Department of Neuropathology for remote image analysis. We intent to evaluate both socioeconomic and medical indicators to measure the tool's impact. Examples for evaluation criteria are economic feasibility, usability, data reliability and medical outcome. The study started in January 2019 with a duration of 36 months.

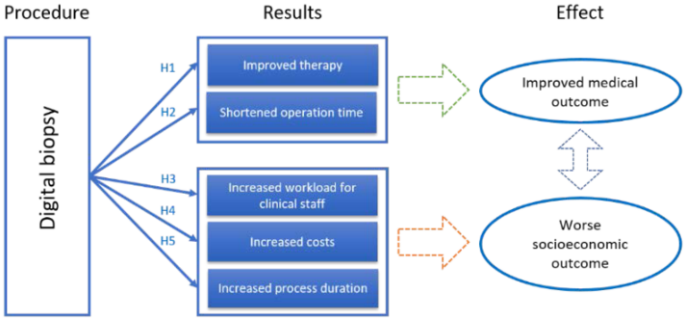

Figure 2: Conceptual model visualizing the hypothetical basis for the project

To establish a common theoretical basis and guide future project activities, the authors began by developing a conceptual model (Figure 2) to determine and visualize the working hypotheses following the framework suggested by Gray and Sockolow [8]. The model was tested analyzing current literature and conducting seven interviews with

experts from various relevant backgrounds including neuropathology, neurosurgery, nursing, quality management and medical engineering.

3. Results

Several studies have shown that CLE combined with a fluorescent agent allows for better resolution and determination of tumor edges. Faster histopathologic examination and more extensive resection are possible. The procedure is non-invasive and the number of samples is not restricted [2-4; 7; 9]. An additional benefit is the shorter time needed for surgery which is also advantageous for patient recovery [2; 9]. All seven interviewed experts confirmed the assumptions of an improved medical outcome and the chance to avoid reoperations using CLE (quotes translated from German by MF): *"If it is reliable, it is great and can increase efficiency and in particular patient safety and avoid reoperations.", "Using digital biopsy processes will be sped up. We will have markedly shorter surgery duration; we do not have to bridge the time gap until the results arrive."*.

Few studies report on socioeconomic outcomes of CLE. We assume that the procedure harbors technical and operative challenges. The device must be scheduled, prepared and maintained for surgery, which was also mentioned by the experts: *„For the nurse, I think, it probably means an increased effort. […] It is another piece of equipment that has to be prepared for surgery and maintained."*. All clinical staff has to be trained and in particular surgeons and pathologists need to get accustomed to CLE-images [1; 3]. The neuropathologist must be available on call, ready to assist with the diagnosis. An increased workload for all clinical staff is expected.

Initial investment costs for CLE are high, which was mentioned by experts: *„Replacing a procedure that normally costs approximately 16€ with a device that costs half a million - the question is, if this helps."*, *"I think there are systems that make sense and help to save money but innovation is always expensive in the beginning."*. The literature did not mention the cost aspect. Work flows in neurosurgery and -pathology will change as confirmed by both literature and experts [3; 4; 9]: *"To have neuropathologists in centers that diagnose via telepathology at some point, will be reality, I think."*. However, no evidence could be found confirming an increased process duration overall. Table 1 summarizes these preliminary results.

Table 1. Overview of results

Hypotheses	Literature	Expert Interviews
H1	confirmed	confirmed
H2	confirmed	confirmed
H3	partly confirmed	confirmed
H4	not confirmed	confirmed
H5	not confirmed	not confirmed

4. Discussion

Available literature primarily focuses on the medical outcome of CLE. H1-H3 (improved therapy, shorter operation time, increased workload) could all be confirmed, at least partially. The literature does not include evidence on an increase of costs. Consequently, H4 could only be confirmed by expert interviews. Peyre et al. [5] recommend to combine CLE with fluorescence-guided surgery to increase cost-efficiency, suggesting high costs

of CLE. Certainly, investment costs for the device are high. Streamlining the process and reducing operating costs might counterbalance initial spending. The economic feasibility of the procedure requires further investigation.

CLE promises medical improvements by reducing errors, shortening operation time and decreasing the number of reoperations [2]. The technique is not yet equivalent to instantaneous sections and scientists currently do not agree whether it should replace [2; 3] or only complement the current procedure [1; 5]. CLE is more expensive, including not only investment costs but also potentially process costs, and increases the workload for clinical staff. Neurosurgeons and –pathologists are not familiar enough with CLE-images to replace instantaneous sections [3]. Process duration might increase through use and maintenance of the device (H5). It is however possible that time saved during surgery and gained efficiency compensate for the increased process complexity.

Study limitations include a lack of generalizability of interview data. The data represent opinions and the analysis is person-dependent. CLE in neuropathology is a very specific topic and results might not be transferrable to other areas. The seven interviews are not sufficient to confirm the hypotheses. The literature review was not exhaustive and existing studies might have been missed. Nevertheless, the results strengthen the hypothetical basis and provide support and justification for the planned study.

Neuropathology is a highly specialized field and CLE provides a chance to more efficient use of this expertise. The development of telemedical centers where one neuropathologist assists several clinics could reduce the personnel demand and contribute to overcome socioeconomic challenges mentioned here [2; 3; 10]. Further research and evaluation of the method is necessary to advance the establishment of CLE.

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Colorectal Cancer Registration: Data Approach to Knowledge

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Abstract. For ensuring the quality of data and facilitating data exchange between healthcare providers and professional organizations, it is necessary to define a standard data set. The main aim of this study was to define a national minimum data set for colorectal cancer in Iran. To develop this data set, a combination of literature review and two rounds of a modified Delphi technique were used. An initial checklist was proposed based on a literature review and comparative studies. Based on the literature review, main categories, including: demographic information, diagnostic information, treatment information, clinical status assessment information, and clinical trial information were proposed. In this study, the national minimum data set of colorectal cancer was collected. Developing this data set through standard contents can improve effective health information exchange for both healthcare providers and health information systems.

Keywords. Minimum Data set, Registry, Colorectal Cancer

1. Introduction

Colorectal cancer (CRC) is one of the most common invasive cancers in the world and causes physical, emotional, and social problems [1]. CRC is the third most common cancer in the United States [2]. In Iran, the standardized incidence rate is 11.3 in men and 10.9 in women ($p < 0.001$) in 2009 [3]. In Iranian men, CRC incidence ranks 5th and 3rd in women, and it is 4th in overall cancers [4]. The Existence of Information as a mediator in effective care and treatment is essential in health-care systems and should be distributed properly among users of health-care systems [5]. The World Health Organization (WHO) has mentioned that accurate, timely, and accessible healthcare information has a crucial role in planning, development, and supporting healthcare services [6]. To ensure the quality of collected data, professional organizations have attempted to provide and distribute guidelines for Minimum Data Sets (MDS) for different kinds of cancer [7]. Variation in data collecting processes do not allow the use

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of patient data for directing efficient care processes and also limit the reusability of them for other applications [8]. The purpose of designing such data sets for colorectal cancer is to facilitate communication between healthcare providers and to increase the reusability of information through avoiding repeated tests for patients in various referral settings. Because no such a data set exists in Iran, we decided to design a data set of required information related to colorectal cancer registration using national and international guidelines and expert opinions for specific documentation of colorectal cancer in Iran.

2. Methods

This applied descriptive study was conducted in Tehran and Mashhad, two cities of Iran. The researchers used mixed methods to extract data items. In first phase a complete literature review was done in PubMed, Science Direct, Scopus, Google Scholar, Magiran, SID, and Iran Doc Iranian websites, both in English and Persian. All of these resources were considered and relevant data items were extracted and inserted into a checklist with checkboxes entitled "yes" and "no" for each item and had enough free space to write in additional comments from the participant. In second phase we used Delphi technique. We invited 15 medical informatics specialists, 15 surgeons, and 15 oncologists. Participants were asked to give us their comments and suggestions about the necessity of all elements. Whenever more than two-thirds of participants agreed on the necessity of an item, it was considered essential and was entered in to the second checklist. Finally, this phase was completed in 2 rounds of Delphi. The prepared checklist was standardized by clinical physicians and informatics specialists, and the data set was finalized.

3. Results

In first phase 85 data items were obtained and classified as 10 categories. In phase2, total of 15 medical informatics, 7 surgeons, and 7 oncologists responded to our invitation. Participant's comments and suggestions were considered for development and improvement of the checklist. For every item, these comments were reviewed separately by researchers and used to develop the second checklist (Table 1).

Table 1. Categories of Data Items in Two Rounds of Delphi.

Main Categories	Sub-Category Information	Round 1 Data Items	Round2 Data Items
Demographic	Referral	11	10
	Patient Identification	11	9
Diagnostic	Colonoscopy	21	16
	Pathology	20	19
	Diagnosis	7	6
Treatment	Treatment	15	22
Clinical Status Assessment	Clinical Status Assessment	7	9
	Palliative Care	4	-
	Completion of Primary Treatment	2	2
Clinical Trial	Clinical trial	2	2

Most of the recommendations were related to the treatment and side effect of colorectal cancer including categorization and integration of elements in the treatment

category. In round2, the subgroup related to palliative care was omitted. Data elements were standards by 2 medical informatics specialists.

4. Discussion

In this study, a complete data set of colorectal cancer was gathered. This study was done in three phases and used combined methods including literature review and a Delphi technique. This data set was classified into 5 main of "demographic information," "diagnostic information," "treatment information," "clinical status assessment information," and "clinical trial information." According to our investigation, this study is the first of its kind in colorectal cancer in Iran.

In Iran, all kinds of cancers are recorded through the National Program Cancer Registry in Ministry of Health. Cancer recording in Iran started 30 years ago. Under the best conditions for cancer recording, 80% of cancers could be reported by pathologists and other cancers such as lung or liver cancer that are not diagnosed by biopsy can be reported by a population-based cancer registry method [9]. This program is not specific enough to record complete information for each cancer.

Cancer documentation systems in different countries can be classified into main groups, including demographic data, tumor, and its treatment, and information about death [10]. The present study had 5 categories including these 3 main categories. Diagnostic information included colonoscopy, pathology, and final diagnosis information. Because the gold standard of colorectal cancer diagnosis is colonoscopy [11], we did not include other diagnostic methods such as imaging in this study. High-quality histopathologic reporting is crucial in colorectal cancer management, which includes cancer stage and completeness of surgical excision, and can be used to predict progression and future treatment options. Therefore, it is essential that the pathology report should include accurate data for these purposes [12]. To achieve this aim, we searched for protocols and MDS for reporting histopathology of colorectal cancer. Finally, 4 studies [13-16] were considered and compared for essential data items that should be provided in histopathology reports. Common data items in these studies were imported to our checklist in phase 1.

Treatment information categories included treatment plan and type of treatment that included surgery, medicines and chemotherapy, and radiotherapy. If the treatment plan is changed, data items for recording the cause of this change should be considered. Categories of clinical status assessment consist of metastatic status, laboratory information, number of appointments, comorbidity, recurrence date, complications, and information about death. The last category is clinical trials that patients might participate in. It is reported that 35% of colorectal cancer patients in Iran had a family history of colorectal cancer and 42% were under 50 years old. Also, it was suggested that genetic factors can be important in its progression [17] . In our study, data about family history were available but the professionals did not suggest investigation of genetic factors or their role. This could be due to its not being a priority or because of the high cost and its being time-consuming. Moreover, tumor size, tumor stage, distant metastasis, and tumor grade are the most important prognostic factors for colorectal cancer [18], which have been considered in our study. Because this study was the first of its kind in Iran about a minimum data set of colorectal cancer, it maybe need ongoing updates. Future investigations can study the reliability and validity of the present study results, focus

group meetings on grading the most important data items for colorectal cancer registry, and determine priorities in Iran.

This dataset can improve cancer registry and prevent additional costs of repetitive tests and accelerate research processes. In technological view, it can increase interoperability and facilitate data sharing between health care systems.

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Fundamentals of Implementing a National Clinical Registries Program

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Abstract. A National registry program is a resource intensive initiative involving multiple stakeholders, multi-institutional/multi-role/multi-users collaborative effort, where various aspects starting from work culture, research culture, registry conceptualization, resource availability, data format, data storage/retrieval techniques, data sharing protocols, data/dataset standards, data quality etc. vary drastically between different institutions. The biggest challenge for a national program will be to map these aspects under a common umbrella to establish standards for operations/execution, policies and procedures, which means aligning the registry operations with the operative process of each institution at first, due to this only a handful initiatives are implemented with limited success, hence it is advisable to study such implementations in great details as a guideline to build a solid foundation for future national initiatives[1][2].The idea goes around building a solid database for holding all clinical registries under a single repository, along with streamlining and generalizing the policies and procedures for any disease or medical device registry, in order to save infrastructure spending, streamlining, saving on management and operational costs and overheads.

Keywords. Clinical Registries, National registry, registry electronic data capture

1. Introduction

Clinical registries have been identified as a source of information and evidence for patient collective monitoring and the generation of decision-making about specific diseases/disorders and medical devices since the late 1980's. [1]. The experience in implementing various national registries within the kingdom of Saudi Arabia would be a reference for the process, activities, methods and protocols to be discussed further. A national registry application would ideally record patient's information which would including the basic demographic data, patient's medical history, diagnosis, procedure, and follow-up information. The program would have a nationwide coverage, running in collaboration with various tertiary care specialized centers for specific diseases or devices. This registry program forms an umbrella for various disease / device registries. The Aim of the paper is to generate a roadmap for any ideal national registry program within the kingdom of Saudi Arabia or the Region.

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2. Methodology

A high-level design needs to be drafted to have multiple registries under a unified platform to be run as a comprehensive registry program on a national level. A high-level dataset and database needs to be defined in order to organize the data elements within each registry with a robust and dynamic structure taking into consideration the multi-institutional and multi-disease aspect of the program. A step-by-step process starting from conceptualization of the idea till the execution of the pilot run would be documented, so that it forms well defined model comprising guidelines and procedures which will build a foundation for any other national registry or a program.

3. Conceptualization & Planning

3.1. Concept

The concept involves establishing a multi institutional national registry program holding multi disease/device/disorders as individual registries, this demands a complex architecture as far as the system development or data structuring is concerned. The conceptualization process consists of two major areas: Designing a dataset for the diseases/devices to be included in the registry at the initial phase, and studying the feasibility across the major participating hospitals to identify the availability of the data/resources, the EHR implementations at the site, data warehousing capabilities, methods of data extraction and data capture, quality control process, audit etc.

3.1.1. Drafting a development plan

A team of experts in different areas needs to be instituted as a part of the planning team, to cover all major aspects such as the data set development, designing policy, procedures and operational guidelines, designing a comprehensive electronic system, for data capture, reporting and analytics[3], also covering the administrative and operational aspects. A separate scientific committee needs to be instantiated, which would include the industry experts, medical specialist and research experts, the purpose of which would be to give proper direction to the initiative to provide a better scientific approach generating good clinical outcomes.

3.1.2. Defining the Data-Set structure and Design

After intensive literature review and analyzing the best practices of various individual disease / device registries worldwide, data elements were studied based on which the common minimum dataset was conceptualized, where common and standardized data elements were framed into a common minimum dataset. Information like patient's demographics remain common irrespective of the devices/registries, whereas the patient's history and the diagnosis information capture can be classified using ICD-10 AM; all this information defines the common minimum dataset [4]. It was observed that only the surgery/procedure and follow-up information include differential information based on the device type. The common minimum dataset was used as the template for finalizing any device dataset which involve mere modification to the surgery/intervention and follow-up entities of the dataset. Any registry dataset in general commonly covers the 5 aspects; namely the demographics and socio-economic

information, patient's medical history (including chronic conditions), primary/secondary diagnosis for patient presentation, the surgery/procedure/therapy for the specific disease/device and the follow-up.

3.1.3. Feasibility Study

The feasibility study would be a kind of assessment survey which is carried out at a few major participating institutions/hospitals. The purpose was to develop the best framework for a national level that serves the objectives of the program as well as to check on the readiness of the institution in accepting the draft framework of a national registry initiative. The primary aim of this assessment survey is to verify on a few aspects such as resource availability, data entry/extraction methods, data availability, Electronic Health Records implementation, data warehousing capability, current procedural abilities and future planning capacities. Also, an assessment visit is paid to cross validate the common minimum dataset and gather a few inputs of key data elements and garner other suggestions to build synergies of all parties involved [5][6].

4. Research & Development

Based on the program blueprint three core teams needs to be instituted to work on each major aspect of the program (discussed below) these teams would necessarily do their homework by carrying a thorough literature review, review case studies and follow the regulatory guidelines and standards to outline the framework to comply to in order to develop their expected outputs.

4.1. Data Set Design

Based on the common minimum dataset as a foundation a comprehensive dataset for different disease/devices were derived, with reference to various device specific registries globally and other literature specific to these devices, as mentioned earlier the surgery/procedure/intervention/therapy was the only area where differential or device specific data elements which are critical or rather significant enough to be included in the device dataset, and their inclusion was covered with a solid justification. The data set elements were coded, and necessary data dictionary was created [4].

4.2. Design and Develop Policies, procedures and operations guidelines

Based on the policies of the provider, an operational framework needs to be defined which should include the policies covering all the aspects of a national program and related procedures to be followed in order to run this national initiative. The program is supposed to run in accord with the laid down framework, including operational protocols and the defined data governance policies [2].

4.3. Designing and developing an Electronic System for the registry program

The electronic system forms the heart of the program, which acts as an information exchange hub, hence needs to be designed taking into consideration the complexities of a national program. Developing the multi-registry electronic database for various diseases/devices under a single repository was a challenge, due to the complex nature of

the datasets related to various devices which had to be streamlined under a single umbrella. A dynamic approach needs to be followed in order to achieve the required results, where the system would be split into 2 applications; the administrative application would give the administrator the power to create and manage users, roles, privileges, classification data, search parameters, and other administrative aspects of the mother registry, also it would include a tool to create dynamic data capture forms based on the defined data set for each registry keeping the demographics, patients history and diagnosis standardized [1].On the other hand, the registry application needs to be multi institutional where the user access was institutional as well as role based, these roles were flexible enough to give the user different kind of access cascading to the form or even variable level. Proper security measures should be in place to handle the data privacy and confidentiality within institutions and even between users. The application access needs to be privilege based covering all the necessary features for data entry/management/download/search/ analytics and custom reporting [6].

5. Training & Pilot Run

Training and knowledge transfer workshops need to be held at each participating hospital for each of the registry. Where hands on training is provided to the research registrars, investigators and the data entry staff. This included interactive discussions/interactions pertaining to the structure of the dataset/electronic system/policies and procedures, followed by real time use and application of the data set and policies over the system.

6. Discussion and Conclusion

It is indeed a huge challenge to integrate the multi registry data from coming from various institutions nationwide, under a single platform, secondly running the nationwide operations seamlessly is another challenge where change management needs to be very well planned with effective and efficient training and support. The approach followed is well studied and well implemented in a step by step manner to ensure success, where these best practices are well extracted from the experience in implementing various national registries. Challenges faced are mostly related to data availability, data extraction, and system integration, and interoperability which can be automated in the future by creating standard API and a data warehouse-based integration approach.

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Drug Interaction Advisory Service for Clinical Decision Support of Multimordity Patient Centric Care Plans in the C3-Cloud System

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Abstract. C3-Cloud is a project aiming to provide an ICT infrastructure, which will allow patient centric and integrated care, based on best practice guideline, for patients with multi-morbidity. Clinical Decision Support, by checking the patient's record for known adverse interactions when the medication changes. The drug interaction advisory service provides recommendations in the three languages used in the project's pilot sites, for over 1000 substances, based on the UK's NICE BNF body of knowledge.

Keywords. pharmacovigilance, multi-morbidity, clinical decision support

1. Introduction

C3-Cloud is an e-health ICT system, offering integrated, patient-centered care, considering all aspects of multi-morbidity, creating a collaborative environment for all involved stakeholders [1]. The navel of the system consists of the patient care plan, a digital shared picture of the patients' needs and care regime. The care plan allows all professionals to review and understand the implications of one condition in the presence of others; this by its nature is complex, containing a considerable amount of diverse information. Navigating, understanding, and interpreting all the information can be confounding. The C3-Cloud Clinical Decision Support service (CDS) offers an automated means of interpreting the available data. CDS connects to the care plan repository, and continuously searches records for relevant data. One of the CDS services focuses on potential drug-drug interactions. The current implementation of C3-Cloud cares for multi-morbidity patients with up to four conditions, including diabetes, renal failure, chronic heart failure, and depression. Medication regimes for this combination of conditions may include drugs that when combined, may result in adverse reactions [2]. Drug Interaction Advisory Service (DIAS) is part of the C3-Cloud CDSS, offering advisories of potential interactions.

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2. Drug Interactions Service Architecture and Integration with C3-Cloud

C3-Cloud has adopted a modular architecture, which can be deployed locally on an organization's intranet, as well as a distributed system; depending on the scale and integrated care model [3] requirements of the service that needs to be offered to patients.

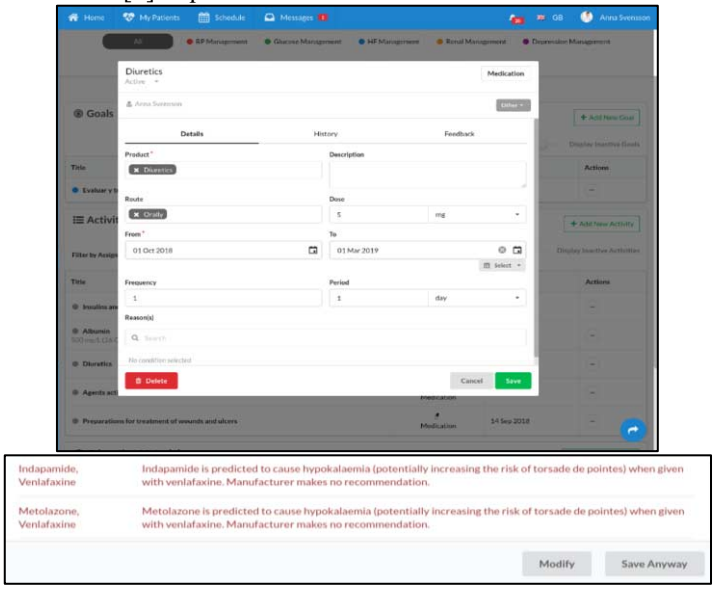

Figure 1. a) C3DP (care plan) medication prescription view (top) b) test extract from the interactions notification pop-up dialogue (bottom); it gives interactions between diuretics (ATC: C03) and existing medication in the patient's record.

The Patient Empowerment Platform (PEP) provides a dedicated interface module to the patient, adapted to their needs. The Coordinated Cure and Care Delivery Platform (C3DP), shown in figure 1a, offers the interface to healthcare professionals, who will create, monitor, negotiate and customize a care plan with the patient. When loading a care plan from the repository, the C3DP will interact with the Clinical Decision Support (CDS) service, and will receive a number of automated recommendation. All communication amongst C3-Cloud components, as well as storage of information is achieved by accessing FHIR resources.

Healthcare professionals can amend a patient's medication via the C3DP. When a new medication request is entered the C3DP will issue a request to DIAS with the ATC codes of the patient's medication. DIAS will then return a list of all the identified interactions amongst the substances that correspond to the ATC codes. The service can check all codes in a record, as well as only potential interactions of a newly prescribed medication. The latter is the default notification method, by a pop-up dialogue, to avoid fatigue alert. DIAS is accessed via a RESTful API using a GET request, and returns the results in JSON. Figure 2 shows an example of a request checking 3 ATC codes (Fig.2a), and an extract in JSON (Fig.2b) from the returned result. The JSON results are then presented in a friendlier format, in a pop-up dialogue (Fig.1b), once the user clicks the save prescription button, and only if interactions are found. The service returns an advisory and does not make any decisions. Furthermore, users are advised that lack of interactions, may not necessarily mean that there are not any, as this is limited to the knowledge body of the specific database.

```
GET https://DIAS_Service_Host/ATC?code=J01CA04,B01AA03,G03XA01
```


```
{
    "DIAS_id": 101762,
    "chemical": "Warfarin",
    "chemical_ATC_code": "B01AA03 ",
    "interactant": "Amoxicillin",
    "interactant_ATC_code": "J01CA04 ",
    "interaction_criticality": "Severe",
    "interaction_effect": "Amoxicillin potentially alters the anticoagulant effect of warfarin.
        Manufacturer advises monitor INR and adjust dose.",
    "interaction_effect_ES_auto": "La amoxicilina altera potencialmente el efecto anticoagulante de la
        warfarina. El fabricante aconseja monitorizar el INR y ajustar la dosis.",
    "interaction_effect_SV_auto": "Amoxicillin förändrar potentiellt warfarins antikoagulerande
        effekt. Tillverkaren rekommenderar att INR kontrolleras och dosen justeras.",
    "interaction_evidence_basis": "Anecdotal"
},
```


Figure 2. a) A typical DIAS GET request (top) b) extract from interactions returned in JSON (bottom).

3. Design of the Drug Interactions Advisory Service

DIAS implements the interactions between drugs, as specified by the National Institute of Care Excellence's implementation of the British National Formulary (BNF) [4]. BNF is a pharmaceutical reference book, used by the UK NHS. The information provided by the service, includes potential adverse interaction between substances, the effects of the interaction, the severity of the interaction, as well as the evidence basis of interaction.

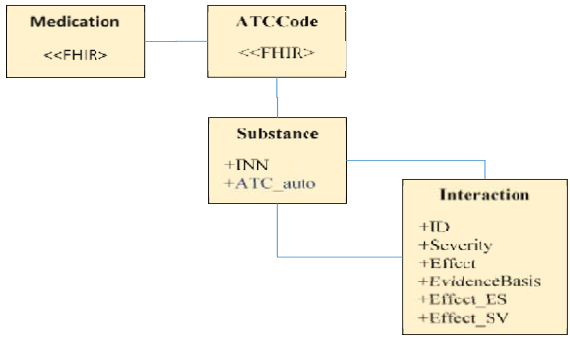

Figure 3. The DIAS Database Model.

For example, Acarbose is a drug active ingredient Alpha-glucosidase inhibitor, commonly used by patients with type 2 diabetes, reducing the effects of carbohydrates on blood sugar. Acarbose is listed as having a pharmacokinetic interaction with Digoxin, used for congestive heart failure to improve quality of life and prevent hospitalisation. The interaction is listed as moderate in criticality, decreasing the concentration of Digoxin. The information is encoded as a database using as the international nonproprietary name (INN) of each substance. Substances have been matched to the ATC codes automatically using the NCBO BioPortal's [5] mappings, whereas the ATC codes in the patient's care plan have been coded by C3-Cloud clinicians. The mapping was tested with random sampling covering 50 substances. The database contains over 50,000 interacting pairs of substances for over 1,000 substances. Figure 3 shows the logical view of the database. *Medication* and *ATCCode* are data from the FHIR

repository, accessed through the C3DP, whereas *Substance* and *Interaction* are the DIAS entries. *Substances* are associated via an *Interaction*. *Severity* of an *Interaction* can have the values *Severe, Moderate, Mild and Unknown,* and *EvidenceBasis* can be *Study, Anecdotal or Theoretical.* Effects have been translated to Spanish and Swedish for the pilot sites. Translation was done using an automated translation service, and tested with manual random sampling. C3DP gives the option to users to access the original language as well as to flag a translation issue.

In ATC, substances are classified in a 5-level hierarchy, which from the higher to the lower level contains: anatomical main group, therapeutic subgroup, pharmacological subgroup, chemical subgroup and chemical substance [3]. The hierarchy of ATC codes allows for further flexibility, offering identification of potential interactions between substance and classes of medication. For example, the service can check for interactions between plain ACE inhibitors (C09AA) which is a chemical subgroup, with blood glucose lowering drugs, excluding insulins (A10B), which is defined at the pharmacological subgroup. Although this trades coverage for accuracy (54 interactions), this was considered a more realistic implementation as in many cases, patient records will contain information that matches a higher ATC level. It was decided that the advisory should be offered to healthcare professionals who could investigate further.

4. Summary

The Drug Interaction Advisory Service is a component of the C3-Cloud integrated care for multi-morbidity, IT infrastructure. It provides the system with over 50,000 interactions between chemical substances, in three languages. It has a RESTful API and returns results in JSON, which are shown during medication changes in a patient's care plan. Future work will extend DIAS to include advisory on probability of side-effects.

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Developing a Digital Mental Health Platform for the Arab World: From Research to Action

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Abstract. Individuals within the Arab world rarely access mental health services. One of the major reasons for this relates to the stigma associated with mental disorders. According to the World Health Organization (WHO), untreated and undiagnosed individuals living with moderate to severe mental health disorders are more likely to die 10-20 years earlier than the estimated life expectancy of the general population. Mental disorders also cause a large amount of costs to economies. Access to mental health services is out of reach for many individuals within in the Arab world due to insufficient planning, inadequate community resources, and military conflicts. Online mental health information and services are growing within the region; however, they are embedded and often sidelined within a wealth of other general health information. The purpose of this paper is to present the conceptual framework of the Mental Health Assistant (MeHA) digital platform being developed for the Arab world. The aim of this platform is to provide mental health information and educational resources through the use of a conversational agent, multi-media information, and to digitally connect patients with mental health service providers. The conceptual framework for the platform is based on mental health and information technology expert feedback, review of both academic and gray literature on mental health, and an examination of leading mental health digital platforms. As a result of this process, we developed a conceptual framework that will guide the development of the MeHA platform.

Keywords. Mental health, Arab world, depression, anxiety, Qatar

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1. Introduction

The burden of mental health disorders will cost the global economy close to $1 trillion every year until 2030 [1]. The one-on-one traditional gold standard approach for mental health interventions is too costly and labor intensive for today's health care system where digital technologies for self-care can provide the complementary support necessary to deliver mental health services to patients in need [1]. Within the Arab world, mental health remains stigmatized due to the social, educational, cultural and economic ramifications that come with being labelled as an individual living with a mental health disorder [2]. Although misinformation and stigmatization related to mental health is a worldwide phenomenon, the social repercussions and stigmatization for mental health disorders in Arab countries are so severe that it leads to denial and then blaming external factors such as supernatural or paranormal powers [3]. The fear of dealing with and recognizing a mental health disorder within the Arab world can lead a person towards social isolation and the feeling of shame [3]. To exacerbate the issue, many Arab countries have not adopted mental health legislation or a mental health policy [4]. With regards to the mental health workforce, the Arab world (7.7 per 100,000 population) falls below the global average of 9 mental health workers per 100,000 population [5]. There are also challenges for providing mental health services in the Arab world especially in conflict zone areas such as Palestine, Syria, Yemen, and Libya [6] where mental health services and personnel are ill-equipped to deal with the growing mental health epidemic arising as a direct result of conflict.

Today, there are a number of new technologies being developed to address the issue of mental health. In the mobile health sphere, close to 30% of the 15,000 mobile health applications available today focus on mental health. The vast majority of the applications primarily focus on one mental health condition such as depression and/or anxiety while ignoring other related mental health conditions [7]. Within the Arab world, in general, a gloomier picture emerges about the dearth of evidence-based as well as reliable mobile health apps that address local and regional needs. More work in the development of evidence-based and regional mental health apps in the Arabic language are needed for the Arab world.

The objectives of this project is to establish and evaluate the effectiveness of a personalized approach to the provision of mental health self-care services for individuals in the Arab world by developing a digital mental health platform using evidence based mental health guidelines and machine learning techniques. In this paper, we focus on introducing the conceptual framework of the Mental Health Assistant (MeHA) digital platform.

2. Methods

Multiple methods were used in the development of the conceptual framework guiding our approach to building the MeHA platform. First, a search of the mental health literature was conducted between December 15, 2018 and February 10, 2019. A team of experts in the Arabic medical language, computer science, human computer interaction, mental health industry, psychology and psychiatry were included as part of a team providing input and feedback into the development of the MeHA framework. Feedback from experts was obtained through individual discussions, group meetings, messaging service (text messages and WhatsApp), e-mails, and document feedback between

January 5 and April 10, 2019. A rapid review of existing digital mental health platforms, mobile applications, and serious games for mental health were also conducted within the same time frame to provide insights into the functionality and digital components that can be used for the MeHA platform.

3. Results

We developed a preliminary conceptual framework that is based on a variety of inputs, processes, outputs, and outcomes (ee Figure 1). Our assumptions are that individuals seeking mental health support will use MeHA for self-care. Our inputs are loosely based on the mhGAP Intervention Guide developed by the WHO guidelines psychoeducation and self-care concepts [8]. At this stage, we are focusing on the 18 to 64 age range for Arabic speaking adults. For **inputs**, we envision that patients will visit/use the MeHA platform to obtain information and register on the platform to share demographic information such as age, education, location, email and name or pseudonym. They may also browse the site, or use the conversational agent and/or chatbot to access MeHA services. The conversational agent will screen the individual using validated depression, anxiety, and/or stress scales/questionnaires. Once the screening is complete, a number of activities will be performed with the individual through the conversational agent. For **activities**, the conversational agent will provide the individual with information about their condition in the form of a video, infographic, or text. Then the individual will have two options; namely, connecting the individual to an online or local mental health provider or continue with the conversational agent with a cognitive behavioral therapy based on the severity of the assessment. For **output**, the users will be asked about their satisfaction using the service and if it led to any improvements in their mental health condition. For **outcomes**, we anticipate that continuous improvement based on user feedback will help inform, empower and educate individuals seeking mental health services for self-care and improve access and the delivery of mental health services to the population of the Arab world.

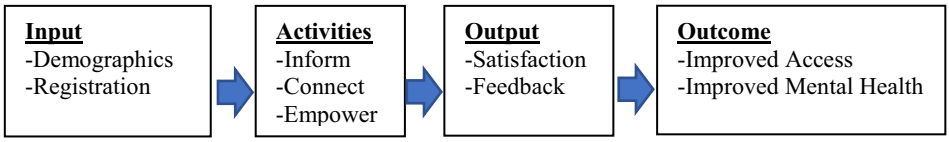

Figure 1. Conceptual Framework/Logic Model for MeHA digital platform.

4. Discussion

The preliminary work presented in this paper attempts to guide the development of the MeHA digital platform. The conceptual framework is based on the inputs from the literature, stakeholder feedback, and an evaluation of other mental health digital platforms. Although the work presented in this paper is preliminary, it builds the foundation of the future development of this project. We believe that the innovative features of this project include: (a) extension of existing digital mental health platforms to support adults and adolescents at risk for common mental health disorders by providing evidence-based and personalized mental health advice, recommendations and

support through a digital health platform at point of care and at home to be used by individuals and families; (b) development of a mental health digital platform in the Arabic language that can be used locally in the Arab world; (c) a comprehensive platform that will include more than one mental health disorder (e.g., anxiety, depression, phobias, post-traumatic stress disorders, bipolar disorders); and (d) providing access to low-cost and free mental health advice especially to individuals living in high conflict zone areas where access to mental health services is needed but limited (e.g. Syria, Yemen, and Gaza). With regards to limitations, collection of data was not systematic in nature, but was based on multiple rounds of input and feedback from the stakeholders involved in the project. The construction of the conceptual framework was developed based on the impressionistic views of the authors included in the study. We anticipate further validation of the conceptual framework as the development, testing, and evaluation of the MeHA digital mental health platform continues.

5. Conclusion

The access to mental health services in the Arab world is severely lacking and a need to improve individual access to mental health information, educational services, and access to mental health professionals will be provided through the MeHA platform. The preliminary conceptual framework presented in this paper provides a roadmap for further exploration into the development of a conceptual model for the MeHA platform. There are many technical challenges that need to be overcome in this research. One of the main challenges is the creation of an adaptive platform that "learns" overtime from its users. We believe that Active Learning will allow us to realize a platform that benefits from the wisdom of the crowd (i.e., patients and service providers). Also, the platform should be designed carefully to provide a "natural" interface to its users. Toward this end, we plan to depend on a story-telling approach that utilizes rich multimedia content (i.e., audio, video). The design of this multimedia content is a challenge and should be done carefully with advice from subject matter experts.

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Subject Index

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J. Mantas et al. (Eds.)
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Author Index