THE PRACTICE OF PATIENT CENTERED CARE:
EMPOWERING AND ENGAGING PATIENTS IN
THE DIGITAL ERA
Studies in Health Technology and Informatics

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The Practice of Patient Centered Care: Empowering and Engaging Patients in the Digital Era

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In memory of Assa Reichert
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Preface

The EFMI STC 2017 was jointly organised by the European Federation for Medical Informatics (EFMI) and the Israeli Association for Medical Informatics (ILAMI). The aim of EFMI Special Topic Conferences is to provide a forum for discussing achievements and actual experiences on specific topics in medical informatics. STCs are organised in close collaboration with EFMI Working Groups and the national society of the hosting country.

Carrying on the series of EFMI Special Topic Conferences started in 2001 in Bucharest, under the presidency of Assa Reichert and Rolf Engelbrecht, and it is of great appreciation to his lifetime achievements, that we hold EFMI STC 2017 in Israel in memory of Assa Reichert. EFMI STC 2017 is one of the key European events in the common sphere of medicine and informatics in this year. Its major goal is to increase interaction and collaboration between the stakeholder groups from both health and ICT across, but not limited to, Europe. The 2017 event has been actively supported by the EFMI Working Groups “Health Information Management Europe (HIME)”, “Education (EDU)”, and “Portable Personal Devices (PPD)”.

The theme of STC 2017 is “The practice of patient centered care: Empowering and engaging patients in the digital era”. STC 2017 provides a platform for researchers, practitioners, decision makers and entrepreneurs to discuss ways for sustainable and inclusive innovations aimed at patient’s/consumer’s uptake, engagement and empowerment. Realising the potential of consumers’ eHealth products (electronic tools for patients, informal caregivers and healthy consumers) in improving health care delivery and outcomes requires practitioners and designers to take account of existing diversity among users. This diversity contributes to differential access, uptake, and benefits derived from emerging eHealth technologies.

STC 2017 brings experience, innovation, new concepts and actual research and development into a constructive discussion resulting in a partnership for modernisation. Success stories but also failures which provide a basis for further improvement of health information systems’ applications will be presented.

This publication reflects the objective of the conference to highlight research and development supporting the use of information and communication technology (eHealth) at national, regional, and also at international level. It results in requirements for national and regional solutions for medical informatics and health information management.

ILAMI was founded in 1983. Israel is a long standing member of the European Federation for Medical Informatics. ILAMI is representing Israel in EFMI and organised MIE1993 in Jerusalem.

Fostering partnerships for modernisation with this important country is another goal of this STC 2017. Efficient and effective delivery of health care requires accurate and relevant methodologies, e.g. patient-centered clinical data, its communication and application in medical decision support. This publication enables some insight in the use of information and communication technology in different countries. It is designed to have a high relevance in practice and further research.
The editors would like to thank all the authors for their excellent work as well as the reviewers for lending their expertise to the conference, thereby contributing to the final achievements. Furthermore, they are indebted for sponsoring the publication of the proceedings. Final thanks are dedicated to Carina Gutharz, who collaboratively organised the review processes.

Rolf Engelbrecht, Ran Balicer, Mira Hercigonja-Szekeres (Editors)
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Section 1

Full Papers
A Socio-Technical Analysis of Patient Accessible Electronic Health Records

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Abstract. In Sweden, and internationally, there is a movement towards increased transparency in healthcare including giving patients online access to their electronic health records (EHR). The purpose of this paper is to analyze the Swedish patient accessible EHR (PAEHR) service using a socio-technical framework, to increase the understanding of factors that influence the design, implementation, adoption and use of the service. Using the Sitting and Singh socio-technical framework as a basis for analyzing the Swedish PAEHR system and its context indicated that there are many stakeholders engaged in these types of services, with different driving forces and incentives that may influence the adoption and usefulness of PAEHR services. The analysis was useful in highlighting important areas that need to be further explored in evaluations of PAEHR services, and can act as a guide when planning evaluations of any PAEHR service.

Keywords. EHR, Electronic Health Record. PAEHR, socio-technical analysis

1. Introduction

eHealth is often suggested to have the potential to revolutionize the way healthcare and prevention is provided, shifting the balance of power and responsibility from healthcare professionals to patients and citizens [1]. Sweden recently updated the national eHealth vision that now states that all residents from 16 years of age should by 2020 have access to all health related information documented in county-funded health and dental care [2]. However, implementing these eHealth services are controversial for the healthcare professionals [3] and it is challenging to realize on a national scale [4]. Internationally, there is also a drive towards providing Patient accessible EHRs (PAEHRs), but it has been limited in part by professional resistance and concerns about security and privacy [5][6], legal constraints [7] and low uptake of other online resources for patients.

As described by Baxter and Sommerville the problems that arise in procuring, developing and operating complex IT systems are not just technical, engineering problems [8]. These systems are developed and operated by people, working in organizations, and these people and organizations inevitably have different, often conflicting, views on what the system should do and how it should inter-operate with other systems. The IT system is therefore part of a broader ‘socio-technical’ system, and we are convinced that we have to approach the design and evaluation of PAEHR

1 Maria Hägglund, Karolinska Institutet/LIME, Tomtebodavägen 18A, 17177 Stockholm, Sweden. Email: maria.hagglund@ki.se
services from this broader socio-technical perspective if we are to improve their quality and effectiveness. Baxter and Rooksby argue that socio-technical approaches are especially appropriate in health and social care “because the problems of developing technology for healthcare lie not with the complexity or novelty of the technology itself, but in the complex ways healthcare is practiced and organized” [9]. This is very relevant also in the context of PAEHRs, where relational, legal and organizational challenges have been identified [10].

The purpose of this paper is to analyze the Swedish PAEHR service *Journalen* using a socio-technical framework, to increase the understanding of factors that influence the design, implementation, adoption and use of the service. The results will be used as input into the planning of future evaluations and improvements of PAEHR services.

2. Methods

In this study we will utilize the Socio-Technical framework proposed by Settig & Singh [11] to structure the analysis of the Swedish PAEHR service. The model provides a multi-dimensional framework within which any health information technology innovation, intervention, application or device implemented within a complex adaptive healthcare system can be studied. The framework identifies 8 dimensions of socio-technical systems in healthcare that needs to be considered in both development and evaluation (table 1).

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>Hardware and software</td>
<td>Focuses on only on the hardware and infrastructure required to run the applications</td>
</tr>
<tr>
<td>Clinical content</td>
<td>An important success factor in any eHealth application is that the clinical content in the application is sufficient and relevant for the clinical situation. This dimension in the framework includes everything on the data-information-knowledge continuum that is stored in the system.</td>
</tr>
<tr>
<td>Human-computer interface</td>
<td>The usability of the system. The International Standard Organisation (ISO) defines usability as a process-oriented standard which states that a piece of software is usable when it allows the user to perform tasks effectively, efficiently and with satisfaction in a specified context of use [12]</td>
</tr>
<tr>
<td>People</td>
<td>Represents the humans involved in all aspects of the implementation and use of the eHealth application, and how they experience the use.</td>
</tr>
<tr>
<td>Workflows and communication</td>
<td>Focusing on collaboration and communication between different users, and assessing how well the eHealth application supports the current clinical workflow.</td>
</tr>
<tr>
<td>Internal organizational policies, procedures, and culture</td>
<td>Acknowledges how the organization’s internal structures affect every other dimension in the socio-technical model. Therefore it is important to also include any internal IT-policy documents and managerial procedures that may influence the implementation and usage of eHealth.</td>
</tr>
<tr>
<td>External rules, regulations &amp; pressures</td>
<td>External forces that facilitate or place constraints on the design, development, implementation, use and evaluation of eHealth in the respective clinical settings.</td>
</tr>
<tr>
<td>System measurement and monitoring</td>
<td>The importance of monitoring and measuring the impact of eHealth is stressed. This is in line with the third part of the WHO ITU eHealth strategy toolbox which also underlines the importance of monitoring and evaluation [13].</td>
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The framework breaks down components of the technology to enable researchers to identify specific problems with implementation. It also includes monitoring processes and government structures that need to be in place for the system to achieve its goals [11]. The interrelatedness of the components makes the framework ideal when eHealth technologies and users are at the core of the investigation. The results presented in this paper are based on a retrospective analysis of the design, implementation and evaluation of PAEHR in Sweden. The authors have been following this work over the past 7 years, and have had opportunity to observe the debate and decision making processes. These experiences, combined with publicly available resources regarding the current usage of the national e-services [14] and current scientific publications on the Swedish PAEHR constitutes the data source for our analysis.

3. Results

The socio-technical framework was used to structure the results of previous work done to identify challenges of implementing the Swedish PAEHR [10]. Today (June 2017), 19 of the 21 Swedish counties as well as one large private care provider have given patients access to EHR data through Journalen. The PAEHR is accessed through a national patient portal (1177.se) and contains clinical and administrative content from many different EHR systems (table 2 – clinical content). Currently around 3.9 million citizens have set up accounts in 1177.se (about 39% of the Swedish population) and of those approximately 1 million use the PAEHR.

3.1. Analysis using the socio-technical framework

We applied the socio-technical framework to the Swedish PAEHR service in order to identify and categorize challenges and opportunities of implementing the service that can guide future evaluations as well as improvement work.

Table 2. Analysis of the Swedish PAEHR according to the socio-technical framework.

<table>
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<th>Dimension</th>
<th>Lessons learned from the Swedish PAEHR</th>
</tr>
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<tbody>
<tr>
<td>Hardware and software</td>
<td>A national Health Information Exchange (HIE) platform is in place enabling not only the PAEHR to access information from all EHR systems in use in Sweden, but also other eHealth services, such as a national patient overview for healthcare professionals. Establishing this infrastructure has taken time, and one of the hurdles to overcome in the implementation process was to get all EHR systems connected to the HIE platform and publishing the right information [10].</td>
</tr>
<tr>
<td>Clinical content</td>
<td>The Swedish PAEHR can contain notes from the EHRs (from all healthcare professions and all regions), a list of prescribed medications, lab results, warnings, diagnosis, maternity care records, referrals and vaccinations. In addition, there is a log list showing everyone that has accessed the record. The patient also has the possibility to share their EHR with anyone they choose, e.g. a close relative or an agent, and parents can access their children’s records until the age of 13. Different care providers however choose to make different information accessible to their patients [15], causing a fragmented view that does not contribute to equity.</td>
</tr>
<tr>
<td>Human-computer interface</td>
<td>Some issues regarding usability and human computer interaction have been identified, but few usability studies have been published. It is e.g. difficult for the user (patient/citizen) to get an overview of what content they can expect to be accessible from their care providers. All functionality is visible, regardless of whether there is any information available or not, and if you have your lab results from one care provider but not from another it might be confusing. This causes many support errands from users asking where their information is [16].</td>
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</table>
Although patients or citizens are the main user group, many other stakeholders are affected by the implementation of PAEHR, and the service remains a much debated topic. Although the research indicates that patients’ experience mainly benefits [17][18], fears among healthcare professionals remain high [3][19]. Hypotheses as to why this is so intimidating are many, but it is clear that the research on different stakeholders’ experiences and perceptions need to be followed by more in-depth studies of actual impact.

An expected benefit of PAEHR is to increase patient participation in healthcare. Having access to one’s own data is an important first step, but participation requires a dialogue and collaboration between patients and healthcare professionals. In Sweden, the implementation has rather been performed under the premises that this is a tool for patients, so healthcare professionals will not need to change their way of working. Focus in the PAEHR is on giving patients access to information, not to support a two-way information exchange. Basic health declaration forms have been designed, and functionality for patients to comment on notes in the health record is available – but neither are implemented or used outside Uppsala. In order to support patient participation and communication more interactive ways to exchange information would be required, including integration of data from personal health apps or self-trackers, yet there are few studies of how the PAEHR influence workflow and communication.

The Swedish eHealth strategy highlights the importance of giving citizens access to their health information, putting pressure on the local care providers to introduce the PAEHR service. This standpoint has developed over time, and the first attempt to give patients online access to their EHR was shut down for legal reasons and not until a change in legislation was made in 2008 the PAEHR could be launched [20]. One of the major challenges in the implementation process has been to reach national consistency in the guiding rules for PAEHR. A National Regulatory Framework (NRF) was developed, however, the first version of the NRF contained electable paragraphs that were interpreted and applied differently [16], [21]. In the recently launched second version of the NRF, the goals of the European and national eHealth strategies are used to create a number of principles, ensuring the citizens the same opportunities to access their data [16].

Sweden has a decentralized healthcare system and the different interpretations of the NRF causes uneven information access depending on which care providers you have visited. A patient that moves between care providers and/or counties, which is quite common, risk misunderstandings or frustration as information from parts of their care process can be completely missing (when care providers are not connected) or partly missing (when care providers give limited access).

Evaluations of the effects of PAEHR have so far been project based and there’s a lack of long-term evaluation planned. Within the DOME-consortium, researchers from different disciplines collaborate to research the impact of PAEHR, but financial support is scarce. Project-based assessments do not cover long-term effects and there are many questions that remain to be answered.

4. Discussion and Conclusion

The results of this study confirm that introducing a national PAEHR service is a complex socio-technical challenge. The analysis also highlight that there is a lack of research in certain areas, e.g. concerning the infrastructure and the usability of the PAEHR as well as how workflow and communication are affected. Using the Sitting and Singh socio-technical framework [11] as a basis for analyzing the Swedish PAEHR system and its context indicated that there are many stakeholders engaged in these types of services, with different driving forces and incentives that may influence the adoption and usefulness of PAEHR services. The analysis will inform further evaluation studies within the PACESS research project [10], as well as act as a guide when planning evaluations of any PAEHR service.
Acknowledgements

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References

Availability of Computerised Medical Record System Data to Compare Models of Child Health Care in Primary Care Across Europe

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Abstract. Computerised medical record (CMR) system data can be used to compare different models of health care for children. We identified sources of data from the Models of Child Health Appraised (MOCHA) project that compares family doctor led with paediatrician led and mixed models of child care using index conditions. Asthma and immunisation coverage are the first of these. We explored the extent to which an established Patient Registries Initiative (PARENT); MOCHA’s own survey (MIROI); the European Centre for Disease Control (ECDC) immunisation information system survey and the European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP) registry of data sources provided data to make comparisons of child health care. Five countries had data repositories for our index conditions from paediatrician lead services, compared with 14 for mixed, and 11 for family doctor led services. PARENT identified 212 sources, MIROI 148 sources, ECDC 17 sources and ENCePP 42; with immunisation related data sources found in all four but asthma in only three. There are less sources of electronic data available to study paediatrician led systems than other models; this risks unequal sample size bias.

Keywords. Medical record systems computerised; Health, Child Health, Health Information, Surveys and Questionnaires Systems

1. Introduction

Information and communication technologies (ICT) solutions are increasingly used in healthcare across Europe. The availability of technologies and the introduction of policies to encourage computerization of health records are seen as key tools for supporting the improvement of health care delivery, especially in primary care [1]. Electronic health records (EHRs) and digital interactions, have been demonstrated to contribute to increased adherence to guidelines in clinical practice and reduce medical errors with better knowledge management and evidence-based decision making. They have also contributed to better health services integration and continuity of care with improved communication among physicians, patients and specialists with consequent savings in time and costs [1].

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However ICT implementation and applications varies across countries resulting in a heterogeneous and complex data ecosystem to study child public health across Europe [2]. This is a significant challenge for researchers who are investigating common health issues in the region. Common data models created from heterogeneous data sources are required for conducting pan-European routine data studies [3]. The aim of this study is to report the availability of data sources to compare the number available to compare family doctor, paediatrician and mixed models of child health care.

2. Types of child health service and indicator conditions

The Models of Child Health Appraised (MOCHA) Horizon 2020 project compares models of health care. The models compared are family physician/general practitioner led, paediatrician led or mixed models [4]. MOCHA uses index conditions to compare health systems. The first two being considered are the quality of asthma management and immunisation coverage.

3. Data source registers selected – PARENT, MIROI, ECDC, ENCePP:

The Patient Registries Initiative (PARENT, http://parent-ror.eu) has collected data about 227 registers [5]. It was established with the goal of enhancing cross-border interoperability of patient registries in the EU area. This initiative has collected metadata covering details about registry establishment, governance, funding, data sources, data quality indicators, standards used and interoperability.

In the MOCHA project, we have developed the MOCHA International Research Opportunity Instrument (MIROI) instrument to identify data sources that can support studies related to child health. Responses were collected through a network of country agents appointed for all participating European nations in the project. The survey instrument is an offline questionnaire in word document format which was completed by data custodians through the coordination of the country agents. In our initial data collection, we were able to collect 146 responses from 26 countries. By conducting metadata collection in multiple projects previously, we have learnt that metadata collection needs to be incentive driven in order to attain the maximum number of responses. We used the EMIF (European Medical Information Framework) web catalogue to enable sharing of the metadata collected through MIROI. The EMIF web catalogue was developed to share metadata from multiple projects using a single web-based portal (http://emif-catalogue.eu) [6].

The European Centre for Disease Prevention and Control (ECDC) recently published a technical report based on results of a survey of immunisation information systems in the EU and EEA. This survey focused mainly on implementation and system characteristics of immunisation information systems. Although the results of the survey have not been shared as a repository unlike the previous three cases, we have
considered it in the comparison since immunisation in children is one of index conditions [7].

The European Network of Centres for Pharmacoepidemiology and Pharmacovigilance (ENCePP) is a network initiated by the the European Medicines Agency to support post-authorisation studies in Europe. In addition to research centres and networks, the ENCePP registry also contains profiles of a number of health databases in Europe [8].

4. Comparing MIROI and other EU metadata resources for study of child health outcomes

We undertook a comparison of metadata from PARENT, MIROI, ECDC and ENCePP based on whether the child health system was GP focused, Paediatrician focused or combined to understand the range of routine data sources profiled in each country [4] [9].

Table 1. Data sources listed in each resource based on the type of health system

<table>
<thead>
<tr>
<th>Country</th>
<th>Type of child health system</th>
<th>Listed data sources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>GP based system</td>
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<tr>
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<td>x</td>
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<tr>
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<td>x</td>
<td>14</td>
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<td>Sweden</td>
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<td>UK</td>
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<tr>
<td>Total</td>
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</table>
We then looked at the candidate data sources available in each EU country for specific use case scenarios (infectious disease/chronic diseases). There is limited overlap of data sources between these resources (only 5 common databases between MIROI and PARENT).

Table 2. Data sources to support immunisation studies

<table>
<thead>
<tr>
<th>Country</th>
<th>PARENT</th>
<th>MIROI</th>
<th>ENCePP</th>
<th>PARENT</th>
<th>MIROI</th>
<th>ECDC</th>
<th>ENCePP</th>
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<td>4</td>
<td>17</td>
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</table>

Five countries had data repositories for our index conditions from paediatrician lead services, compared with 14 for mixed, and 11 for family doctor led services. PARENT identified 212 sources, MIROI 148 sources, ECDC 17 sources and ENCePP 42; with immunisation related data sources found in all four but asthma in only three. There was a higher percentage of candidate data sources for both asthma and immunisation studies in countries with combined system compared to countries with family doctor led services. The countries with paediatrician lead services had a significantly lower representation for both index conditions considered (Table 3).
### 5. Conclusion

Using multiple searches identifies a greater number of data sources. Whilst the MOCHA survey instrument (MIROI) identified data sources other databases added to it. Investigators should not rely on single survey instruments and repositories to identify data sources. However, a key limitation is that the data sources considered in this paper were originally created for other purposes than comparing models of child health care; their metadata fitting the aims and scope of the respective studies.

There are only a relatively limited number of data sources available describing paediatrician led child health care services. This may be because primary care was one of the first services to computerise, and it is a service that lends itself more to computer use than hospital practice [10]. This limits the scope to make comparisons between methods of care delivery.

### Funding

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### References


Connecting Parents to a Pediatric Emergency Department: Designing a Mobile App Based on Patient Centred Care Principles

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Abstract. Introduction: Patient centred care fosters a holistic approach of care switching the focus from a disease perspective to a patient’s experience perspective. Patient centred care is of particular importance in the context of paediatric emergency medicine. Indeed, parents entering a paediatric emergency department (PED) are usually under stress caused by their children’s illness, the unfamiliar setting of the PED and delays of care. All these factors can deteriorate their experience as well as the relationships between healthcare providers, the patients and their parents. Methods We explore potential areas to improve the patient experience during his journey into PED. The dimensions of the picker’s patient centred care are used to guide observations, conduct interviews and focus groups. The areas of improvement are then operationalized through their translation into app functionalities. Results Our novel application allows supporting users on 7 of the 8 dimensions of picker’s patient centred care model. The app supports parents in their decision-making to consult a PED, it provides relevant medical information to avoid unrealistic expectations and accompany the family after discharge thanks to tailored information sheets about diagnostics. Conclusion: Our mobile app allows to make a big step toward the improvement of the patient-caregiver relationship. The direct benefits will be shared by patients and caregivers, as well as the institution.

Keywords. Patient Centred Care, mHealth, Emergency Medical Services

1. Introduction

Patient centred care is defined by the Institute of Medicine as a care that is responsive to individual patient needs and values and that guides treatment decisions [1]. This concept is targeted on a holistic approach that does not focus only on the patient disease but encompasses also the illness experience, understanding the whole person, the search of a common ground, incorporating prevention and health promotion, enhancing the patient-physician relationship, and being realistic. Although there is no clear consensus about the exact dimensions that must appear under this umbrella.
concepts, one of the most popular model (picker’s) delineates 8 dimensions, including: 1) respect for the patient’s preferences 2) information and education; 3) access to care; 4) emotional support; 5) involvement of family and friends; 6) continuity and transition; 7) physical comfort; and 8) coordination of care [2]. Recent research has shown that there are many benefits to patient centred care, broadly categorized as care experience, clinical and operational benefits. Studies show that when healthcare administrators, providers, patients and families work in partnership, the quality and safety of health care rises, costs decrease, and provider and patient satisfaction increases [3].

In the context of visits to the paediatric emergency department (PED), patient centred care is of particular importance [4]. Parents often arrive with a high level of stress and expectations due to the perceived emergency of their children’s illness. When in contact with the PED unfamiliar setting, they endure delays of care in case of crowding and have to deal with caregivers’ diagnosis. This may lead to a poor experience and deteriorate their relationships with healthcare providers.

Thanks to their unique features, mobile apps have the potential to improve experience of parents going to PED with their children. We present in this paper the identification of potential areas to improve the patient experience during his journey into PED. These areas for improvement are then operationalized through app functionalities.

2. Methods

In order to build an app following the picker’s patient centred care principles, we explored each principles with stakeholders and translated our findings into functionalities of an app.

![8 Dimensions of Patient-Centered Care](image)

The areas of improvement were identified through semi-structured interviews of 15 parents visiting the PED to understand their needs. Additionally, observations were performed at the PED to generate a map of their journey [5]. Finally key stakeholders were interviewed and guided by the patient centred thematic. Based on our findings we conducted several focus groups involving psychologists, clinicians and computer scientists to translate the collected needs into functionalities of a novel mobile app. Finally, an app called “InfoKids” was implemented with the requested functionalities.
3. Results

3.1. Identified areas for improvement

Respect for the patient’s preferences: During the semi-structured interview of parents in the PED, most of them revealed their difficulty to evaluate the condition of their children. Indeed, the perceived severity of the illness is often difficult to evaluate leading to many non-urgent visits. This reveals the necessity to support parents in their decision to visit or not the PED [6,7]. Providing support for decision making has the potential to both reduce stress and to diminish the unnecessary visits to the PED.

Information and education: Our interviews also revealed a great demand for information before arrival and after discharge. Before arriving at the PED parents usually do not know what will happen during their journey. As a consequence, they tend to frequently interrupt caregivers to ask information about the care process and may develop frustration due to their misunderstanding [8]. These interruptions also disturb caregivers, obliging them to repeat over and over the same explanations.

Access to care: Access to the location of hospitals is not always simple. In case of stress nobody want to have to struggle to find the entrance of the emergency, or to identify the closest way to the hospital.

Emotional support: Disappointment is the experience of sadness involving unfulfilled hopes or expectation. Parents have limited information about the occupation in the PED and thus can have inappropriate expectations about their waiting time. Expectations of appropriate waiting times in the PED may vary considerably. While some expected to be seen by a physician within 1 hour, others expected a 3- to 6-hour wait. Moreover, non-users seem to expect faster service than users.

Involvement of family and friends: Managing children health is not always simple from an administrative point of view. When parents have to perform a PED administrative entry it is often a source of burden for them and for the administrative clerks. Beside the discomfort that administrative entry can represent in emergency situation, the accuracy of this information is critical in emergency care. Correctly and fully matching patient names and unique identifiers, with relevant clinical information, is of prime importance. Misidentification of a patient can lead to hazardous errors [9].

Continuity and transition: Once their children have received cares, the parents should receive discharge information by the physician. The short period of time devoted to this transmission, the confusing medical jargon used, the lack of careful listening by the parents and many other external factors may lead to misunderstanding of the aftercare instructions. Some studies demonstrated as many as 78% of persons discharged from an emergency department do not clearly understand their aftercare instructions, yet only 20% are aware of their lack of comprehension [10].

Coordination of care: A good care coordination is strongly dependant of a good organization. In emergency department, it is difficult to forecast crowding and thus to liberate the associated care resources that would be required to deal with it [10]. Emergency caregivers could better organize their work if they have a better forecast of
the emergency occupation. The ability to accurately forecast affluence in emergency
departments has also considerable implications for hospitals to improve resources
allocation and strategic planning.

3.2. Proposed functionalities

**Respect for the patient’s preferences:** In order to support the decision of the
parents to depart or not the emergency, the app integrates a list of symptoms linked to
advices on immediate measures and explaining when to consults. The advices have
been elaborated based on those contained in a textbook on paediatric diseases from two
paediatrician, the Prof. Gervaix and Prof. Galetto. In order to facilitate the information
retrieval, these symptoms are organized in a hierarchy elaborated using card sorting

**Information and education:** The app contains educational videos explaining the
care process aiming at responding the most common interrogations of the parents
visiting the PED. For instance, these videos present the whole process of emergency
care helping the parents to clearly understand the different stages he will go through.
Moreover, hot topics such as the classification of the patients into the different
emergency levels depending on the severity of the situation are explained in specific
videos.

**Access to care:** The application provide a map locating the PED and the closest
parking spot in order to facilitate their arrival. Additionally this map provides the
shortest way from the user location to the emergency.

**Emotional support:** To avoid unrealistic expectations, the application provides a
real time view on the waiting room occupation and a forecast of daily occupation. This
current occupation is displayed through the 5 lanes representing the different level of
emergency. Each patient is presented by an avatar allowing everyone to understand the
number of people waiting. The other view provides statistic on the daily occupation
based on the average occupation computed on the 5 last days.

**Involvement of family and friends:** Administrative entry is facilitated by the
automatic transmission of pre-entered administrative information by the user to the
institution. A software, at the administrative clerk’s disposal, displays this information
allowing him to compare it with the one already in the clinical system. The differences
are automatically highlighted in order to facilitate corrections of inaccurate data.

**Continuity and transition:** In order to offer a continuity of care after discharge
the application provides automatically a medical information sheet about the diagnosis
to the user. This information sheet is based on a paediatric textbook providing advices
related to paediatric diseases. To select the most adapted information sheet, the
diagnostic entered by the clinician in charge of the patient is automatically mapped into
one of the sheets explaining the diagnosis.

**Coordination of care:** Although the app can function standalone, it has the
capability to be connected to a software accessible to the caregivers allowing a bi-
directional communication between the user and the care institution. Through this
channel the user can to announce its arrival at the PED and the reasons for the visit. Thanks to this system, the caregiver is able to forecast the affluence and future occupation of the PED by visualizing the list of incoming patients. This offers the possibility to take adequate measures to limit PED overcrowding.

4. Conclusion

Patient centred care is increasingly recognized as a critical dimension of high-quality health care since the landmark Institute of Medicine report, Crossing the Quality Chasm [12] included it as one of the six quality aims for improving care. Our work with patients and caregivers allowed to identify 7 areas where an app have the potential to improve patient centred care. The single dimension that we didn’t discussed was the physical comfort since it wasn’t directly impacted, although indirectly the possibility to wait outside the emergency room and to be recalled on due time improves indirectly users’ comfort.

Although, it still need to be validated by a formal evaluation, we expect that the benefits won’t be exclusively for the patients but also for the caregivers and the institution. Indeed, as pointed out previously, there are a lot of non-urgent visits that can be avoided if parents are able to evaluate more accurately the illness of their children. Also the resource will be managed in a more efficient way by knowing in advance what will be the affluence to the PED and expected occupation. Finally, the caregivers will be supported in their communication with the parents.

References

Identification and Description of Healthcare Customer Communication Patterns Among Individuals with Diabetes in Clalit Health Services: A Retrospective Database Study

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Abstract. HMOs record medical data and their interactions with patients. Using this data we strive to identify sub-populations of healthcare customers based on their communication patterns and characterize these sub-populations by their socio-demographic, medical, treatment effectiveness, and treatment adherence profiles. This work will be used to develop tools and interventions aimed at improving patient care. The process included: (1) Extracting socio-demographic, clinical, laboratory, and communication data of 309,460 patients with diabetes in 2015, aged 32+ years, having 7+ years of the disease treated by Clalit Healthcare Services; (2) Reducing dimensions of continuous variables; (3) Finding the K communication-patterns clusters; (4) Building a hierarchical clustering and its associated heatmap to summarize the discovered clusters; (5) Analyzing the clusters found; (6) Validating results epidemiologically. Such a process supports understanding different communication-channel usage and the implementation of personalized services focusing on patients’ needs and preferences.

Keywords. Professional-Patient Relations, Electronic Health Records, eHealth, Clustering, Diabetes epidemiology

Introduction

The data collected by Health Maintenance Organizations (HMOs) are comprised of medical information and documentation of its interactions with patients through different channels such as: face-to-face, phone calls, internet sessions, and mobile applications. These channels allow an HMO to measure its activity, the efficiency of and adherence to a treatment, subject to different quality indicators, social-

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demographic and clinical profile, as well as each patient's communication profile with the Healthcare Providers (HPs) and administrative teams. The communication, and particularly the Points-of-Contact (PoC) between the patient and the HPs, were explored by considering different kinds of channels (e.g., face-to-face, SMS, emails, calls, or forums) [1, 2, 3]. Moreover, Machine Learning approaches are used to (re)define groups of patients according to their healthcare condition and socio-demographic information. Other research employed a systemic approach to group healthcare customers (HCs) according to their socio-demographic, health care, and communication data to improve the communication between these patients and the HMO, follow-up quality, and medication adherence [4, 5]. These studies were performed on relatively small populations. Our objectives are to identify communication patterns and to describe their corresponding population segments on a large, representative population. Our hypothesis is the COMPAT methodology can provide health care management leaders with a tool to find more efficient ways to maintain contact with HCs. In the present paper, we introduce COMPAT (COMmunication PATterns), a methodology for finding communication patterns of HCs within a specific HMO, which may provide HMO executives with a tool to find more efficient ways to maintain contact with HCs.

Material and Method

Material

COMPAT was applied to a retrospective cohort analysis study focused on diabetes [6]. The data were extracted from Electronic Health Records (EHRs) of Clalit Health Services (Clalit), which is the largest healthcare payer/provider in Israel, covering over 4,400,000 members. The study population focused on 309,460 adults who had diabetes for at least 7 years and were aged 32 or older. As an input COMPAT received a large administrative dataset, comprising of the following data from 2015: (1) socio-demographic data; (2) “Communication channels data” (e.g., Physician consultation, Nurse consultation, emergency room visit, or a hospitalization; appointment scheduling in person at the clinic, calling the clinic or the HMO call-center, using the Clalit website, or using the smartphone application; requests (e.g. prescription renewal) without visiting a HP, from here on out referred to as "no queue requests"); and (3) biomedical data ([e.g., comorbidity index – such as the Adjusted Clinical Groups (ACG)] [7], BMI, HbA1c, lipid profile, diabetes medication adherence, smoking status, and other chronic diseases). The study was approved by the Clalit Ethics Committee and is funded by the Israeli National Institute for Health Policy Research (Grant 2015/188).

Method

First we performed a dimension reduction by mapping variables with continuous values to variables with categorical values. Each variable was discretized into a six-category relative scale. The discretization was performed either by running K-means clustering or by a domain expert based on the data distribution of each variable.

Second, we found the number of hidden clusters \( K \) in the “communication channels” data only, using the K-means algorithm. We clustered the data for any \( k \)
between 2 and 100, on 100 randomly selected samples of 20% of the cohort. The Ray-Turi criterion [8] was computed each time and the results were put on a graph to locate the elbow [9] and find the relevant $K$.

Once $K$ was found, we performed a hierarchical clustering on the $K$ clusters based on a Manhattan distance function and Ward’s criterion as agglomeration method.

Then we built a heatmap representation. The median of the relative use of each communication channel was reformulated to a color scale from lighter to darker colors, corresponding to the channel's usage level.

The last step consisted of describing and characterizing the corresponding sub-populations defined by the clusters, their hierarchy, and the heatmap.

The statistical analysis was performed using R version 3.3.1 [10]. *data.table* [11] was used to maximize computing efficiency given the large data size, and *gplots* [12] was used for drawing the heatmap and the hierarchical clustering dendrogram.

**Results**

The methodology we used discovered 7 main communication patterns (Figure 1). We assigned each cluster with a short title to summarize their patterns.

![Figure 1. Hierarchical clustering and the related heatmap for the 7 discovered clusters](image)

The first cluster, “Relative Low Contact”, relates to HCs having relatively low interactions with all PoCs and access to medical services compared with the overall cohort population (e.g., median number of Physician consultation: 10/year vs. 18 in the...
Among this cluster more than 20% of patients have missing values for follow-up clinical measurements (e.g., HbA1c, BMI) that are recommended for individuals with diabetes. This percent is high relative to the results of the other clusters. Among those on medication, 30.4% have a medication adherence of less than 80% (calculated by medication possession rate [MPR]) and 30.1% of the cluster are not on medication at all. The HCs of this cluster are relatively young (median age, 64 [interquartile range [IQR] [56,74]) years vs. 68 [59,77] years for the cohort), and are less morbid than the full cohort (ACG 3 vs. 4). Similarly, HCs from the second “Measured human contact” cluster have relatively very little access to PoCs, but when they interact with the HMO, they prefer human contact, such as face-to-face appointments at a clinic, call, and offline (in-person, by phone) "no queue requests". They have a larger representation of immigrants than in the full cohort (60.2% vs. 53.3%). The follow-up clinical measurements for diabetes is relatively complete in this cluster, with only 8% of patients have missing data. Increasing PoCs and improving follow-up of the "relative low contact" and "measured human contact" clusters is critical. Moreover, a large part of these HCs are not native Hebrew speakers.

The third and the fourth clusters, labeled “High online contact” and “High contact by mobile”, respectively, relate to individuals interacting with the HMO mainly using the internet, website, and the mobile communication facilities. They are also medium-low users of medical services relative to other groups. “High online contact” is comprised of more males (54.6%), HCs with a high socio-economic status (SES) (52%), and live in the urban center of the country (96.6%). Cluster four, “High contact by mobile” is comprised of more females (54.4%), relatively young patients (median age, 63 [55,71] years), and those having a medium SES (47.4%). Both groups have an average morbidity (median ACG 4) and a complete follow-up with less than 5% missing measurements. Accordingly, the use of e-tools to communicate with the HMO looks efficient and provides these populations with additional e-services that may maintain good results at follow-up, medical services utilization, and medication adherence.

The fifth cluster mainly uses nurse PoCs and has a medium level of other medical services utilization. However, this sub-population overall does not schedule appointments and does not use “no queue requests” to communicate with the HMO. The related population is mainly located in the North (51.2%) and has a low SES (40.8%). Despite that, the follow-up of this cluster is fairly complete, and the medication adherence is similar to the full cohort (moderate-high MPR of 72.3% vs. 70.3%). This analysis shows the positive impact of a high involvement of nurses. Training HCs to use the e-tools for communicating with the HMO should reduce the nurses’ work load.

The last two clusters have a large volume of PoCs with HPs, are relatively high medical services consumers, are over half women, 70+ years old, and have a high ACG (median ACG, 5). Patients in the cluster “High human contact” are heavy users of traditional communication tools, such as face-to-face appointment scheduling at the clinic and on the phone, but are medium-low users of non-human communication facilities (online and offline). Their follow-up of clinical measurements is the most complete (approximately 3% of missing data). “Overall high contact” cluster has a relatively high access to all PoCs and a high utilization of medical services. Their SES is medium-high (85.6%) and has a proportionally large representation of immigrants (73.8%). Considering the age and the ACG of the HCs of these clusters, it may be relevant (1) to educate them and their relatives to reduce their visits so as to reduce the
risk of opportunistic contamination at the clinic when the visit is not imperative and to use the “no-queue requests” tools; (2) to develop tools adapted to the older HC population.

Conclusions and perspectives

COMPAT proposes a visual-based method for identifying population segments based on the quantification and clustering of their communication patterns, thereby using the clusters as patient profile abstractions. It presents results in a user-friendly format and may be used for supporting communication technology upgrades and health policy updates and as a part of the decision-making process at the HMO management level. This study shows how clustering patients based on their communication patterns is an abstraction that reflects both their socio-demographic and biomedical dimensions. Based on the analysis results, we suggest that improving the multi-lingual support for online services such as “no queue requests” can increase their use and reduce unnecessary visits. Furthermore, this analysis can help adjust the message, education efforts, and tools to the HPs and appropriate sub-populations and may have a positive impact on follow-up quality and medication adherence.

References

De-Identification of Medical Narrative Data

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Abstract. Maintaining data security and privacy in an era of cybersecurity is a challenge. The enormous and rapidly growing amount of health-related data available today raises numerous questions about data collection, storage, analysis, comparability and interoperability but also about data protection. The US Health Portability and Accountability Act (HIPAA) of 1996 provides a legal framework and a guidance for using and disclosing health data. Practically, the approach proposed by HIPAA is the de-identification of medical documents by removing certain Protected Health Information (PHI). In this work, a rule-based method for the de-identification of French free-text medical data using Natural Language Processing (NLP) tools will be presented.

Keywords. Medical data, data protection, privacy, HIPAA, Natural Language Processing (NLP), de-identification, anonymization.

Introduction

Medical data contains various types of Personally Identifiable Information (PII) or otherwise Sensitive Personal Information (SPI). In this context, legislation has been defined to ensure personal data protection. The most significant legal document produced to face the challenge of healthcare data management is the US Health Portability and Accountability Act (HIPAA) of 1996 and its revisions. In Europe, the General Data Protection Regulations (GDPR) have recently been approved (April 2016) and entered in force. These texts provide a legal framework and a guidance for using and disclosing health data. Practically, the approach proposed by HIPAA is the de-identification of medical documents by removing certain Protected Health Information (PHI).

This paper deals with the de-identification of French free-text medical data for secondary usage (medical research, quality measurement and improvement, public health, epidemiology and other purposes). Since it has been proven that manual de-identification of medical records is time-consuming [1], automating the work with the use Natural Language Processing (NLP) tools to perform this task is mandatory. In particular, pre-processing tools, electronic dictionaries, and local grammars constructed in the Unitex corpus processing system2 will be applied to the medical narrative data.

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After a brief overview of previous work in the field (chapter 1), chapter 2 is devoted to the approach and the method used for the de-identification of narrative data. The results of a preliminary evaluation are presented in chapter 3.

1. Related work

De-identification is generally approached as a specific Named Entity Recognition (NER) task targeting PHI (Protected Health Information). NER is defined [2] as “the task of recognizing expressions denoting entities, such as diseases, drugs, people’s names in free text documents”.

The great need for de-identification techniques is reflected by the large number of systems that were built over the last 20 years. Some of them are rule-based systems, while others, like MIST [3], use Conditional Random Field (CRF) models trained for text processing. Systems like VHA’s BoB [4] and the Cincinnati Children’s Hospital Medical Center’s (CCHMC) inhouse de-identification system [5] follow hybrid approaches. Other de-identification systems are the Scrub system [6], Datafly [7], the MIMIC de-identification filter [8, 9, 10], HIDE [11] and deid [12]. While most of the tools are available for the English language, a rule-based de-identification system for Serbian medical narrative texts was built [13]. Finally, some multilingual systems were developed: MEDTAG [14] is designed for French, though with some documents in German and English, another for Korean and English [15] and finally a system for text documents in English, German, Portuguese and Spanish [16].

2. Method

Following HIPAA [1], 18 categories of information such as names, geographic locations, elements of dates, social security numbers, telephone and fax numbers must be removed from medical texts. In the framework of the 2014 i2b2/UTHealth Natural Language Processing (NLP) shared task3, where one of the tracks focused on identifying PHI in longitudinal clinical narratives, new categories like hospital, room, department and IDs concerning devices, vehicles and biometrics were added. By removing only a given number of identifiers, de-identification preserves the data integrity.

De-identification will be viewed as a Named Entity Recognition (NER) task targeting PHI (person names, dates, geographical locations, contact information). To perform this task, pre-processing tools (tokenization, sentence splitting, part-of-speech tagging), lexicons of simple and compound words, and rules with orthographic (capitalization, punctuation), pattern, negation, lexical and context features, symbols and special characters will be applied to medical texts. The grammars that have been constructed use data from the electronic dictionaries of simple and compound words incorporated in Unitex and produce some output based on the notion of transduction. Furthermore, as already mentioned, the use of right and left context -either positive or negative- contributes to the identification of PHI. For instance, a negative right context could describe the fact numbers should not be followed by the abbreviations mg (milligram) or cp (capsule) in the grammar recognizing dates to avoid detecting it as a

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3 https://www.i2b2.org/NLP/HeartDisease/
drug dose. Also, the presence of the determinant *de, de la* in certain proper names should be predicted in local grammars (positive left context). All identified information is replaced by credible surrogate structures and not by generic strings. For instance, dates contained in the documents are replaced by surrogate ones consistent with the various types of dates found in the text. Some representative examples of dates are cited below:

- *le 06 janvier 2012* [on 6\textsuperscript{th} January 2012]
- *en novembre 2011* [in January 2011]
- *du 9 au 16 janvier 2012* [from 9\textsuperscript{th} to 16\textsuperscript{th} January 2012]
- *à la fin du mois de février 2012* [at the end of February 2012]

After having been identified, days and months are replaced but years are kept in their initial form. More precisely, the patterns *le 06 janvier 2012* [on 6\textsuperscript{th} January 2012] and *en novembre 2011* [in January 2011] will be transformed to *le 30 février 2012* [on 30\textsuperscript{th} February 2012] and *en février 2011* [in February 2011] respectively.

For the detection of names, trigger words have been used. In particular, titles such as *Monsieur* (Mr), *Madame* (Mrs), *Professeur* (Professor), *Docteur* (Doctor) and others are considered as triggers for person named entities (NE). Like dates, patients’ names also present various structures:

- *Title (Mr or Mrs) + First name + Last name* (small or capital letters)
- *Title (Mr or Mrs) + Last name* (formed by two or more constituents with or without dash in small or capital letters)
- *Title (Mr or Mrs) X’X* (apostrophe between the constituents of the name).

Likewise, in doctors’ names, the title (*doctor, Dr, professor, etc.*) could precede the name followed or not by the specialization (*general practitioner, oncologist, cardiologist, etc.*).

### 3. Results

The local grammars have been applied to a corpus of 11’000 discharge summaries in French. The table below shows the PHI categories found in the corpus followed by the number of occurrences:

**Table 1. Identified PHI categories**

<table>
<thead>
<tr>
<th>Dates</th>
<th>Patients’ names</th>
<th>Locations</th>
<th>Doctors’ names</th>
<th>Nurses names &amp; nursing care services</th>
<th>Telephone &amp; fax numbers</th>
<th>Addresses</th>
<th>Health insurance companies &amp; health care insurance funds</th>
</tr>
</thead>
<tbody>
<tr>
<td>29’221</td>
<td>27’357</td>
<td>7’907</td>
<td>4’685</td>
<td>483</td>
<td>83</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

In this work, the “Locations” category comprises countries and cities as well as hospitals and medical institutions.
The first processing steps are the segmentation of the corpus in sentences, the tokenization, the part-of-speech tagging and the morphological analysis. Then, the local grammars are applied in the replace mode to modify the identified sequences. An example of a de-identified sentence is given below:

Initial sentence: Monsieur X a été transféré aux Hôpitaux Universitaires de Genève le 5 novembre 2012.
[Mr X was transferred to the University Hospitals of Geneva on 5th November 2012].

De-identified sentence: Monsieur Christian a été transféré à l’Hôpital le 30 février 2012.
[Mr Christian was transferred to the Hospital on 30th February 2012].

Next, an evaluation was performed on a random sample of 20 discharge summaries (7'147 words) manually de-identified. The system achieved 0.98% total recall and 100% precision. Although the corpus is small and the results could not be generalized, the performance of the system is promising.

4. Discussion

The fact that discharge summaries are often written in a hurry and contain as a consequence spelling, orthographic and typographic errors has already been pointed out (among others [13, 17]). The quality of discharge summaries can affect the de-identification process. Dates like en 2011 [in 2011] and du 27.07 au 01.08.2014 [from 27.07 to 01.08.2014] are difficult to detect automatically. In fact, during the evaluation, a date was not detected because of a spelling mistake where the number 0 appeared at the position of the month (01.0.). Moreover, spelling mistakes in the trigger words (e.g. Monseur, Monsier, Monsiuer, instead of Monsieur) can prevent the system from recognizing the named entities.

On the other hand, “anatomic locations, devices, disease and procedures could be erroneously recognized as PHI and removed” [13]. During the processing of the discharge summaries, similar remarks have been made. In the following terms, the identified proper noun (in bold) should not be de-identified: classification de Los Angeles [Los Angeles classification system], score de Lille [Lille model], maladie de Parkinson [Parkinson’s disease]. Actually, the corpus contains 1’339 such occurrences. Diseases, syndromes, classifications and scores containing a proper name are detected by the local grammars and excluded by the de-identification process.

5. Conclusion

In this paper, a rule-based method for the automatic de-identification of French clinical narrative data has been presented. The local grammars constructed via the Unitex corpus processing system have been applied to a corpus of 11’000 discharge summaries. The evaluation results show a good performance of the system. The corpus de-identified using this method could then be used for further research.
Acknowledgements

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References

Regional Monitoring of Cervical Cancer

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Abstract. Cervical cancer is one of the most important causes of death in women in fertile age in Romania. In order to discover high-risk situations in the first stages of the disease it is important to enhance prevention actions, and ICT, respectively cloud computing and Big Data currently support such activities. The national screening program uses an information system that based on data from different medical units gives feedback related to the women healthcare status and provides statistics and reports. In order to ensure the continuity of care it is updated with HL7 CDA support and cloud computing. The current paper presents the solution and several results.

Keywords. regional screening, cervical cancer, database, reports, analytics, HL7 CDA

1. Introduction

Cervical cancer is the first cause of mortality of women of fertile age in Romania and occupies the first place in the world in relation with this type of medical condition. Currently, the most effective way of preventing cervical cancer is the Pap Test [1]. This test is a simple test and can detect precancerous conditions and hidden, small tumors that may lead to cervical cancer. In Romania, in order to reach a rate of over 90% from the women population it is necessary to implement a system for PAP Test as a service for General Practitioner, and active mobilization of subjects realized by a methodology similar as the one for the vaccination program.

92.6% of the General Practitioners in the Western Region in Romania are involved in the screening program, two thirds attended the data gathering activities and a quarter really followed all the necessary steps [2]. A physician with 1700 patients on his/her list, corresponding to 500-800 women in the target group must spend 2 hours per day, 2 days per week for targeted testing of all patients in a 1 year time span. Modern technologies, as cloud computing, support the activity of the physician and the public healthcare authorities, ensuring continuity and fewer errors in the current activity.

It is important to prevent and discover the risk situations in early stages for better managing the woman health status. In order to support the medical staff’s work, the group developed an application for screening cervical cancer. To continue prevention is important to send information to other medical units to complete the electronic health record of the patient, and for public health institutions.

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Microsoft Azure is a cloud computing platform and infrastructure created and provided by Microsoft. The purpose of this platform is to build, deploy and manage applications and services through a global network of data centers managed by Microsoft [5].

2. Methods

The national screening program’s role is to manage the analyses of cases for cervical cancer nationwide. This program implies physicians from the Western regions of Romania: Timis, Arad, Caras-Severin and Hunedoara counties, involving over 1000 medical staff (physicians, nurses, registrators, and lab staff). Figure 1 presents the actors involved in the system and the communication between the modules.

The restrictions from the Ministry of Health state that during centralization and monitoring of all women an eligible person can participate to a free test only once in 5 years.

The application for this program uses PHP technology and MySQL for databases. The major objective of the application is data collection and management followed by financial reports and healthcare statistics.

The screening application provides the following basic features:
- encryption of information transmitted over the Internet;
- registration of providers (medical practices with one or more doctors);
- registration of family doctors, collectors, anatomopathologists, personnel involved in information management;
- generating monthly, quarterly, annually and general predefined reports for the Ministry of Health;
• ensure temporary access blocking of the application for successive attempts with erroneous credentials as a security form;
• user guidance for data validity;
• ensuring the uniqueness of patients accessing free test funds.

The actors involved in the system are:

a) General practitioner:
• releases a referral (contains a unique ID which is specific for a region)
• gives the referral to the patient and fills-in the application data related to his/her area of competence

b) Obstetrics-Gynecology physician
• verifies the accuracy of the patient data
• takes the sample and sends it to the laboratory
• fills the specific section in the application and on paper

c) Laboratory staff
• receives the samples
• fills-in the section with the test results.

The application supplies reports. Some reports are exported in specific formats as pdf, xls, csv and are sent to the Ministry of Health for centralization of data nationwide. The application reduces the amount of work and time required to obtain statistical reports, economic and financial management.

In order to ensure the continuity of care, the system ensures the interoperability using XML files as HL7 CDA. The XML file is created in HL7 CDA standard format, and it is sent to the unit requesting the data [6] (e.g. General Practitioner will request the results of his/her patient). Communication is made through the Windows Azure cloud as a platform offering the possibility to create a container from which the files are accessed by the specific medical unit.

The cloud computing benefit consists in the fact that the physician can access the application data from anywhere and anytime. The data may be shared with other physicians or statisticians for research in the field and beyond.

3. Results

Figure 2 presents an interface from the application and the file that is filled-in for each patient.

![Figure 2. Patient data](image-url)
During January – December 2015 the amount of work included 1210 patient files, 145 files were unfinished and 1144 of women received the file. 63 patients got positive results and 1081 negative results. The age range was between 25 – 64 years. Figure 3 presents a graphic showing the number of patient per age range.

Another generated application report is based on the total number of harvests depending on the age of the patient (Figure 4). This report it is important for viewing the profile of women who are more likely to visit the screening program. As seen in Figure 4, those most interested in screening are the ones most exposed to illnesses, aged between 30 and 50 years.

Figure 5 presents a distribution of infections by age for the screening patients. This distribution is useful to view the number of infections and their type by age category. Thus, we can observe the large number of common candida infections in obstetrics and not only. These untreated infections may lead to further complications, and monitoring patients is benefitting because the infections may be detected and treated earlier.
4. Conclusions

The main goal of this paper is to present a regional screening application for the national screening monitoring women with ages between 25 – 64 years. The application is based on cloud computing technology, ensuring the continuity of care through standardized communication with other medical units using HL7 CDA. In order to have the information always available the application has the possibility to send the results in the cloud from authorized medical units accessing it.

The monitoring application is accessed by medical personnel, general practitioners, obstetrics-gynecology and laboratory staff. The action is important in relation with the cervical cancer prevention, one important mortality cause in women in Romania. For the future, the plan is to implement communication with other medical units, and to save important data in the patient’s electronic health record. The interdisciplinary team – physicians and IT staff – are working to develop the methodology for system evaluation. Future work includes developing a module using Big Data and smart analytics to identify profiles of women that have high risk in developing cervical cancer.

References

Weighting Experience-Based Decision Support on the Basis of Clinical Outcomes’ Assessment

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Abstract. Technologies such as decision support systems are expected to help clinicians implement clinical practice guidelines (CPGs) with the aim of decreasing practice variations and improving clinical outcomes. However, if CPGs provide recommendations to improve patient care, they may fail to take into account actual clinical outcomes associated to the recommended treatment, such as adverse events or secondary effects. In this paper, we present a novel experience-based decision support approach applied to the management of breast cancer, the most commonly diagnosed cancer among women worldwide. Capitalizing on the clinical know-how of physicians and the modeling of patient’s outcomes and toxicities in a computer interpretable way, we are able to discover new knowledge that helps improving patient-centered clinical care. This work is conducted within the EU Horizon 2020 project DESIREE.

Keywords. Experience-Based Clinical Decision Support, Patient-Reported Outcomes, Clinical Practice Guidelines, DESIREE

1. Introduction

Clinical practice guidelines (CPGs) have been proven to be reliable knowledge resources that reduce practice variations, improve the quality of care, and decrease costs [1]. Nevertheless, CPGs have some limitations and are often described as incomplete and ambiguous. These defaults may lead clinicians to not comply with guideline-provided propositions in certain clinical situations.

Guideline-based clinical decision support systems (CDSSs) have been proposed to help multidisciplinary tumor boards (MTBs) decide according to CPGs for cancer patients [2]. CDSSs are designed to improve clinical care and decrease medical errors by providing the best patient-specific propositions (based on patient’s clinical parameters) in a short execution time. However, CDSSs efficiency rely on the

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knowledge formalized in guidelines. Consequently, they are not able to adapt to special clinical cases and to discover new knowledge related to toxicities (e.g. adverse events) or patient outcomes (e.g. ICHOM questionnaires [4]).

This paper presents an extension of usual guideline-based CDSSs by processing the experience acquired from previous cases. The approach allows the production of new knowledge and the assessment of its reliability by the evaluation of a set of clinical outcomes. This method has been applied within the EU project DESIREE, developed in the context of breast cancer management.

2. Clinical outcomes usage

When measuring the response of a patient to a given treatment, different kinds of outcomes could be considered. In the next subsections, we will analyze the main patient- and treatment-related outcomes.

2.1. Patient Reported Outcomes (PROs)

Patient reported outcomes (PROs) are subjective reports provided by patients that define how they feel about a health condition or the treatment they are following [5]. PROs reflect the information related to clinical signs and functional status. Moreover, they involve patients to directly retrieve the information related to symptoms, perceptions, and treatment tolerance in a subjective way. These outcomes are usually collected in the form of questionnaires, which include not only clinical measurements but also the satisfaction that patients may have with a given treatment and the quality of life resulting from it.

2.2. Adverse Events (AEs)

An adverse event (AE) is defined as “any unfavorable and unintended sign (including an abnormal laboratory finding), symptom, or disease temporally associated with the use of a medical treatment or procedure that may or may not be considered related to the medical treatment or procedure” [6]. Identifying and estimating a treatment-related AE is not a straightforward task. In the one side, the information about adverse events comes usually from previously studied clinical cases, so not being totally applicable to new incoming cases. On the other side, the more reliably adverse events measurements come from around a decade old clinical trials [7]. Several efforts have been made to report and grade these adverse events. One of the most relevant systems is the one developed by the US National Cancer Institute (NCI) and known as the NCI Common Terminology Criteria for Adverse Events or CTCAE2.

2.3. Treatment response outcomes

Treatment response outcomes are valuable in order to adapt the planned treatment regarding the patient response. Analyzing this response could guide clinicians when deciding to continue the therapy or to stop it based on a subjective medical judgement guided by the study of clinical parameters evolution [8]. Some of the guidelines that

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2 https://evs.nci.nih.gov/ftp1/CTCAE/About.html
define improvement, stagnation, or deterioration of the patient condition during
treatments are RECIST\(^3\) (Response Evaluation Criteria In Solid Tumors) and the World
Health Organization (WHO) criteria.

3. Including outcomes into the reasoning process: Experience-based CDS

Using clinical outcomes as an evaluation tool of CPGs at a time \(t\) is vastly known [9].
Nevertheless, CPGs do not evolve continuously on the basis of upcoming cases and
taking into account clinical outcomes as a source of knowledge. Thus, this information
is lost for the decision-making process and CPGs need to be checked and updated
offline. In this work, we propose to use various kinds of clinical outcomes to assess the
confidence value (CV) of the new knowledge coming from non-guideline-compliant
decisions, which is the basis for developing experience-based CDS.

Experience-based CDS relies on a Decisional Event (DE) structure that allows the
exploitation of all the information related to a decision, including the clinical know-
how and other parameters such as the toxicities and outcomes of a treatment. The DE
structure is made of the following components:

1. The set of patient clinical parameters
2. The set of clinical statements expressed in a computer-interpretable format
   (i.e. IF-THEN rules)
3. The final decision made by clinicians which could be compliant or not with
   the recommendation coming from the clinical statements output
4. The treatment administrated after the decision has been made
5. The set of criteria considered by clinicians to justify a non-compliant decision
6. The set of clinical outcomes of the given treatment to be able to assess the
   success or failure of the final decision made [11]

New knowledge is acquired through the building of new rules, which the IF-part is
the conjunction of the set of patient clinical parameters, enriched by the set of criteria
taken into account by clinicians to decide, and the THEN-part is the decision made by
clinicians. The CV of the newly generated rule is zero at the time it is built. Then,
clinical outcomes are integrated to increase the CV of the rule when positive outcomes
are collected after the application of the rule, and to decrease the CV of the rule when
negative outcomes are observed. The principle of the CV computation of an expert-
based rule \(R\) is as follows: 

\[
CV_R = \frac{\# \text{ of positive outcomes of } R - \# \text{ of negative outcomes of } R}{\text{number of observed outcomes as the result of applying the rule } R}
\]

When talking about patient’s outcomes we make the following classification:

- Outcomes coming from AEs (e.g. the ones measured in the CTCAE)
- Outcomes coming from the treatment response (i.e. generic outcomes
  such as survival, local relapse, loco-regional relapse, metastasis, exitus
  related to the disease and exitus not related to the disease along with the
  neoadjuvant therapies clinical response if any)
- Outcomes reported from the patient (i.e. PROs)

\(^3\) http://www.irrecist.com/recist/
4. Experience-based decision support and clinical outcomes assessment in the DESIREE project

The DESIREE project aims at providing the best available treatment options in the domain of breast cancer management using guideline-based knowledge, experience from previous cases, and patients’ outcomes. Therefore, DESIREE overcomes the limitations of pure guideline-based CDSSs with new experience-based and clinical-outcome-adjusted rules that model the clinical know-how expressed in non-compliant decisions. The principle is to analyze the patient profiles for which physician decisions do not comply with guidelines along with the criteria defined in the decision-making process to justify the non-compliance. In each case, extracting what is specific in the patient profile that justifies the non-compliance will allow the generation of a new experience-based rule. This rule integrates the new knowledge coming from that patient in the IF-part (e.g. the inclusion of the specific clinical parameters identified in the decision-making process) and the actual final physician decision as the THEN-part. To assess the CV of the new rule, clinical outcomes are studied. The CV of the new rule is initialized at zero and is continuously updated according to the assessment of the performance of the rule quantified by the quality of its clinical outcomes. The goal is to apply the presented methodology based on the study of different known outcomes to represent the CV of new experience-based rules. The next points define AE outcomes and PROs used in DESIREE along with the treatment response outcomes, defined in this context as “survival”, “relapse” or “exitus”.

4.1. Common Terminology Criteria for Adverse Events (CTCAE)

The NCI CTCAE is a report that gathers and grades the different AEs for several illnesses using an agreed grading scale and a descriptive terminology. The defined grade scales go from 1 to 5 and refer to the severity of the evaluated AE where 1 represents mild, asymptomatic symptoms, with no intervention indicated and 5 represents death related to the AE [5]. The CTCAE has proved to be valid and reliable in a large heterogeneous US sample of patients suffering from cancer with at least one symptom reported by 99.8% of the patients from the first visit questionnaires [11].

4.2. ICHOM questionnaires

The International Consortium for Health Outcomes Measures (ICHOM) is a non-profit organization that provides standard measurement sets of patient-centered outcomes for a variety of illnesses and medical conditions [4]. The aim of these questionnaires is to improve the doctor-patient relationship while reducing health care costs, supporting informed decision-making processes, and improving the overall health care quality.

5. Conclusions

In this paper we have proposed to improve the clinical knowledge used by clinicians in the decision-making process by including the study of clinical outcomes in experience-based decision support. This approach is applied to the management of breast cancer patients within the DESIREE project. The clinical know-how of MTB clinicians has been modeled in a computer interpretable format that allows for the discovery of new
knowledge. This new knowledge needs to be evaluated on patient clinical outcomes before being widely used. Different kinds of outcomes have been studied (i.e. PROs, AEs, and treatment responses) that should be integrated to weight the validity of this new knowledge.

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References

DisEpi: Compact Visualization as a Tool for Applied Epidemiological Research

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Abstract. Outcomes research and evidence-based medical practice is being positively impacted by proliferation of healthcare databases. Modern epidemiologic studies require complex data comprehension. A new tool, DisEpi, facilitates visual exploration of epidemiological data supporting Public Health Knowledge Discovery. It provides domain-experts a compact visualization of information at the population level. In this study, DisEpi is applied to Attention-Deficit/Hyperactivity Disorder (ADHD) patients within Clalit Health Services, analyzing the socio-demographic and ADHD filled prescription data between 2006 and 2016 of 1,605,800 children aged 6 to 17 years. DisEpi’s goals facilitate the identification of (1) Links between attributes and/or events, (2) Changes in these relationships over time, and (3) Clusters of population attributes for similar trends. DisEpi combines hierarchical clustering graphics and a heatmap where color shades reflect disease time-trends. In the ADHD context, DisEpi allowed the domain-expert to visually analyze a snapshot summary of data mining results. Accordingly, the domain-expert was able to efficiently identify that: (1) Relatively younger children and particularly youngest children in class are treated more often, (2) Medication incidence increased between 2006 and 2011 but then stabilized, and (3) Progression rates of medication incidence is different for each of the 3 main discovered clusters (aka: profiles) of treated children. DisEpi delivered results similar to those previously published which used classical statistical approaches. DisEpi requires minimal preparation and fewer iterations, generating results in a user-friendly format for the domain-expert. DisEpi will be wrapped as a package containing the end-to-end discovery process. Optionally, it may provide automated annotation using calendar events (such as policy changes or media interests), which can improve discovery efficiency, interpretation, and policy implementation.

Keywords. Visual Data Mining, Clustering, Heatmap, Epidemiology, Public Health Informatics, Facilitation, ADHD

1. Introduction

During the last decades, data collection and storage have been facilitated by a large number of Computer Science and Computer Engineering evolutions. In the Healthcare realm, the numbers of datasets and their diversity have grown at a dramatic rate. These changes facilitate rapid progress in outcomes research and evidence-based medical practice. The Knowledge Discovery in Databases (KDD) [1] framework provides mathematical and Artificial Intelligence based approaches, such as Data Mining and particularly, Machine Learning and Information Visualization [2], for extraction of
useful and non-trivial information about patterns and relationships existing within the huge available data that might otherwise be missed by classical statistical approaches.

Public Health Informatics (PHI) is a link between Public Health (PH) as a discipline of caring for the community health in general, risk groups in particular, and Informatics, which is a discipline residing in the combination of Computer and Information Sciences and Engineering. PHI focuses on development of methodologies and applications of Informatics systems in PH and particularly in Epidemiology and its application subfields (surveillance, prevention, preparedness, and health promotion).

One of the main roles of PH Informaticists is to support KDD through tasks, such as indicating behavioral patterns in administrative and bio-clinical data. A large number of statistical techniques and Machine Learning methods can be used to fulfill these objectives. One main use of the data mining step of KDD in PH is supplying Management-level decision makers with simple tools to support the development of new healthcare policies. Data and Information Visualization allows the domain expert (e.g. the biologist, the physician, the public health expert) to comprehend, better and faster, numerical and textual data, based on human innate abilities and basic learning. Summarized and synthesized information lend themselves to rapid digesting of data and making relevant decisions. Viewing visualizations saves time and improves understanding. These representations and interactions allow easy efficient acquisition of complex information. Enriched data may also be readily placed online with appropriate visualizations for open use [3, 4].

In the present paper we introduce a novel method, DisEpi (Discovery in Epidemiology), for visually exploring epidemiological data in order to detect trends within sub-populations, so as to allow focused interventions.

DisEpi is an efficient Information Visualization tool. The tool receives, as input, a large administrative dataset (e.g. individual level demographics, socio-economic, medical, and therapeutic data) for a large number of individuals, and, without explicit modelling, creates an easy, compact visualization [5] of the data at the population level affording the executive professional rapid discovery of (1) Links and associations between events, (2) Association changes over time, and (3) Clusters of characteristics with similar trends. Thus, “DisEpi” is designed to support PH practitioners and researchers by providing semi-automated hypothesis generation and by reducing time to investigation and interpretation.

2. Background

Incorporation of very large databases in epidemiological studies involves complex integration of demographics, socio-economic, medical, and pharmacological data collected over the course of several years. Thus, epidemiological data mining is designed to detect and describe patterns, trends, and relations in medical data, allowing definition of specific research questions, as part of the knowledge discovery process. Various research studies have been conducted to support classical descriptive and predictive epidemiological studies [6, 7, 8, 9, 10], each one with a specific point-of-view.

DisEpi applies Abstraction, Reformulation, and Approximation [11] concepts and techniques which provides the epidemiologist and PH professional with compact visual information at the population level. DisEpi thus overcomes some limitations of the classical statistical approaches. It utilizes Hierarchical Clustering (HC), a well-known
unsupervised machine learning approach comprising of successive agglomeration of cases with minimal distances between them as defined by suitable metrics [12]. DisEpi uses heatmaps [13], a symbolic gradient reflecting the epidemiological metrics' values with HC as one dimension (e.g. columns) and time or time-associated variables as a second dimension (e.g. rows) and where color shades as the third dimension reflect disease levels.

3. Material and Method

3.1. Material

DisEpi was applied in the context of a study of Attention-Deficit/Hyperactivity Disorder (ADHD). ADHD is one of the most commonly diagnosed mental conditions in children. It may have lasting social, psychological, educational and clinical effects throughout life [14].

The data were extracted from electronic health records (EHR) of the Clalit Health Services (Clalit), which is the largest healthcare payer/provider organization in Israel, covering more than 50% of the population, over 4,400,000 members. The study population focused on 1,605,800 children aged between 6 and 17 years, from 2006 and 2016.

The children's estimated relative ages in year in school (class) were split into thirds of the calendar year, with the youngest third born between August and November, the middle third born between April and July, and the oldest third born between December and March. The study was approved by the Clalit Health Services Ethics Committee [15].

3.2. Method

The output of DisEpi is a compact Visualization combining the graphical representation of the automatically generated HC and a heatmap, wherein a color gradient reflects either (a) incidence or (b) prevalence values over the sub-time ranges over the research time-range.

As a first step of the knowledge discovery process, we built an abstraction process discretizing the available data of each attribute into several classes, e.g.: age groups in two year spans, number of siblings (0-1, 2-3, and 4 or more), and ordinal month of birth relative to the school-year (categorized into youngest, middle, and oldest thirds).

As a second step, we approximated all attributes, from individual child data to sub-population snapshot values, describing respective statuses. These approximations were computed by using epidemiological metrics such as incidence and prevalence, at the relative age thirds' level.

As a third step, we computed a Euclidean distance matrix between all epidemiological metrics values describing the classes of each attribute (one value per attribute per relative age in class per year) within which we applied unsupervised HC.

The fourth step of DisEpi discovery flow is the reformulation process. This process is based on the use of a heatmap for each epidemiological metric (e.g. incidence and prevalence).
We used R version 3.3.1 [16] for the statistical analysis. R Package doParallel [17] was used to maximize computing efficiency given the large data size. R Package gplots [18] was used to perform automatically the HC and then to draw the heatmap.

4. Results

In the context of ADHD, DisEpi allows the domain-expert to visually analyze data mining results in a summary snapshot (Figure 1). Looking at the snapshot of ADHD medication usage, he/she is able to grasp the following results, simultaneously: (1) Relatively younger children in class are treated more than older; (2) First medication incidence increased between 2006 and 2011 but then stabilized; (3) Progression rates of medication incidence are different for each of 3 principal clusters.

Figure 1. DisEpi Visualization for ADHD medication incidence over the explored attributes.

The pharmaco-epidemiological goal of this DisEpi experimentation was to identify characteristics and medication treatment patterns of Clalit’s youngest population treated for ADHD and to compare these patterns to sociological and demographical data, such as relative age in class, sex, ethnicity, family size, sibling order, and other socioeconomic status attributes. DisEpi results are similar to those discovered in a previous research using classic statistical approaches [15], but are delivered in a more rapid, concise, and user-friendly way.

Furthermore, in the previous research on the same data [15], by using a priori based data analysis, one could not readily identify the similarity of the children population born overseas to the lately treated group. This means that DisEpi supports new epidemiological discoveries which must be later validated by the domain-expert.

5. Conclusions and perspectives

In this paper, we presented DisEpi, a tool allowing for the identification of clusters of population characteristics having similar trends, and thus defining profiles of patients,
with relatively short delays (a few days instead of a few months). It allows users to deal with very large medical numerico-symbolic data by reducing their dimensionality and complexity, and making them more accessible to PH decision makers. Therefore, it can support development of health policies by reducing delay by providing the medical decision makers a “data/analysis” integrated tool.

DisEpi will be wrapped as a package containing the end-to-end discovery process and will provide automated annotation using calendar events (e.g., “news”), which will reduce both time to discovery, interpretation and policy implementation [19].

References

The Meaning of Patient Empowerment in the Digital Age: The Role of Online Patient-Communities

Eugenia LAMAS, Rodrigo SALINAS, Carla COQUEDANO, Marie-Pierre Simon, Cedric BOUSQUET, Marcela FERRER, Sergio ZORRILLA

Abstract. Traditionally, patient empowerment has been used as a strategy for health promotion. The rise of online communities of patients represents a good example of how patient empowerment occurs, independently of the intervention of existing healthcare providers and insurers, allowing thus a more accurate definition of meaning of this concept. We describe two situations related with the development of health-related social networks: (1) The emergence of a new biomedical research model in which patients lead research, shifting the equilibrium of power from the professionals to research subjects themselves, and (2) The emergence of Lay Crowd-Sourced Expertise in these communities, arising from the daily exchange among patients affected by chronic conditions and their relatives, giving place to a new era of bottom-up data generation, previously unknown in biomedical sciences. We enrich these descriptions by analyzing interviews to key actors of these “on line” communities: Michael Chekroun, founder of “Carenity, France”, and Paul Wicks Vice President at “PatientsLikeMe, USA”.

Keywords. Community-Based Participatory Research, Ethics Research, Social Networks, Patient Empowerment

1. Introduction

Since the eighties, empowerment has been understood as a concept intimately involved with the emancipation of the disadvantaged, aimed at empowering them for the exercise of their rights, for participating actively in the process of decision-making and shaping of society [1] and in redefining the role of consumer in the governance of health systems and as co-creators of the value embedded in them [2]. In 2012 the World Health Organization widened its scope, considering it, together with patient-centred care, as “important elements for improving health outcomes, health system performance and satisfaction”. Patient empowerment as a concept, has been

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occasionally blamed as lacking a clear theoretical underpinning [3], being usually merged with autonomy and participation, allowing various and occasionally contradictory understandings of this key component of a modern, rights-based, approach to health, and maintaining the traditional paternalistic approach in its characterization [4, 5, 6] instead of incorporating digital health-literacy as a precious tool for health-systems value co-creation.

Empowerment has been the subject of mounting interest in health-care [7]. The emergence of health-related social networks and online communities of patients, in digital age, represents a good example of patient empowerment, in which previously disempowered individuals seize power by themselves, taking advantage of new technologies. Some authors have discussed the role of online communities in fostering patient’s empowerment in their relationship with physicians and healthcare providers, but they did not attempt to redefine the concept based on their observations [8]. The development of these networks helped the creation of a novel kind of patient communities: Online Patient Networks, whose members interact among them through a number of different Internet based social networks. The members of these communities take advantage of these networks to interchange about disease related real-world experiences, current treatments and, in particular, available drugs, their adverse effects, recent scientific research results and ongoing randomised trials, concerning their conditions. There are a number of examples, in the United States of America, of such communities, involving themselves in either observational or experimental clinical research, together with health professionals, sharing information in a peer to peer manner, and generating relevant new data for their conditions. A well-known example is the online platform PatientsLikeMe, which organised in 2009, the lithium study for amyotrophic lateral sclerosis, launching a new paradigm for planning and conducting clinical research [9, 10]. Recently, stakeholders of this new model of investigation have proposed the term “participants-led research” (PLR) to describe it, emphasising its participative nature, identified as one of its original and characteristic features [11].

All these expressions describe this novel research model, highlighting different distinctive aspects of its innovative structure, having so many embedded particularities, that they challenge the pertinence of the ethical principles themselves, which currently govern and regulate clinical research, giving an entirely new meaning and scope to the role patient empowerment plays in the progress of health care and biomedical knowledge. We affirm that the rise of health-related social networks and online communities of patients in the digital age— and the emergence of PLR in particular— represent a good example of how patient empowerment occurs, and may help to redefine the actual meaning of this key feature of a modern and equitable approach to health care.

2. Methods

Based on previous experience in the field of patient empowerment we selected several publications identified in a non-systematic review of the literature, using the MeSH term “patient participation” and the free term “empowerment” in PubMed database from 1966 onwards, and their bibliographies. We also analyzed interviews with key actors involved in patient’s online communities: Michael Chekroun, President and founder of “Carenity” (personal communication) a free social network created in France in 2011 aimed at people affected by chronic diseases, and Paul Wicks, Vice
President of Innovation at “PatientsLikeMe”, available through open-access publications [12]. Our methods were aimed at evaluating the role patients play in the management of these organizations, in order to assess if the objectives of these online communities are consistent with the concept of patient empowerment we propose, particularly in those aspects related with the innovative ways of conducting research. We identified two major issues related to the functioning and objectives of online patient’s communities that may help in providing a new definition of patient empowerment, suitable for an era pervaded by fast and easily available digital interactions among patients and their relatives.

3. Results and Discussion

3.1 First issue: Emergence of PLR

In PLR, patients not only participate in organising and conducting the investigation, but also on the collection and analysis of data resulting from research. As a result of this involvement, the centre of gravity of research is displaced from the professional interests to those belonging to the patients, differentiating this innovative model from traditional research. Paul Wicks states: “...we’re not going to use the existing infrastructure of research, like hospitals and trained scientists, etc. We’re going to take some of those skills and transfer them to participants themselves”. [12]. This entirely new situation blurs the border between the patient as passive participant and its new role as protagonist of the research, actively involved in planning and conducting the investigation, as well as in defining which is the acceptable standard of evidence for evidence-based medicine, and for the elaboration of recommendations included in clinical practice guidelines.

PLR represents a challenge to current ethical framework for research, and begs the elaboration of a new social contract for research [11, 13]. Concerning the way this new sort of research may affect the current ethical guidelines for research, Paul Wicks says “the ethical rules assume that there is such a thing as a researcher and such thing as a participant, and there’s never situation in which one person can be both things (uberization). I think it assumes an imbalance of power where one person knows more than the other, has access to more social capital and somehow control other person”….It doesn’t take into account what happen when the people themselves who have a condition want to self-experiment [12]. Thus, PLR represents a challenge to current ethical framework for research, and begs the elaboration of the new social contract for research [11, 13] Paul Wicks, when questioned about the responsibility of PatientsLikeMe as collector of research data and author of the scientific report, says: “...as a place that collected the data and published the research? I think that’s all unclear. But I think until the research establishment has more of a discussion about this, we’re not really sure where to go. I think what you can’t do is close it all down; you can’t put the genie back in the bottle. Because if it weren’t PatientsLikeMe, it would be Google, or it would be Twitter, or it would be Facebook. You can run participant-led research over the telephone. The medium is not the issue here. The issue is this social activation that’s occurred and the really simple group formation that social media allows”[12].
3.2 Second issue: Lay Crowd-Sourced Expertise.

The appearance of Internet in the nineties, and the subsequent development of social media in the last decade, have multiplied the potentialities of online patients' communities have given place to the emergence of Lay Crowd-Sourced Expertise (LCE) [14], nourished by a myriad of simultaneous interactions and free access to real-time updated scientific information. These interactions allow participants gathering other patients’ experience and gaining new knowledge. Michael Chekroun told us: “I believe real-world patient data should be a greater source of inspiration for the health authorities and industries.” On the same topic, he added: “the collection of the relevant information from the real-world patient’s experiences represents a Lay Crowd-Sourced Expertise, which is complementary to conventional knowledge”. This is consistent with Carenity’s goal that is to understand the needs of patients and raise information generated by them to inform and guide medical research. On this respect Michel Chekroun said: “(We) put on route medical research in areas where there are “holes”. The studies with the public and private institutions are collaborative. We don’t sale the data. (Personal communication). This collaboration permits a previously inexistent mix of lay expertise (coming from those patients acting as research subjects themselves) and professional expertise (coming from those physicians and pharmacists that collaborate with the execution of the study).

3.3 Towards a new definition of patient empowerment

The spread of digital interaction among patients, through the organization of patient’s online communities, have changed the traditional approach that health care professions had towards patient empowerment. From the paternalistic approach [4] to health promotion [3], representing the paradigm of patient empowerment in the nineties, in which health policies were designed by learned professionals and granted to patients to be passively adopted, the role of patients has moved towards a completely different role. The distinctive characteristic of patient empowerment, in this new scenario, is no longer the adoption of top-down designed health policies, but the free interchange of experiences among patients and their relatives, producing initiatives free from bureaucratic restrictions, imposed by the legal framework that governs health care and clinical research. Good examples of these novel initiatives are PLR and Lay Crowd-Sourced Expertise, as mentioned above. Furthermore, the emergence of patient empowerment, with these new defining characteristics, points towards a new and fresh understanding of the principle of autonomy of the patient, that goes beyond the common understanding of it as a recognition of the freedom of the individual as such, but the acceptance of autonomy as a social phenomenon leading to the creation of dependable and equitable systems of healthcare.

This new understanding of patient empowerment is consistent with the modern understanding of health promotion, as a tool for social change, used by individuals to seize power [15]. Indeed, as Paul Wicks said “The medium is not the issue here. The issue is this social activation that’s occurred and the really simple group formation that social media allows”. We believe that the development of digital networks has meant a revolution in the possibilities for empowering patients and communities in the care of their health and bodies, as illustrated by the examples we give in this short report, and that this has to be taken in account when redefining patient empowerment for this century.
References


DataWell: Public Involvement in the Development of a Federated Platform for Shared Patient Records in Greater Manchester, U.K.

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Abstract. Sharing personal health data for direct care, health improvement, planning and research is recognised as important to improving the quality and safety of care. However, the complexities of sharing data, including technology, information governance and consent issues, means that many projects have difficulty communicating with the public about why they wish to share data, or what the benefits might be. Great Manchester Academic Health Science Network has established a Public Experience Group to help co-design the requirements for a health information exchange, called DataWell, across over 30 health and care organisations in Greater Manchester. This group has allowed the programme to uniquely respond to questions of how consent and data sharing should work with DataWell for direct care, as well as exploring other uses of the data, including planning and research.

Keywords. Public involvement, health information exchange, user centred design, co-production.

1. Introduction

In the UK, health and care records are stored within individual NHS, health and social care organisations, under strict governance rules that make it difficult to share patient information. Greater Manchester (GM) Academic Health Science Network (GM AHSN) has developed the DataWell Health Information Exchange (HIE) to share patient records across NHS organisations and Local Authorities, integrating data from different health and social care sources to enable better, more connected care. A key objective is to ensure that any healthcare professional within Greater Manchester involved in the care of an individual patient can see, and share the information needed to make more informed decisions; improving the quality and safety of care each patient receives. DataWell provides the essential infrastructure for direct care and health improvement initiatives, and mechanisms for patients to access their own records from multiple health providers.

This year the DataWell Exchange will support the exchange of pathology, admission, discharge and transfer data from six hospitals across GM, enabling clinicians to view data from outside their own organisation. We view public and patient involvement in the design and implementation of this programme as critical to its success and in this paper describe our approach.

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2. Background

The sharing of patient data beyond their local area for purposes of direct care and health improvement has had a difficult response from the public in recent years. A lack of clarity in the purpose and use of health data, and increasing recognition of the risks associated with data loss and hacking have meant that the public is less willing to support the sharing of information without clear purpose, even when there is a legal basis for doing so. The national care.data project in England[1], and the partnership between the Royal Free Hospital in London with Google[2], have both received negative attention in the British press. The recent Wannacry ransomware virus has also highlighted significant weaknesses in the security of NHS systems[3]. However, it is well recognised that there are significant health and health economic benefits to HIE[4, 5].

It has therefore been critical that the public has been involved in the design of the DataWell project, in particular, debating appropriate information governance arrangements for direct care and secondary uses, and their thoughts on accessing their own shared record. This debate is happening at national level, including the latest Caldicott Review[6], the Wellcome Trust report on attitudes to commercial use of health data[7] and Citizens’ Juries work on health data sharing[8]. However, the DataWell team wanted to discuss these issues as they relate to DataWell and to the GM locality, and to ensure that public and patient views influenced design and policies of the programme.

3. Method

GM AHSN recognises that publicly funded streams of work in the NHS and affiliated organisations should be accountable to the public. As such GM AHSN has decided to actively promote and embed public involvement and engagement activities within all strands of its work. To support this, GM AHSN engaged with local Healthwatch England organisations at the start of the DataWell programme. Healthwatch England is a consumer champion for health and care in England, and is composed from multiple organisations serving their local communities. A representative from the Manchester Healthwatch was invited to participate in the early design and development of the DataWell project. This person was involved in design sessions, a member of the initial Steering Group and is now a member of the Reference Group. Their role is to highlight key learnings from the feedback that Healthwatch receives from patients, as use cases, to guide the design, to advise on public messaging and to disseminate updates and information about DataWell with the other GM Healthwatch organisations.

There was also a need for a wider consultation and engagement with the public to inform questions of consent, of suitability on how the data can be used and to discuss complex issues of information governance and technical implementation. It was also recognised that ad hoc groups may have difficulty with the complexity of these issues so, with support from Healthwatch Manchester, the GM AHSN Public Experience Group (PEG) was formed in autumn 2015 to enable the development of a longer-term relationship to help co-design these important components of the project. The group comprises nine members of the public, drawn from across the region, plus two professional members from GM AHSN staff.

GM AHSN defines ‘public’ as anyone not already actively involved within health and social care in a professional capacity. The PEG was established to support all GM AHSN activities, and so facilitates the inclusion of members of the public in shaping the
work and decision-making processes, enabling understanding of public perspectives on GM AHSN’s work. The group meets regularly, discussing a range of topics relating to GM AHSN’s work streams.

Figure 1. Matrix tool for discussion of consent options for different purposes of use of data: the x-axis is the degree of identifiability (anonymised to identifiable), the y-axis is the nature of consent (no consent required to explicit consent.)

4. Results and Discussion

It was important that technical complexities of the DataWell programme did not hinder effective incorporation of the public voice into the work, so early PEG meetings were spent discussing the technical approach, and exploring commonly used terms in information governance. This enabled a shared understanding and language. The PEG then debated the rationale for sharing health records for direct care, secondary uses, and views on patient access to their own records. The group shared stories of their own experiences of the NHS, caring for others and participating in research. The group used a matrix (see Figure 1) to support their discussion by allowing them to visualise their thoughts on appropriate consent mechanisms and degree of anonymity for different data uses. They wanted to ensure that their data was secure, and that they could say who could view their data, but they also wanted it to be available to improve their care and to help others by being available for research, so long as there is a clear public benefit. Sumaira Khalid Naseem (Vice Public Co-chair of the GM AHSN PEG) said: “On a human level [DataWell] would alleviate a lot of the time consumption I experience and maybe then I can focus on staying as well as I can.”

The outputs from the PEG group directly informed the consent mechanism and DataWell policies. As a result, DataWell will allow patients to control access to their record, share information with carers, and see who else has accessed their record. The decision was also taken to use a federated approach to the information architecture and governance of DataWell. There is no central warehousing of data and records remains
with the original data controllers, who grant permissions for how and what data are shared through specific data-sharing agreements. This approach aims to create a culture of trust and shared objectives.

The DataWell programme also needed to develop resources to inform the wider Greater Manchester population about the project, and the PEG have guided the programme approach, for example: helping in the selection of an external communications agency and in co-authorship of the public narrative.

PEG members have also become advocates for the DataWell programme, sharing their own stories and reasons for wanting their health records to be shared with the wider Greater Manchester NHS community. Their input ensures the patient voice is heard in discussions of the programme with NHS colleagues in IT, information governance, and management and planning. To enable this insight to be used on a larger scale, members of the PEG agreed to be interviewed on video, shared via the GM AHSN website and YouTube[9]. This video has been well received and led the PEG to consider follow up ideas for further videos. The first of these deals with questions of security, and it was agreed that it would take the format of two members of the PEG interviewing the GM AHSN Director of Informatics and the supplier Chief Technology Officer. One of the PEG members has a strong academic IT security background and so was confident in asking about technical detail. The second member reflected more lay person concerns about security and confidentiality. These videos are being edited and reviewed by the PEG themselves, for release and future project ideas are under discussion.

DataWell will enable many different NHS interoperability projects within the GM region, including direct care, audit, service planning, risk stratification and research. It is important to ensure safe, ethical use of the platform, to promote collaboration and maximise benefits to the Greater Manchester population. The programme has set up a DataWell Oversight Board to consider any technical and Information Governance issues presented by new uses, and this Board includes representation from our PEG group. The patient role on the Board is to encourage new projects to consider patient and public views and involvement, but also to scrutinise use of the platform and ensure this is being used appropriately and for the benefit of the GM population.

The DataWell pilot is being implemented at six centres across the GM region and will present initial results in October 2017. The pilot focused on three “Accelerator” projects: 1) a shared pathology view to enable rapid access to collated laboratory test results from four hospitals for improved clinical care, 2) GM NHS participation in the 100,000 Genomes Project, and 3) Sharing of information between patients, primary and
social care providers. These pilots test the principles of the model with NHS member associations, local authorities and patients. The ambition is to install DataWell connections across all 29 GM NHS sites by the middle of 2018 and a pipeline of future projects has been developed (see Figure 2).

This new technology will bring benefits for patients, carers and clinicians but also raises issues that require public debate, such as the uses to which the platform might be put and the organisations who may participate, whether the general public would support sharing some components of their records with social services or the police? For example, a police officer would not normally have access to a person’s care record but is likely to be the first on scene when someone is suffering a mental health crisis. Other questions will include the nature of the social contract for use of data for analytics and other secondary uses of the data. The impact of the General Data Protection Regulations on the legal basis for use of data and consent will also be significant, and we will continue to work with the GM AHSN PEG to debate and explore these emerging issues as they relate to DataWell.

Since the programme was initiated the creation of the Health and Social Care Partnership in GM has created a new central governance structure for health and care. This raises questions of how health data might be used across wider services where there is a need for further care. The need to explore public acceptability and the rules for enabling what data could be shared, with whom, and under what circumstances will be explored further with the PEG and other patient engagement.

The role of the PEG is vital to the success of DataWell as it provides an insight into the benefits of HIE for patients and provides a critical challenge to the expectations of the health and care system, as well of how the HIE is implemented to patient benefit.

5. Acknowledgements

The authors wish to thank Neil Walbran of Healthwatch Manchester and all the PEG members: Cara Afzal, Ingrid Brindle, Alan Campbell, Joan Chantrell, Chris Ellison, Nicholas Filer, Karen Hasid, Sumaira Naseem, Penny Noel, and Sorie Sesay for their support and input to the DataWell programme over the last two years.

6. References

Decision Support Systems in Health Care – Velocity of Apriori Algorithm

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Abstract. The amount of stored data in health information systems can reach terabytes and petabytes and application of specific algorithms in the field of data mining makes finding useful information suitable for making quality business decisions. A frequently used method for determining the rules of the relationship between attributes is the Association rule by applying Apriori algorithm. Lack of basic Apriori algorithm is derived from the slow work due to multiple scanned data sets. By examining the speed of generating the basic rules in relation to the improved Apriori algorithm by using software RapidMiner confirmed that the time required to generate rules for Improved algorithm is shorter, the rules are quickly generated particularly for large data sets, which is an advantage for making decisions.

Keywords. Decision support, generate rules, Apriori algorithm, Health care

1. Introduction

Ambulances, laboratories, outpatient clinics, expert opinions in the field of health care are the source of information with an exponential trend of collecting and conducting successful treatments. Correct structuring of data and usage of various analysis techniques and related algorithms of information may be used to make better business decisions in which the credibility of obtained rules is proportional to the amount of data.

Data mining (DAP) [1], known as knowledge discovery in data sets, a complex extraction of information from a potentially useful and unknown data stored in databases. Association rules [2] allow the generation of rules based on the relationship observed attributes depending on their values. Basic Apriori algorithm (AA, Apriori) that is used has a drawback that stems from multiple data scanning and resulting is a slow work. Application of advanced and improved analysis techniques in business certainly enhances business processes, especially when working with large data sets that are commonly present in healthcare.

The paper will show a version of improved AA and analysis of multiple data sets in the field of health with the use of RapidMiner software to examine the extent to which the size of the data will affect quick generation of rules for basic and improved AA.

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2. Disadvantages of basic Apriori

From the moment of AA application (R. Agrawal, 1994.) to date deficiencies were observed that are reflected in reduced efficiency at work [4] and it was also sought to eliminate the development of new, advanced, algorithms based on the basic algorithm: AprioriTid, AprioriHybrid [5].

In their papers, many authors describe advanced Apriori algorithms and point out the shortcomings of basic ones. X. Fang [4] points out two main disadvantages: scanning large databases leads to reduced efficiency due to large inputs, i.e. the data that must be loaded and when re-scanning data sets, the algorithm does not use the results from the pre-scan. S. Rao and P. Gupta [6] state that if in the first scan the number of occurrences of each attribute is $10^4$, then Apriori generates $10^7$ pairs of attributes stored and tested for frequency of occurrence, which requires huge resources and multiple scan data sets.

3. Association rule

Association rules of one of the DAP methods allows determination of rules of association of individual attributes with defining of parameters of support, which is the lowest frequency of occurrence of each attribute in the data set and confidence, which is the ratio of the number of records that contain two attributes and the number of records that contain one of these attributes, one that is defined as conditional.

Algorithm that is applied is Apriori [3] and the data scanning process consists of stages of unification and trimming. In finding the rules, algorithm finds frequent items in the database with multiple passes through the data set. Initially it goes looking for frequency of occurrence of one item based on parameter support conducts, trimming and unification. Then, it searches for occurrence of two items (pair), three items, etc., always performing the trimming considering the parameter support.

4. Improved Apriori

The version of improved Apriori will be described by example [7] which contains a set of ten data tracks (Z0…Z9), with each containing two to five attributes (A1…A5). Each entry is marked by primary key ID_Z (Z0…Z9). The input parameter is minimal support 4.

<table>
<thead>
<tr>
<th>Id_Z</th>
<th>Attribute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Z0</td>
<td>A1,A2,A3</td>
</tr>
<tr>
<td>Z1</td>
<td>A1,A4,A5</td>
</tr>
<tr>
<td>Z2</td>
<td>A1,A2,A3,A5</td>
</tr>
<tr>
<td>Z3</td>
<td>A3,A5</td>
</tr>
<tr>
<td>Z4</td>
<td>A1,A2,A3,A4,A5</td>
</tr>
<tr>
<td>Z5</td>
<td>A1,A3</td>
</tr>
<tr>
<td>Z6</td>
<td>A1,A2,A4</td>
</tr>
<tr>
<td>Z7</td>
<td>A2,A3</td>
</tr>
<tr>
<td>Z8</td>
<td>A1,A2,A3</td>
</tr>
<tr>
<td>Z9</td>
<td>A3,A5</td>
</tr>
</tbody>
</table>
In the initial scanning, the algorithm counts the appearance of each attribute, and in the following step eliminates those that do not meet the minimum requirements according to the support parameter. In ten transactions, the attribute A4 occurs three times and does not meet the minimal support requirement. Table 2 shows all attributes with associated support and records where they also appear.

Table 2. Extract individual attributes (1-element).

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Support</th>
<th>Id_Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1</td>
<td>7</td>
<td>Z0,Z1,Z2,Z4,Z5,Z6,Z8</td>
</tr>
<tr>
<td>A2</td>
<td>6</td>
<td>Z0,Z2,Z4,Z6,Z7,Z8</td>
</tr>
<tr>
<td>A3</td>
<td>8</td>
<td>Z0,Z2,Z3,Z4,Z5,Z7,Z8,Z9</td>
</tr>
<tr>
<td>A4</td>
<td>3</td>
<td>Z1,Z4,Z6</td>
</tr>
<tr>
<td>A5</td>
<td>5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
</tbody>
</table>

In the next step, according to Table 3, all attribute pairs are separated and their occurrence is counted. The basic AA here scans every record, while the improved scans only those where attributes occur according to the minimal support condition to the additional Min parameter. In the example of pair attribute (A1, A2) according to Table 2., the attribute A2 has less support (Min) than attribute A1, so the records where A2 appears are separated. Further set scanning eliminates those attribute pairs that do not meet the minimal support (4).

Table 3. Extract pairs of attributes (2-elements).

<table>
<thead>
<tr>
<th>Attribute (pairs)</th>
<th>Support</th>
<th>Min</th>
<th>Id_Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1,A2</td>
<td>5</td>
<td>A2</td>
<td>Z0,Z2,Z4,Z6,Z7,Z8</td>
</tr>
<tr>
<td>A1,A3</td>
<td>5</td>
<td>A1</td>
<td>Z0,Z1,Z2,Z4,Z5,Z6,Z8</td>
</tr>
<tr>
<td>A1,A5</td>
<td>3</td>
<td>A5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
<tr>
<td>A2,A3</td>
<td>5</td>
<td>A2</td>
<td>Z0,Z2,Z4,Z6,Z7,Z8</td>
</tr>
<tr>
<td>A2,A5</td>
<td>2</td>
<td>A5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
<tr>
<td>A3,A5</td>
<td>4</td>
<td>A5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
</tbody>
</table>

As in the previous step, the unification forms trio of attributes and eliminates those that do not meet the minimal support requirement (Table 4).

Table 4. Extract triplets attributes (3-elements).

<table>
<thead>
<tr>
<th>Attribute (triplets)</th>
<th>Support</th>
<th>Min</th>
<th>Id_Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1,A2,A3</td>
<td>4</td>
<td>A2</td>
<td>Z0,Z2,Z4,Z6,Z7,Z8</td>
</tr>
<tr>
<td>A1,A2,A5</td>
<td>2</td>
<td>A5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
<tr>
<td>A1,A3,A5</td>
<td>2</td>
<td>A5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
<tr>
<td>A2,A3,A5</td>
<td>2</td>
<td>A5</td>
<td>Z1,Z2,Z3,Z4,Z9</td>
</tr>
</tbody>
</table>

Generation of associative rules on the basis of minimum confidence occurs after the verification of support parameters for each record combination (individual, pair and trio). In the stated example, the amount of scanned records of the starting data set with basic and improved AA application followed by examination of occurrence of individual, pairs and triplets of attributes is presented in Table 5.

Table 5. Number of scanning with basic and improved AA.

<table>
<thead>
<tr>
<th></th>
<th>Basic Apriori</th>
<th>Improved Apriori</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 attribute</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>2 attributes (pairs)</td>
<td>60</td>
<td>34</td>
</tr>
<tr>
<td>3 attributes (triplets)</td>
<td>40</td>
<td>21</td>
</tr>
<tr>
<td>Total</td>
<td>150</td>
<td>105</td>
</tr>
</tbody>
</table>

At the initial scan of records with individual attributes, the number of scans with both algorithms is equal, and the difference in the amount of scanned data is
proportional to the number of attributes generated by unification (double, triple, quadruple, etc.). In total, the number of crossings of the improved AA for the stated example is almost 30% less than in the basic AA.

5. Testing data

The analysis of the speed of generated rules used actual, publicly available data on the amount of performed ambulatory interventions in each medical field in hospitals in America. [8]. The data stored in Access database was used and exported in Excel table that was used in analysis of RapidMiner application. The original data set contains 15 attributes and 4119 records. The data was reduced for the purpose of analysis and converted in a numeric type and all missing values were removed. [9]. Final starting analysis collection contains 9 attributes and 3405 records. For the purpose of this paper, the amount of records in the 2nd set was doubled, while in the 3rd tested set the amount was increased three times in relation to the starting set (Table 6).

RapidMiner process (Figure 1.) consists of operators for: data import, frequency discretization with two classes, transformation of numerical into binominal values, search of frequent data sets and operators that generate association rules. The support parameter is defined in the operator’s settings for the search of frequent data sets, and confidence in the operator’s settings for the generation of association rules.

The testing was conducted on a computer with the Intel Core i3 processor, with 3,4Ghz frequency and 3GB of RAM with installed 32-bit Windows10 operating system. The RapidMiner 5 version of program support has an open code and is based on Java platform.

![Figure 1. Analysis process with applied operators in RapidMiner.](image)

6. Test results

Table 6. shows the testing results for the data sets with different numbers of records with appropriate parameters of minimum support and confidence. The number of attributes and the minimal support have equal values with each tested set.

Basic AA needs the most time for the total scan of data sets with the largest number of entries and confidence parameter 0.6 while the least amount of time is necessary for the set with the least amount of records and confidence parameter 0.9. Only 2.2 seconds were necessary for the scanning of a set with 3405 records with
confidence 0.9. The difference in the speed of the generating rule with medium and largest set with the reliability 0.9 is 1.3 seconds, and with the application of the improved Apriori in the second scanning of data sets it will be less, in the third even less, etc. Assuming that on the basis of Min parameter the set in the second scan is half the size shows that the rule generating time is less by approximately 20%.

Table 6. Test results for different data sets.

<table>
<thead>
<tr>
<th>No. of Attributes</th>
<th>No. of records</th>
<th>Time analysis (sec.)</th>
<th>Min. Support</th>
<th>Min. Confidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>3405</td>
<td>4.8</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>34105</td>
<td>2.2</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6810</td>
<td>5.9</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6810</td>
<td>3.1</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13620</td>
<td>7.2</td>
<td>0.6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13620</td>
<td>4.4</td>
<td>0.9</td>
<td></td>
</tr>
</tbody>
</table>

7. Conclusion

Improved AA allows faster generation of rules, because after the initial scan of the entire set, in the next rounds through sets it uses additional support parameter and scans a portion of the initial data set. The difference in the number of scans between the basic and improved AA increases with the increase of the attribute combination whose frequency the algorithm examines. Time saving in generation of rules, particularly with the analysis of large data sets is more pronounced, and the application of the improved eliminates the shortcomings of the basic AA.

In addition to correct selection of DAP procedure and interpretation of the obtained rules, the speed of generating rules becomes an important factor for making quality business decisions in today’s e-business in the healthcare sector.

References


A Case Study of the Technology Use and Information Flow at a Hospital-Driven Telemedicine Service

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Abstract. Health care services face the challenge of providing individualised treatment to a growing ageing population prone to chronic conditions and multi-morbidities. The research project Patients and Professionals in Productive Teams aims to study health care services that are run with a patient-centred teamwork approach. In this context, a case study was made of a hospital-driven telemedicine service for chronic obstructive pulmonary disease patients after hospital discharge, with a focus on information flow and technology use. The methods used were observation and interviews with key informants. The results showed that the technology was perceived as well-functioning for telemedicine support, but the technology used was a standalone system and not integrated with the electronic health record of the hospital. In addition, there was lack of support to provide the patients at home with written instructions on advices of medical treatment and care. The electronic information used for this telemedicine services, allowed shared access of information for teamwork between professional only within the hospital.

Keywords. Patient-centred care, telemedicine, videoconference, information technology

1. Introduction

Demographic changes demand the health care services to face the challenge of individualising treatment to a growing ageing population that is prone to chronic conditions and multi-morbidities [1]. The World Health Organization (WHO) has emphasised that there is need to focus on patient-centred health care service models [2]. There is a need to understand how to operationalise patient-centred care with technology that efficiently supports team collaboration, where quality of care and patient outcomes are central. In this context, the research project Patients and Professionals in Productive Teams (3P) aims to study health care services that are run with a patient-centred teamwork model [3][4]. 3P is a 4-year long project (2016-2020), approved by the Research Council of Norway and funded through Helseforsk, a program for national funding from the Regional Hospital Trust Funds of Norway to cross-regional health care services research projects [5]. The 3P project involves four innovation arenas in Norway and Denmark, that are included in the research of models for patient-centred health care

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teams. This paper presents a case study made in one of the innovation arenas, which is a hospital-driven telemedicine service for chronic obstructive pulmonary disease (COPD) patients after hospital discharge. The focus was on information flow and technology use within a teamwork setting. The research questions (RQs) stated for the case study were:

RQ1: How does information technology support the communication and work processes at a telemedicine service?
RQ2: What are the benefits and constraints of the telemedicine technology for patient-centred care?

2. Methods

Qualitative research methods were used in the case study [6][7]. A field study with observations was made at the telemedicine service together with individual- and focus group interviews to gain an understanding of the technology interactions and information flow within the patient-centred procedures of the involved health care team. A total of 12 informants contributed to the study during the spring of 2017. The group of informants included health care professionals, patients, technicians and administrators.

The data collection, consisted of audio-video recorded interviews and field notes from observations and demonstrations of the technology.

The Norwegian Centre for Research Data (NSD) approved the study, with project number 53771 [8]. The participation in the study was voluntary and the informants received written information about the project and signed a consent form.

3. Results

The collected data were categorised into two main topics: 1) organisation and workflow and 2) technology interactions and information flow.

3.1. Organisation and Workflow

The telemedicine service was organised as a separate unit at a hospital, with two nurses that were responsible for running the daily operations. New patients were enrolled into two categories: 1) a randomized controlled trial (RCT) with a protocol to follow for 10 telemedicine consultations [9], 2) telemedical follow up in sustainable operational services as long as the medical conditions required or 14 days [10]. The nurses at the telemedicine service made phone calls to eight wards at the hospital every day and visited one local ward, to identify patients with COPD that would benefit from the remote monitoring procedure. In addition, General Practitioners (GP) could refer patients on short notice for telemedical service. For the 10 telemedicine consultations, there was a guide with 10 topics, such as inhalation techniques, nutrition and physical activity, to go through in order to give adequate training and support to the patient. For the telemedical consultations the nurse collaborated with physiotherapist, occupational therapist, and nutritionist as a part of the team at the hospital, and they also had individual telemedical consultations with the patients. The primary medical responsible for the patient’s treatment was the GP. In addition, there was a local doctor at the hospital that was available for medical advises. During the period when a patient was enrolled into the
telemedicine service, it worked as a one-point-of-contact for the patient. The nurse could assist with contacting or sending referral to health care professionals and related services when needed due to medical circumstances. At day-time the nurses were present at the telemedicine service, and during evening, night and weekends there was a nurse on duty in a ward that patients could contact by phone. When a patient in the RCT category was discharged from the service, an appointment was made for a six month follow up consultation.

3.2. Technology Interactions and Information Flow

Two technical systems were used at the service: the hospital electronic health record (EHR) from the vendor DIPS and a solution for the telemedicine consultations by the vendor Imatis. Both systems were used simultaneously. The time appointment system and medical notes were made in the EHR system. The telemedicine consultations were made through the Imatis web-based system where transmission to cloud-based server storage was made through Hypertext Transfer Protocol Secure (HTTPS). For this system, the patient’s administrative information had to be manually registered, see description of the information flow and technology use in Figure 1.

![Figure 1. The information flow and technology interaction in the telemedicine service.](image)

For the telemedicine consultation, the nurse used a desktop with an external web-camera and two screens, one for each system, see Figure 2 (left). The patient at home used a tablet with a stand, provided in a small suitcase, and with a pulse oximetry using Bluetooth for communication with the system, see Figure 2 (right). During consultation, the pulse and peripheral capillary oxygen saturation ($\text{SpO}_2$) results were shown live on screen for the telemedicine system.
When enrolling a new patient to the telemedicine service, an inclusion letter was sent electronically to the patient’s GP. During the first telemedical consultation the nurse created a journal note in the patient’s EHR and during the following consultations, the pulse oximetry results were manually transferred to journal note in the EHR from the information observed in the telemedicine system. This note was finally signed when the patient was discharged from the service, meaning that all measurements and medical notes were documented in the same journal note for the whole period. At discharge from the service, the nurse wrote a discharge letter (epicrisis) sent electronically to the patient’s GP. When needed for technical reasons, as if the patient were not able to answer the video call, the nurse could remotely control the tablet with the Teamviewer program and accept the video conference on behalf of the patient. For privacy reasons, such remote control was agreed on during a phone call in advance.

During the field study, it was stated that being able to see the patient on the screen was beneficial for evaluating the respiration pattern and colour of the skin. In addition, it was expedient for instructions of inhalation technique for medication, as the actions of the patient could be observed. It was not a systematic use of written instructions for temporary changes in medication and an electronic message could not be sent to the patient’s tablet.

4. Discussion

This paper has presented a case study of the technology interactions and information flow at a telemedicine service driven with a patient-centred team model. The research questions (RQs) formulated at the beginning of this paper are answered based on the results.

For RQ1, asking about how the technology supported the communication and working processes at the telemedicine service. The study showed that the technology was perceived by the informants as well-functioning for telemedicine consultations between health care professionals and patients at home. Phone was used for communication to identify COPD patients within the hospital for the telemedicine service. Phone was also used for contacting the patient’s GP. The telemedicine system was a standalone technology and not integrated into the EHR of the hospital organisation, which created some double work with manual registrations in two separate systems. The
telemedicine service used one journal note for the patient in the EHR, covering the entire period of enrollment, to ease the overview.

RQ2 asked about benefits and constraints of the telemedicine technology for patient-centred care. The study identified both strengths and weaknesses with the technology used. With focus on patient-centred care, it was beneficial being able to see the patient on the screen compared with phone consultations, especially regarding respiration and inhalation technique as the nurse could continuously measure pulse oximetry data online during the video consultation. The telemedicine service worked as one-point-of-contact as long as the patient was enrolled, but also after the telemedicine service period this group of chronic patients would need a permanent one-point-of-contact, as recommended in [10]. It was observed that written instructions could not be sent to the patient after a telemedicine consultation, due to lack of technology support. The server storage for the telemedicine system was made abroad, which raises some concerns on privacy and security as the access to medical information in Norway is very restricted [11]. The actual technical solution used for the telemedicine service was not suited for teamwork except that incorporated personnel at the hospital could log on to the stand-alone system and get access to information. In addition, the important journal notes were made in the EHR normally used at the hospital; however, without any integration to the telemedicine system.

This study has some limitations, such as including only one innovation arena. Nevertheless, the study had a number of participants with different professions and backgrounds that meaningfully represented the user groups at telemedicine services.

Future work would include similar studies of the other three included innovation arenas in the project, and in a final phase make comparisons of technology support in patient-centred team settings.

References

DNA Encoding Training Using 3D Gesture Interaction

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a University Politehnica Timisoara, Romania/ Faculty of Automation and Computers

Abstract. The work described in this paper summarizes the development process and presents the results of a human genetics training application, studying the 20 amino acids formed by the combination of the 3 nucleotides of DNA targeting mainly medical and bioinformatics students. Currently, the domain applications using recognized human gestures of the Leap Motion sensor are used in molecules controlling and learning from Mendeleev table or in visualizing the animated reactions of specific molecules with water. The novelty in the current application consists in using the Leap Motion sensor creating new gestures for the application control and creating a tag based algorithm corresponding to each amino acid, depending on the position in the 3D virtual space of the 4 nucleotides of DNA and their type. The team proposes a 3D application based on Unity editor and on Leap Motion sensor where the user has the liberty of forming different combinations of the 20 amino acids. The results confirm that this new type of study of medicine/biochemistry using the Leap Motion sensor for handling amino acids is suitable for students. The application is original and interactive and the users can create their own amino acid structures in a 3D-like environment which they could not do otherwise using traditional pen-and-paper.

Keywords. Amino acid, leap motion, 3D images, gesture.

1. Introduction

In order to learn the 20 amino acids resulted from the combination of 3 or 4 nucleotides from the DNA (adenine – A, cytosine – C, guanine – G and uracil – U or thymine - T), the medicine, chemistry or bioinformatics students or the human genetics domain studying passionate people, use domain related books or solve exercises on paper, which are not interactive.

The main objective of our work was the development of an application for students that learn the amino acids in a new interactive manner, through gestures and viewing in a 3D environment.

An amino acid is the result of the translation process. The 20 amino acids formed by the combination of the 4 nucleotides are the following: alanine, arginine, asparagine, aspartic acid, cysteine, glutamic acid, glutamine, glycine, histidine, isoleucine, leucine, lysine, methionine, phenylalanine, proline, serine, threonine, tryptophan, tyrosine, valine. [1]

The application presented in this paper supports the learning of the 20 amino acids in an interactive way not only by displaying them in a 3D space, but also by using
some recognized gestures implemented for the Leap Motion sensor. With this application the users can combine freely any nucleotide from the DNA to obtain an amino acid. The main condition for using this kind of application is that the user should poses a Leap Motion sensor, such a device being not very expensive. Using the application, the students will learn very fast the gestures used for DNA bases control.

The literature study shows some applications using the Leap Motion sensor to control the 3D images of different molecules (lithium, sodium, potassium, rubidium, cesium) to study the reaction that these molecules have with water (as in ChemGrabLab application). [2] The disadvantage of this application is that the gravitation effect overlaid on the 5 3D images of the mentioned molecules is not very well calibrated. Touching the molecules with the virtual hand offered by the Leap Motion package, these tend to flow or many times take a strange trajectory in the 3D virtual space. Another application, ChemEx 3D [3], offers to users the possibility of learning molecules from Mendeleev’s table. The Molecules [4] application allows the control by using gestures in the 3D space of different molecules. In the specialty literature, the Leap Motion sensor is used alongside with Arduino microcontrollers for turning on/off the bulbs from a room [5] with the aid of some gestures implemented for this sensor.

Another device used in gesture recognition is Microsoft Kinect [6], a device used in some studies in checking the correct sitting posture in front of the computer of users of specific ages. The results of this study consist in identifying incorrect user postures when working with a computer. [7]

Combining cutting edge technologies based on gestures with genetic code elements resulting in development of a 3D application supporting the user in visualizing the 3 DNA bases is the main goal pursued in our work and in this paper. The main motivation of presenting the results of our work is to offer the medicine, chemistry or bioinformatics students, or the human genetics domain passionate people a new way of learning the amino acids by gesture, controlling the nucleotides and the 3D visualization of the application.

In this paper we emphasize the importance of using gestures in control of applications, and displaying it in 3D. The final result is that users can view, control, and learn more quickly and in a familiar environment the amino acids than in the classic way.

2. Methods and tools

The novelty of the AminoMotion application compared to other studied applications from the specialty literature is using the Leap Motion sensor by creating new gestures in the application control and the development of a new algorithm based on each amino acid corresponding tag depending on the 3D virtual space position of the 4 DNA nucleotides and their type for learning the amino acids.

The proposed application is a desktop application and based on Unity 5.6 editor and on Leap Motion sensor, a sensor which can recognize the hand gestures. The development language is C# for both, the development process of the Leap Motion recognized gestures and for the nucleotides tagging algorithm to compos the amino acids. We use the Hand Controller [8] script from the Leap Motion Unity SDK (Software Development Kit).
2.1 Unity

Unity is common in the game industry, mostly because of the depth and the quality of its optimizations, but also for its speed and efficiency of its workflow, offering Unity users the possibility of developing high quality content in a very short time. Using Unity the editor the user has the possibility to create content not only for 2D projects but also for 3D ones.

Among other features, Unity offers integration with the stand-alone Visual Studio C# editor. This integration offers the possibility of automatic creation and maintenance of Visual Studio project files. [9]

2.2 Leap Motion

Leap Motion can distinguish between human gestures (swipe, circle, screen tap and key tap), to support interaction with the virtual environment and augmented reality without touch. This sensor allows the creation of new gestures, not just using the 4 predefined ones from its software system. Creating new gestures for the Leap Motion sensor is possible due to its capacity to recognize each finger from a hand and make the difference between the left hand and the right one. [10]

For this complex application of amino acids creation development, in the Unity editor we used 3D objects. All of these 3D objects, have been set on specific positions and dimensions for user interaction in the 3D virtual space.

On the interaction table are present 4 types of nucleotides (A, C, G, U), each of them having a different color, green for the adenine, red for the cytosine, blue for the guanine and yellow for the uracil/thymine (Figure 1.). Each nucleotide having 3 samples for assuring that the user has the possibility to obtain any of the 20 amino acids. One of the important features of the application is that on the 3D objects representing a nucleotide type we applied a gravitational effect. In Unity editor this gravitational effect it is named Rigidbody. The 3D objects are defined as cubes, because it was noticed that after applying the gravitational effect these cubes are behaving better than the 3D spheres used at the begging of application development. All the cubes used in the application have the Finish flag enabled for making it easier to recognize them when they are catch with the predefined catching gesture.

![Figure 1. View of the introduced nucleotides inside the bowl and the name of the created amino acid](image)

*Sticking Gesture* is an original gesture defined for this application. The functionality of this gesture is given by the Leap Motion sensor capacity of recognizing...
the hand fingers. Thus it was used the index finger of the right hand. For sticking a
nucleotide to the right hand index finger, the finger has to be positioned at a 0.3 units
distance from the object. Inside this gesture, in the C# script it is performed a search for
the finger in the right hand fingers list and when this is found (the Leap motion sensor
detects it) and its position is at a smaller distance than 0.3 units, than the 3D object gets
stick to the index finger.

For catching the 3D object (the applying of sticking effect on the hands index
finger of a 3D object) it has been defined the following inequality:

\[ \sqrt{(x_2 - x_1)^2 + (z_2 - z_1)^2} \leq 0.3 \] (1)

Where: \((x_1, z_1)\) – represents the 3D objects coordinates

\((x_2, z_2)\) – represents the coordinates of the hands index finger

After sticking the 3D object (nucleotide) to the finger the user can move it
wherever wants inside the virtual space. For moving the 3D object inside the
nucleotides combination bowl, the user has to be positioned with the stick object to the
virtual hands finger above it. When the object is above the bowl, the sticking effect of
the index finger will disappear, and the 3D object will fall inside the vase, because of
the gravitational effect applied on it. Each nucleotide selected by the user with the aid
of this gesture will result with the displaying of the selected nucleotide’s name on the
screen. The corresponding C# script of this functionality it has been added on top of
Hand Controller object.

The Amino acids algorithm is defining the name of the amino acids created in the
3D interaction bowl (Figure 1) by combining 3 nucleotides. It takes into account the
name and the position (order) of the nucleotides. At the beginning, are read the
nucleotides with the Finish tag, then the position is initialized with zero and the
nucleotide variable with null. If the position is different than 3, the nucleotide will take
one of the following values: A, C, G, U and the position will be equal to 1 and this
process will be repeated until the position will be equal with 3. When the position will
be equal with 3 the name of the formed by combination of 3 nucleotides amino acid
will be determined.

3. Results and discussions

The inequality (1) represents the distance between two points, between the 3D object
coordinates and the hands index finger coordinates. Even if this coordinates are from
the 3D space \((x, y, z)\), it was given up the calculations between the two points and for
the y coordinate, which represents the height, for reasons of application answer speed
to gesture. Thus it is calculated the distance between the two points only on x and z
coordinates which represents the thickness and width in the 3D space.

Cubes are the basis to form the 3D images representing the 4 types of nucleotides.
In our work, initially we used spheres, but when they have the gravitation effect
applied they were rolling and eventually fall of the table, being hard to control.

The developed application offers to users a familiar type of interaction with the
laptop/computer, using gesture interaction. This supports the training of students
learning the 20 amino acids formed by combining three nucleotides. The users have the
possibility to combine freely any kind of nucleotide and they receive as an answer the
name of the created amino acid.
The 3D environment provided by the application, the amino acid name association algorithm and the gesture interaction are the main contributions of our work and presented in this paper.

To evaluate the usability of the application we tested it to calibrate the coordinates of the index finger and the 3D cube, and we refined the application until the result was the best. Using 3D cubes in the representation of the nucleotide at the expense of spheres helps a lot in catching the object with the gesture associated with the Leap Motion device. The AminoMotion application is a new and original application using the Leap Motion sensor for studying human genetics. The testing lot consisted in 27 medical students and 23 chemistry students. The usability study results will be published in the future.

The application test focuses on the impact on the students, how easily they interact using Leap Motion gestures and the ease of learning the amino acids. At the same time, a comparison between the use of 3D and the classic 2D display and outcomes learning of amino acids is planned for near future.

For a better interaction in the future we will implement a gesture that can catch/stick more than one nucleotide at a time. For the future the application will be ready for mobile support.

References

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Section 2

Short Communications
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Japanese-German Collaboration on Electronic Health Record Systems

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Since more than 30 years the German Association for Medical Informatics, Biometry and Epidemiology (GMDS) and the Japan Association for Medical Informatics (JAMI) are closely collaborating. The Collaboration is based on mutual exchange of scientists and students and on joint workshops in Japan and Germany. Currently the focus is on Electronic Health Record Systems (EHRS). Despite the differences in German and Japanese culture there are commonalities in the health care systems and its challenges. Therefore, it makes sense to learn from each other on how

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to build and manage high quality EHRS. Methods are needed for being able to compare both EHRSs and their quality.

In two joint workshops in Germany we defined a Quality Requirements Framework of EHRS (QRF-EHRS) and completed it with requirements stemming from experiences in Germany and Japan. The details of the QRF-EHRS have recently been published in Methods of Information in Medicine [1]. For the QRF-EHRS framework, we defined EHRS as a subsystem of a transinstitutional health information system (tHIS) which is built and managed on site by information management. Based on Donabedian’s quality dimensions, the QRF-EHRS framework considers information management as process quality of EHRS and the available resources for information management as EHRS structural quality. For outcome quality of EHRS its domain and tool layers have to be assessed.

We want to show how cross-cultural collaboration not only helps sharing experiences but also can contribute to methodological progress in the field of health information systems and EHRS.

References

Taking Nursing Informatics into the Future

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EFMI WG NURSIE

Abstract.
The new board EFMIs Working Group have planned the future strategy for involving nurses in informatics. The strategy is to bring nursing informatics into the future. It is important to ensure that the next generation of nurses is involved in the work with Nursing Informatics and share knowledge. It must be done with a targeted effort including of social media and a more offensive effort at the annual MIE meetings.

Keywords. EFMI, Nursing Informatics, Strategy, New generation, social media

1. Introduction

At the EFMI Council meeting in Oslo in 1988 the question of initiating a Nursing Informatics Working Group in EFMI was proposed by Dr. Marianne Tallberg from Finland. The response from the Council was positive and a resolution to start a Nursing Informatics Working Group was passed by EFMI at the MIE’88 conference.

EFMI then approached the European Medical Informatics Association and Nursing Associations in member countries, and invited them to appoint members to the Working Group. For practical and logistical reasons, they were advised to consider appointing the same person to both their Association and the EFMI Working Group.

In a letter sent from EFMI, the members of these Associations were made aware that the representative to the Working Group would not need to be a nurse, but must be a person directly involved with teaching or practicing nursing informatics or, at minimum, is interested in nursing informatics. This requirement was in accordance with the EFMI Working Group’s mandate that, "A Working Group within EFMI must consist of experts selected and assigned in a special area."

At the inaugural meeting of the Working Group held at MIE’90 in Glasgow, the eleven European countries represented all agreed to the following goals:

1. To support nurses and nursing organizations in European countries with information and contacts in the field of informatics.
2. To offer nurses opportunities to build contact networks within the informatics field. This could be accomplished by arranging sessions, workshops and

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3. To support the education of nurses with respect to informatics and computing.
4. To support research and developmental work in the field and promote publishing of achieved results. [1]

Since Glasgow, the Working Group was initially very active in furthering nursing informatics, but over time lost momentum and membership. A meeting of the EFMI Working Group convened in Geneva in 2016 looked to resurrect the Group through membership and recruitment of a new Board.

2. Current Status of the EFMI Nursing Informatics Working Group

At the general assembly at the MIE conference in Manchester, April 2017, a new EFMI Board of the Nursing Informatics Working Group was elected. The new President, Inge Madsen, is a RN with a Master in Health Informatics (1998) from the University of Aalborg, Denmark. Inge Madsen is reg. nurse and holds a Master in Health Informatics since 1998 from the University of Aalborg, Denmark. She has been working with informatics for more than 30 years nationally and internationally and she is currently an associated professor at the VIA Faculty of Health Sciences, Aarhus, Denmark and at the programme of Healthcare Technology engineering, University of Aarhus, Denmark. She is the authors of several publication on nursing informatics and the former chair of Danish Nursing Society and vicepresident of The Danish Medical Informatics Society.

Past President, Patrick Weber, has served the EFMI Working Group as President for many years and must be lauded for his dedication and commitment to nursing informatics. Patrick Weber MA, RN is Director and Principal of Nice Computing in Lausanne, Switzerland. He has over 40 years of health care experience, with more than 30 years in the field of health informatics. Mr. Weber has served as his country’s national representative to the International Medical Informatics Association – Nursing Informatics Special Interest Group (IMIA-NI) for over the past twenty years and currently holds the Vice President chair for IMIA-NI Administration. Mr. Weber is a recognized informatics leader across Europe and has been a pivotal leader in the European Federation for Medical Informatics (EFMI) holding numerous offices in EFMI and in Switzerland’s Nursing Association. Mr. Weber works actively with healthcare organizations and governments extensively across Europe and is a frequent collaborator on informatics projects across the European Union countries. He has numerous publications in both English and French and is a frequent presenter at national and international conferences.

The new Secretary, Laura-Maria Peltonen is a registered nurse with a master's degree in nursing science and a clinical background in the intensive care setting. She is a doctoral candidate at the University of Turku. She teaches graduate students Knowledge Management and Health Technology Supporting Leadership in Health Care. Her doctoral research focuses on information management in the day-to-day management in the acute care setting. She is currently the chair-elect of the IMIA NI SIG Student and emerging professionals group."
3. Looking to the Future

Since the new Board was elected in April 2017, the Working Group has been revitalized and is in the planning stages of the following initiatives that will help take nursing informatics into the future.

- Develop a governance structure and Terms of Reference for the Board that considers member development, attendance at conferences, succession planning, and partnerships with Informatics Associations.
- Develop a White Paper on the status of nursing informatics now and in the future, and look at ways to involve nurses in shaping how informatics will help transform nursing and healthcare.
- Create a social media platform, including a refreshed website and a network for learning and sharing informatics knowledge with and between nurses.
- Increase attendance at informatics conferences by having dedicated sessions for nurses that include presentations, workshops, posters, forums and other opportunities where nurses may present and receive informatics education and knowledge.
- Examine ways in which nursing informatics professionals may share knowledge and experiences between countries, such as visiting professors and invited lecturers.
- Develop a network of nursing informaticians and create a repository of educational material that may be used for promoting nursing informatics at local educational sessions, work fairs, conference exhibits, etc.
- Provide a platform where nursing informatics resources may be available to nurses throughout Europe e.g. EFMI Nursing Informatics website.
- Actively recruit membership to the EFMI Nursing Informatics Working Group.
- Develop a stakeholder management and communication plan to support the outputs of the Working Group in promoting nursing informatics.

The Board will hold a strategic planning meeting within the next months to discuss these and other ideas, and to create a visionary roadmap and timeline that will be shared with the membership. The dedication of the new Board to take nursing informatics into the future is only matched by their extensive knowledge and experience as informaticians.

4. References

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Can International Patient Summary Standards Improve Risk Assessment for Insurers and Payers?

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Keywords. IPS, International Patient Summary, HL7 FHIR profiles

Achievements of medical research and technology have led to longer lives and increased need for healthcare by an aging mobile population living with multiple chronic diseases. Healthcare systems are struggling to meet rising demand, offering timely access to high quality safe services. The digitization of medicine can assist healthcare systems in risk assessment and planning, but essential knowledge sources remain largely disconnected confined in health organizations, insurers, payers, and the patients themselves.

The aim of this presentation is to discuss how International Patient Summary (IPS) Standards might help link these disconnected data sources, leading to higher efficiency and better risk assessment and healthcare planning. Effective management of chronic disease demands cooperation among multiple health professionals, patients and their informal caregivers, as blended models of care emerge. WHO has proposed a framework for integrated people-centered health services based on five principles: engaging and empowering people and communities, strengthening governance and accountability, reorienting the model of care, coordinating services within and across sectors, and creating an enabling environment. Patient summaries based on international standards can help support this paradigm shift.

IPS standards aim to offer limited but essential information on health problems, allergies, active medication and treatment, vaccinations, and perhaps also health goals using well-defined information structures and terms. Depending on the implementation, the actual content of the patient summary may originate from diverse actors across jurisdictions. Starting from the patient summary, HL7 FHIR profiles they can help navigate to detailed information. Aggregating patient summaries, it is possible to reason about the health needs of communities offering concrete evidence for risk assessment and healthcare planning.

However, wide deployment of IPS standards requires overcoming trust and flow barriers. With IPS standards, it is possible to navigate smoothly across connected health data, people and services assembling the evidence necessary to take informed health decisions. High quality patient summaries with clear provenance, granularity, and decision power designation, can improve our understanding of individual and population health needs.

Payers sharing data, knowledge, and insights with patients help build trust. Patients can offer their data and payers knowledge and tips on the individual’s health trajectory

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by effectively use of analytics. In this way, IPS standards can be the starting point to instigate such a trusted ‘healthy’ partnership to meet the formidable healthcare challenges of our times.
EHR Use and Patient-Centred Care in the Inpatient Setting: Challenges and Opportunities

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Keywords. Research literature, ePHR, management information system

1. Background

US hospital EHR adoption rates approach 100%. Potential benefits of EHRs include improving healthcare quality and reducing costs. Prior studies, performed mostly in outpatient contexts, have shown, however, that EHRs impede clinicians’ ability to maintain effective communication and interfere with patient-centered care. Little work examines the ways integration of EHRs into inpatient care influences patient-clinician communication or the extent to which EHRs facilitate patient-centered care.

2. Objective

This study addresses this gap in understanding the influences of EHR use on clinician-patient communication and patient-centered care, aiming to identify patterns in patient experience and clinician preferences regarding inpatient EHR use.

3. Design and Methods

This study, conducted at Brigham and Women’s Hospital (Boston, MA) Medical Wards, comprised 50 hours of observation of 12 care teams during morning rounds, 13 semi-structured interviews with care team members, 5 semi-structured interviews with patients, and a focus group of 6 Patient-Family Advisory Council (PFAC) members. A grounded theory approach was used to extract themes from the interviews.

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4. Results

The observations and semi-structured interviews revealed that inpatient EHR use poses significant challenges and does not facilitate patient-centered care. Patient data is typically not shared with patients but discussed in an excluding manner. Semi-structured interviews with patients, caregivers and the PFAC focus group revealed patient preferences for clinicians’ use of mobile devices, being more involved in decision-making processes, and having mobile access to their information. Patients also would prefer receiving information in writing and not only verbally.

5. Discussion

We have taken stock of the recent literature and described current debate on ePHR. Adoption remains an issue. Novel strategies are experimented with. More research is needed on use of ePHRs; cost-effectiveness of ePHRs use for consumers; and use of ePHRs by consumers of different ages, social- cultural backgrounds, and computer literacy levels. Theories based studies that use ePHRs to motivate change in health behavior are needed.

6. Conclusion

Using EHRs to enhance patient-centered care requires sociotechnical advances: technology design must enable patients to take active roles in care and support triadic (patient, clinician, computer) interactions. Clinicians should be provided EHR-related communication skills training.
A Mobile Video Information Provider (VIP) for Dissemination of Evidence from Patient-Centered Outcomes Research for Improving Symptom Management

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Keywords: Video information, mHealth, symptom management

1. Research objective

The goal of this study was to facilitate the dissemination of an evidence based manual using mobile health (mHealth) technology to improve self-management of adverse symptoms in persons living with HIV/AIDS (PLWH).

2. Study design

We used participatory design methods to incorporate a paper-based HIV symptom management manual into a mHealth application for use in patient self-care. The mHealth application, mobile Video Information Provider (mVIP), incorporated 151 self-care strategies for 13 symptoms that are frequently experienced by PLWH. Following the development of mVIP, we tested the application in a randomized feasibility trial. Linear regression, controlling for age, sex, and race, was used to assess the difference in both symptom experience and average symptom score from week 1 to week 12.

3. Principal findings

Our study sample included 80 PLWH, who were all smartphone owners and living in the New York City metropolitan area. At week 1, fatigue was the most frequently (76%) reported symptom followed by difficulty sleeping which was reported by 75% of participants. Vomiting (19%), weight loss (25%), and dizziness (25%) were the least frequently reported symptoms. At twelve weeks, the intervention group reported improvement in symptom frequency for 12 of 13 symptoms and symptom intensity for all 13 symptoms. Improvement in symptom experience was significant for depression ($\alpha=.05$), and the improvement in symptom intensity was significant for weight loss ($\alpha=.05$).

4. Conclusions

We found preliminary evidence to support the use of a mobile based self-management tool to improve the symptom experience of PLWH

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Perceived and Performed e-Health Literacy: Survey and Simulated Performance Test

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Keywords. Simulated performance, EHL eHealth literacy

1. Background

Connecting end-users to newly developed ICT technologies and channeling patients to new products requires an assessment of compatibility. End user’s assessment is conveyed in the concept of eHealth literacy. The study examined the association between perceived and performed eHealth literacy (EHL) in a heterogeneous age sample in Israel.

2. Methods

Participants included 100 Israeli adults (mean age 43, SD 13.9) who were first phone interviewed and then tested on a computer simulation of health-related Internet tasks. Performed, perceived and evaluated EHL were assessed. Levels of successful completion of tasks represented EHL performance and evaluated EHL included observed motivation, confidence, and amount of help provided.

3. Results

The skills of accessing, understanding, appraising, applying, and generating new information had a decreasing successful completion rate with increase in complexity of the task. Generating new information, though highly correlated with all other skills, was least correlated with the other skills. Perceived and performed EHL were correlated ($r=0.40$, $P=0.001$), while facets of performance (i.e., digital literacy and EHL) were highly correlated ($r=0.89$, $P<0.001$). Participants low and high in performed EHL were significantly different: low performers were older, had attained less education, used the Internet for less time and perceived themselves as less healthy. They also encountered more difficulties, required more assistance, were less confident in their conduct and exhibited less motivation than high performers.

4. Conclusion

The moderate association between perceived and performed EHL indicates that the two are associated yet distinct, the latter requiring separate assessment. Features of future rapid performed EHL tools are discussed.

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A Mobile Video Information Provider
Decision Support Tool for the
Practitioner to Assess Health and Well-Being Mobile Applications

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Keywords. mHealth, GP, assessment, security, safety

The use of digital methods has increased worldwide within health and social services’ patient counselling. The use of mobile technology in healthcare is enshrined in the vision of the future everywhere. In addition, various kinds of health and well-being applications have become widely available. The widespread use of mobile applications in healthcare offers new ways to engage patients to maintain and promote health and well-being. Hence mobile applications are seen as a key factor in developing current services and creating opportunities for new kind of services. As the number of applications grows, the challenge for a professional is to find the most appropriate application for each patient. However, not all new mobile health applications correspond to evidence-based care or well-being promotion. Before a healthcare professional can recommend a mobile app to the patient the trustworthy and responsive to the patient’s need of the application must be ensured.

In Me First – project a decision support tool for assessing health and well-being mobile applications has been created in co-operation with developers and social- and healthcare professionals utilizing previous research. The developed assessment tool can be used in mobile application assessment to respond to individual needs of patients.

The assessment tool consists of three sections evaluating the mobile application:

1. Contents of health and well-being counselling,
2. Usability of the application and

Using existing health and well-being mobile applications with clients and patients is an interesting future opportunity to increase client-centered working methods.

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Personal Health Record:  
A Scoping Review

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Keywords. Research literature, ePHR, management information system

1. Objective  
To review the current development of the Research literature regarding the ePHRs to identify yet the persistent barriers and facilitators to ePHRs adoption among patient groups; What are the existing key management grounding theories for an ePHRs? Also, if the current published literature is neglecting the social-cultural, organizational technical, security-privacy issues. Which is the foundation to advance ePHRs as a reliable tool for patient self-management?

2. Methods  
For this scoping literature review on ePHR systems, we searched in 3 Academic database and 16 Journals related to Management Information systems. The thematic content - data analysis approach was performed using Nvivo software to extract the most relevant data.

3. Results  
Close reading of 56 to see how well they fit in Tang’s categories (Tang et al, 2006) met our inclusion/exclusion. The beginnings findings shows that most of the 56 papers belongs mainly to 4 categories related to ePHR: technical and architecture features; barriers to the adoption; acceptance of ePHR by patient; health benefits of the ePHR; the effective applications of ePHR in self-management.

4. Discussion and Conclusion  
We have taken stock of the recent literature and described current debate on ePHR. Adoption remains an issue. Novel strategies are experimented with. More research is needed on use of ePHRs; cost-effectiveness of ePHRs use for consumers; and use of ePHRs by consumers of different ages, social-cultural backgrounds, and computer literacy levels. Theories based studies that use ePHRs to motivate change in health behavior are needed

Physician-reported underlying cause of death is frequently consistent with evidence from the comprehensive medical record. However, certain causes of death (septicemia, accidents, dementia) are not and should be interpreted with caution.

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Improve Outcomes and Pay-For-Performance Rewards by Facilitating Joint Decision Making by Physicians and Patients to Seek Specialty Consultation

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Keywords. Pay for performance, primary care, decision making

As pay for performance becomes the norm in the US, the UK and other countries, there is increasing incentive for primary care practices to balance overall patient treatment cost with making sure that their patients get the treatments they need. This translates into referring patients for specialty consults when they are determined to be really needed as opposed to be “nice to have”.

A patient portal that creates a secure social network of primary care physicians with their patients and with specialty interpreting physicians is a clinical tool that can uniquely improve treatment outcomes and maximize incentive bonuses in a capitated payment environment. A software system that allows a Primary Care Physician to order diagnostic studies (i.e., echocardiograms, nuclear stress tests, etc.), review results with the interpreting physician (i.e., cardiologist, radiologist, etc.); get detailed explanations about the patient’s specific condition and recommended treatment plan; access an information library with details about the patient’s specific condition; and be able to share this information directly with the patient- allows a primary care physician to retain interaction with the patient; and only incur a specialty consult with an interpreting physician when they jointly determine the need together. This empowers patients to take a more active role in determining their treatment plans and saves the health network money.

This talk will present a case study from the Southeastern United States that uses a pioneering software platform to achieve this goal.

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Demographic changes urge the health care services to facilitate integrated care. The Nordic research project Patients and Professionals in Productive Teams (3P) aims to study health care teams that are providing integrated care in four different innovation arenas. In this context, a case study was made of a patient-centred health care team for elderly people with chronic conditions and multi-morbidities, with a focus on technology support in the integration of care. Qualitative research methods were applied in a field study at a University hospital and municipal health services, also with individual- and focus group interviews. In addition, a workshop with 14 key informants in the patient-centred team was run with focus on technology support for the work processes. The aim was to map out the experienced obstacles in the information flow within and between the involved services, and to outline ideal teamwork situations for the future. The results showed that two separate information systems were used that were not integrated and required a lot of double work for the health care professionals, to be able to coordinate the care for the patients. In addition, there was lack of response on messages sent to other services, so the most reliable communication method was phone, meaning that information and communication was oral and not written. The outcome of the 3P-project is to propose coordinated optimal procedures to improve the existing workflows with the patient at the centre and with one-point-of-contact with the professional health care services.
Health Information Technology Involved in Malpractice Cases: Trends Review and Opportunities for Safety Improvement

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Keywords: safety, malpractice, HIT

1. Background

Only little is known about the potential pitfalls of health information technology (HIT). This study examined and described malpractice cases with HIT involvement and suggested areas for further safety improvement.

2. Methods

We conducted a retrospective analysis of claims in a large proprietary malpractice claims' database covering about 30% of all the malpractice cases filed in the United States over the past two decades (1997-2014). To identify HIT-relevant cases, we used a combination of structured data and natural language processing on a total sample of 51,800 cases. Our final sample included 90 malpractice cases.

3. Results

Most of the HIT malpractice cases were reported in outpatient settings (49%), followed by 27.8% of cases in inpatient settings and about one-fifth in others (e.g., emergency). Cases were most commonly filed as a result of an error involving medications (34%, mostly because of medication ordering errors), diagnosis (31%), or a surgery (10%). Vast majority of HIT malpractice cases resulted in either high (46%, with 24% lethal cases) or medium (39%) patient harm. General and other medicine were responsible for 45% of all malpractice cases, followed by surgery (18%) and obstetrics/gynecology (10%). In 5% of the cases HIT was the leading cause of the malpractice instance while in the rest of the cases, HIT was involved.

4. Discussion and conclusions

Our results identify several valuable lessons for both practicing clinicians and HIT developers and might contribute to reducing the risk of HIT-related harm in the future.

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Particular Image Processing Techniques for Decision Support in Aesthetic Dentistry

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Keywords. Dentistry, designing the dental prosthesis, management information system

1. Introduction

During the last 20 years the focus on aesthetic dentistry has grown, its principles playing an increasing role in choosing the optimal restorative solutions, agreed by the physician and the patient as well. A well-designed dental prosthesis must fit harmoniously with the patient’s general aspect, and this can be achieved by following certain exact aesthetic rules, often based on mathematical analyses. Recent studies showed that, for a normal human being, a certain match can be found between the shape of his face and the shapes of his central superior incisives, as well as a systematic similarity between the plane surface of the face and the plane surface of the central superior incisives.

Our approach aims to develop a simple and fast procedure of shape matching of these plane surfaces, which can help the dental physician in designing the dental prosthesis when necessary and in evaluating the treatment’s final result.

2. Material and Methods

The patient’s facial and oral photos are processed in Corel PhotoPaint in order to detect, automatically or manually, their precise contours. The shapes’ surfaces and perimeters, as well as their matching degree, are measured using customized functions in MATLAB.

3. Results and conclusion

The analysis was performed on 15 patients with different face contours and we found similarities bigger than 75\% in all the investigated cases.

Such analysis is useful in choosing the optimal treatment plan and the optimal shape of the prosthetic restoration in full agreement with the morphological dental-facial aspects.

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Development and Validation of a Novel Rapid Clinical Text Mining Approach Based on Word Embeddings (NimbleMiner)

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Keywords. Text mining, NimbleMiner, NLP

1. Background

Traditional Natural Language Processing (NLP) approaches in healthcare are often lengthy, expertise-demanding and expensive. In this study, we combine the latest cutting edge NLP approaches to generate and validate a novel rapid clinical text mining system called NimbleMiner.

2. Methods

We extracted a corpus of homecare visit notes (n= 1,149,586) for 89,459 patients treated by the clinicians of the largest homecare agency in the United States. We developed and applied our novel NLP system that uses word embeddings (Skip-Gram model) to rapidly generate a vocabulary of terms related to falls and then does machine learning to predict a relevant class. To evaluate the system performance, we used a gold standard dataset of 750 notes annotated by two experts.

3. Results

NimbleMiner outperformed our previously developed rule-based system in all domains. The overall F-score was 88% compared to 80.6% by the rule based-system with the best performance for fall history (F= 88.7% vs. F= 71.5% rule-based) followed by fall risk (F= 88% vs. F=82.9% rule-based) and fall prevention interventions (F= 87.4% vs. F=79.6% rule-based). We observed significant time savings associated with using word embeddings-based vocabulary explorer compared to other NLP approaches (rule based and machine learning).

4. Discussion and conclusions

We report one of the first projects that combine word embeddings with machine learning for the analysis of narrative clinical notes. NimbleMiner outperformed other systems. Importantly, our promising results indicate that clinical data mining can be implemented rapidly without the need in large labeled datasets necessary for machine learning.

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Digital Environment for Cognitive Impairment (DECI) Clinical Study
A Multi-Centre, Prospective, Randomized Study Funded by the European Union

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Keywords. Cognitive impairment, care organization model, patient empowerment

The prevalence of dementia in Israel is estimated at approximately 10% of those aged 65 and over. It increases from ~5% aged 65-74 to 30% at age 85 and older. The number of patients in Maccabi diagnosed with dementia at various stages is ~20,000 patients, and approximately 6000 are diagnosed with Mild Cognitive Impairment (MCI). DECI – Digital Environment for Cognitive Inclusion is an EU research project with the ultimate goal to design and demonstrate the value of feasible interventions in elderly care, enabled by a digital platform.

The project aim is to empower the patients by involving them in improving their cognitive condition. At the same time the caregiver’s burden is assessed and the assumption is that the empowerment of the patient will also ease the burden on the care giver. DECI develops new care organization models, using innovative technologies, information sharing, data interoperability and replicable logics.

The project validates the model in clinical pilots in 4 countries: Italy, Spain, Sweden and Israel, each featuring a significant number of patients. The digital platform includes a patient’s web site, providing physical training, cognitive training and a mobility-sensor. The professional care giver will provide the patient with a treatment plan. The success of the project will be measured in two ways:

1. The cognitive functional level of the patients will be measured at the beginning of the pilots and after 6 months, and

2. The ability of the patients and their caregivers to use the technology with ease will be assessed.

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Enabling Good Healthcare for Children in Europe Through Fit-For-Purpose Electronic Records – Advantage Lost and Significant Work Needed

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Keywords. Child health, health needs, MOCHA project

Child health was one of the earliest fields of development of electronic record systems in health care, with demonstrable beneficial results and initial rapid development and uptake. However, in a groundswell move to modernize health services with the use of digital technology and records, a generic or adult-dominated philosophy has prevailed, to the detriment of children and their important health needs.

E-health, and particularly electronic records, should have a key role in presenting the health needs of children, and in empowering health professionals to act competently and informedly in any new, especially urgent, clinical encounter. However, study of 28 EU and EEA countries in the MOCHA project has shown late issue (or no use) of unique identifiers, only modest use of EHRs in primary care, little use of international data standards, and only patchy inclusion of children’s needs in national e-health plans.

There is also specific challenges in deciding the format, and linkages, of records in school health services, and direct access services for adolescents. These are currently under study.

This lack of systematic recording standards and systems is detrimental to the effective meeting of children’s health needs, including for preventive services, and is jeopardizing the optimization of the health of the next generation of European citizens as well as being disloyal to the early innovation of pioneers. The MOCHA Horizon 2020 project is reviewing all these issues in 20 countries. More cohesive innovation is needed, possibly as an EFMI initiative in partnership with key stakeholders.

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Section 3

Posters
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Identifying Personal Goals of Patients With Long Term Condition: A Service Design Thinking Approach

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Abstract. Care for patients with long term conditions is often characterized as fragmented and ineffective, and fails to engage the resources of patients and their families in the care process. Information and communication technology can potentially help bridge the gap between patients’ lives and resources and services provided by professionals. However, there is little attention on how to identify and incorporate the patients’ individual needs, values, preferences and care goals into the digitally driven care settings. We conducted a case study with healthcare professionals and patients participated applying a service design thinking approach. The participants could elaborate some personal goals of patients with long term condition which can potentially be incorporated in digitally driven care plans using examples from their own experiences.

Keywords. Patients with long term conditions, personal goals, digital care plans

1. Introduction

The prevalence of patients with chronic diseases (people with long term conditions (LTC)) and the healthcare cost for them are much higher than patients with no long-term conditions [1,2]. According to the World Health Organization (WHO), forty million people die every year due to chronic illness and this is equivalent to 70% of all deaths globally [3]. However, LTC care is often characterized fragmented, ineffective, and disconnected. The disjoint between what is important to patients’ lives and the health services they receive is not only wasteful but potentially harmful. While healthcare is often guided by treatment goals, the personal goals, values and preferences of patients have been ignored [4,5]. The tension between personal goals and the functional goals can disappear when the patient’s personal goals can determine the healthcare professional’s functional goals [6]. Goals for persons with LTC have shown to increase motivation. Involving patients in their own cares and pay attention to their own priorities and resulted better health outcomes [7,8].

Home telehealth care for patients with LTC seems to empower patients and potentially improve their medical conditions and reduce the cost [9,10]. However, it has

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been little attention on how to identify and incorporate the patients’ individual needs, values, preferences and care goals in the ICT supporting settings. This paper considers following research question: How to identify and incorporate personal goals of patients with LTC into the digitally driven care settings?

2. Methods

We conducted a case study in June 2017 to identify personal goals of patients with LTC which can be potentially incorporated in digitally driven care settings. For our case study, we chose a pilot site in Norway where a patient-centered health service has been implemented for the patients with multimorbidity.

The pilot site has a patient-centered health services team that a regional hospital created together with two municipalities in Norway in 2013. The team consists of healthcare professionals from both municipalities and hospitals (e.g., homecare nurses employed by the municipalities, pharmacists employed by the hospital, etc.), and have supported patients with LTC through early assessments at the need of emergency help or the risk of acute (re-)admission. Most of the patients are frail patients, elderly with complex and chronic illness.

For the design of our study, we considered service design thinking approach. Service design thinking is an interdisciplinary approach to make services more useful, usable, desirable, efficient, and effective [11]. User-centered, co-creative, sequencing, evidencing, and holistic are the five core elements of service design thinking. We applied these elements when identifying criteria for case study design (See Table1.).

<table>
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<tr>
<td>User-centeredness</td>
<td>Designing service from customers’ perspective</td>
<td>Involving patients</td>
</tr>
<tr>
<td>Value co-creation</td>
<td>Including all stakeholder groups in the service design process</td>
<td>Involving care professionals with different background in the team</td>
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<td>Sequencing</td>
<td>Seeing service as a sequence of interconnected activities</td>
<td>Considering service journeys concept in relation to personal goals</td>
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<td>Evidencing</td>
<td>Visualizing intangible service with physical elements</td>
<td>Using visual artefacts to articulate the service journeys</td>
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<td>Holistic</td>
<td>Considering the whole environment where the service is delivered</td>
<td>Reflecting specific examples from actual experiences</td>
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Based on the criteria, a focus group discussion was designed. To support and user-centeredness and value co-creation, patients and healthcare professionals with different specialties were invited to the focus group. Visual artefacts presenting two components of a service journey (actor and touchpoint [12]) and six life areas (Figure 1-on the left) were created. For the involved actors, a researcher first investigated who the service workers [13] of at the pilot site are and who the secondary service customers [13] of patients with LTC might be. Fifteen actor icons representing a service customer (patient), five secondary service customers (family and friends), and nice service workers (healthcare professionals two from the municipalities and seven from the hospital) were created (Figure 1-in the middle). Twelve touchpoint icons representing types of communication were created (Figure 1-on the right). All icons were attached on different colors of sticky notes. Two group exercises using the icons were then designed to support the principles of sequencing, evidencing, and holistic. Each group was asked to choose a
group leader who could lead the discussion, write down the answers in a large paper sheet, and report the results in a plenary session.

![Figure 1. Icons created for the focus group discussions](image)

The first exercise was designed to identify potential personal goals for patients with LTC. Total seven questions were asked to discuss (Q1. Give an example of what can be important in the LTC patient’s life by reflect your experience. Q2. What can be a personal goal or activity of the patient that is associated with the previous answer? Q3. What can be enablers to achieve the goal? Q4. What can be barriers to the goal? Q5. What can the patient do to achieve the goal? Q6. What the healthcare professionals can contribute to achieve the goal? Q7. Discuss the relevance of six life areas (Figure 1) that the personal goal is belonging to and place the applicable icon(s) on the sheet.).

The second exercise was designed to investigate possible clinical actions that can support the personal goals identified in the first exercise. Total six questions were requested to discuss (Q8. What type of clinical data is important to be collected and monitored to support the personal goal? Q9. Why do you think this data type should be collected and monitored? Q10. Who can collect this data? Place the applicable icon(s) or write on the sheet. Q11. Who can use this data? Place the applicable icon(s) or write on the sheet. Q12. What type of communication medium (Figure 1) would you like to use to monitor the clinical data? Place the applicable icon(s) or write on the sheet. Q13. How does the above answers link to the personal goals discussed in the previous exercise?).

Total twenty people participated in the discussion including six researchers, one patient, and thirteen healthcare professionals from the two municipalities representing various stakeholder groups. The participants were divided into three groups, and the participants representing same stakeholder group were distributed evenly. Each group had two researchers who mainly observed and took field notes. Two groups had four healthcare professionals, while one group had five. Only one group had one patient participant. The discussions were audio-recorded and the results sheets were collected.

3. Results

In this section, we only present preliminarily results since analysis of the data (audio recorded files) is still ongoing. Figure 2 shows a result from the first exercise. One group
answered that for the frail patients to stay at home and manage themselves as much as possible could be important. The personal goal related to this might be able to move between rooms at home. Medical follow-up, rehabilitation or training, adapted housing, aid equipment, supportive wife could be enabler to achieve the patient’s goal. Living in a non-adapted housing, not being motivated for rehabilitation or treatment, and cognitive weakness might possibly be barrier to the personal goal. By taking the offers, being active, knowing own limit, following the treatment, the patient could achieve the personal goal. Offering adapted housing, good communication, and follow-up by the healthcare professionals might contribute to achieve the patient’s personal goal. A life area that the personal goal belongs to could be home and daily life. Figure 3 shows a result from the second exercise. The group chose blood test and pain assessment as clinical data types which can be important to collect and monitor to support the patient’s goal. The reason for monitoring might be to uncover bleeding and to prevent eliminate dizziness, dyspnea, fatigue. Homecare nurse and/or GP could collect the blood test data and the GP self might use the data. SMS, telephone, or electronic (internet or app) communication might be used to monitor the data. Monitoring blood test results could prevent hospital admission and disability which allows the patient to stay at home.

Figure 2. The result of the first exercise done by a group

Figure 3. The result of the second exercise done by the same group

Another group also responded that living at home as long as possible might be an important matter for the frail patients. They said having good health, self-reliance, proper nutrition, and confident could be personal goals for this. The other group answered that social activities, helping at the right time, increased services might be important for the patients. They stated that reading time in the common place, visiting friends, getting up early can be personal goals for these. Various types of clinical data were raised up by the participants to be collected and monitored to support the personal goals.
4. Discussion and conclusion

There has been little attention on how to identify and incorporate the patients’ individual needs, values, preferences and care goals in the ICT supporting settings. We could elaborate several concrete personal goals of patients with LTC which potentially be incorporated in a digital clinical pathway by facilitating discussion and supporting participants to articulate their own opinions and concepts using service design thinking approach. Generating criteria for our case study by applying the five principles of service design thinking allowed us to learn that listening both patients’ and healthcare professionals’ voices, supporting them to articulate their own opinions by providing visual artefacts of important elements of the service, and stimulating them to reflect specific examples from their own experiences could be important when incorporating of a new function to a health service.

5. Acknowledgement

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References

Intellectual Medical Algorithms
Program to Involve Patients and Their Doctors in Remote Monitoring

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Keywords. Diabetes, information management, medical algorithm

1. Introduction

The dynamics of clinical parameters of diabetes, hypertension etc. are vital for successful treatment. Patients could benefit from distant monitoring. The key problem is to convince patients that their doctors will see information on time and ensure doctors that their time will not be overloaded. We have been developing PHR system for the last 10 years using classic medical algorithms for data management.

2. Methods

Pulse, blood pressure, and other data is instantly delivered to PHR from interactive mobile applications.

The doctors can choose multiple forms of interactive presentation. Graphic (multiparametric scalable single time presentation (below) with emphasized trends, notification of new information, alarm notification, generated automatically, based on adjustable intellectual algorithms. Specialized Medical Messenger:

1. Allows the patient to ask questions at any time via personal smartphone or e-mail.
2. Controls doctor’s response according to the agreement.
3. Evaluate “adherence to treatment” via reminders.

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3. Results

We have 50,515 registered clients on www.medarhiv.ru.; 7017 are “active users”; 247 using continuous monitoring.

Self-monitoring technologies work for selected patients but need to be made widely applicable. Combination with Medical Messenger App seems to improve its use, can save time and money for patients and medical professionals. Collaboration with American-based https://usvdc.com/ network will test this program for world-wide application.

Pregnant patient with diabetes monitoring: glucose, insulin type and doses and carbohydrates in food.
What Are the Challenges and Implications of High Online Accessibility?

The e-Health Literacy Levels of Patients

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Keywords. eHealth literacy, online information, health needs

EHealth literacy capabilities to locate and implement online information in order to address health issues have been traditionally examined in the context of the digital disparities. However, recent data indicate that access gaps are consistently diminishing. Today, the online accessibility is relatively high also among weak population groups. Yet, how the high accessibility serves different population groups to promote their health needs has to be addressed.

A recent research characterized in depth various levels of abilities among the population and examined their capability to make informed health decisions, through two methods:

1. population survey and
2. practical experiment that test the abilities of people without a medical background to solve a health dilemma through the internet.

Findings revealed that two-thirds of the population uses the Internet for health. Although some of them change their health routine, many report difficulties in assessing the reliability of information and applying it for health decisions. Results of the experiment exposed people that tend to perceive their ability to utilize online information as high, but in practice it isn’t reflected in actual practical abilities.

Low abilities will not prevent a person from trying to utilize online health information, even in an ineffective way. Additionally, high abilities also spur health behaviors that won’t guarantee proper informed decisions. It is important to understand the unique weaknesses regarding different kinds of abilities characterizing different people, to use the Internet for health purposes. Doctors may adopt an active role in guiding the patient along the information search processes.

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MOPAT@HOME: Electronic Patient Reported Outcomes Filled Out at Home, Evaluated at the Hospital

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Keywords. Mobile patient, evaluation, web-based system

1. Introduction

For better medical care, physicians need to know patient’s context and quality of life. However, it is difficult to gather data in the period between clinical visits, while the patient is at home. Closing this gap, MoPat@Home (Mobile Patient Surveys (MoPat) at Home) provides the opportunity to interview patients at home complying with data protection requirements.

2. Methods

MoPat@Home was developed as an extension to the existing MoPat system using Java programming language. It is currently tested in a prospective cohort study evaluating the employment and quality of life of melanoma patients.

3. Results

MoPat@Home is a web-based system, which allows clinicians to invite patients or study participants to answer a prepared set of questionnaires. The survey can be configured as a one-time or periodic survey, with a certain repetition rate in days. The patient receives a link to the survey via email at the scheduled date. When the patient has completed the survey, the data are transferred via an export interface to the designated system. To date, 88 invitations have been sent to participate in the melanoma study via MoPat@Home. Six surveys were interrupted due to wrongly typed data or other reasons, 31 were not yet answered by the participants and 51 were completed. Thus, 62% of the correct invitations were fully answered by the participants.

4. Conclusion

With MoPat@Home, it is possible to gather medical information from the patient at home and evaluate the data in the clinical setting. Further development will improve MoPat’s functionality and usability.
Empowering Medical Students
Education by Medical Professional
Communication Course as Integrative
Part of Internal Diseases Program

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Keywords. Education, medical professional communication, disease program

Increased data/information flow developed a directive model of doctor’s communication with patient: little time for traditional methods of clinical examination – history taking and physical examination, usually without discussion about patient concerns, treatment plan and outcomes. Studies have shown that young doctors demonstrate insufficient knowledge about communication skills, there is an urgent need for additional clinical training.

To solve this (to teach medical students for communication skills with a patient, patient’s relatives and colleagues) we introduced a separate “Medical professional communication” course (MPCC) consisting of one lecture and six 3-academic-hours-long classes in a hospital (1.5 ECTS points) as the very first one integrative part of Internal diseases program. Different aspects of communication were observed: doctor’s image, office design, doctor-patient relationships, legal issues, “problematic” patients groups examples (pediatric, geriatric, chronic, dying, ethnic, religious, depressive, anxious, etc.). Students presented their essays, visit patients, played role-plays and later having discussions moderated by professor. Course results were evaluated by self-report questionnaire (SRQ) and OSCE exam after the course of Propaedeutics.

SRQ and exam results databases for a period 2009-2014 were assessed. On SRQ students show their interest to the course program (93%), satisfaction with outcomes (87%), 51% of students reported the MPCC length as “too short”. On exam students demonstrated a more stable knowledge of practical skills and solving of situational tasks (127%) in compare with results before MPCC introduction.

Based on results we got, from 2015 MPCC was prolonged till 3.0 ECTS points, consisting of two lectures and twelve 3-academic-hours-long classes in hospital.

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Empowering Patients with Longterm Conditions by Supporting Development of e-Personal Goals

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Keywords. Long term conditions, cost reduction, patient-tailored care plans

The prevalence of patients with long term conditions (LTC) among European populations above 75 years old is higher than 70% with 40-50% multi-morbidity rate. According to a US report, ¾ of the total healthcare cost were sent for the patients with LTC. An Irish report presented that the consumption of health services by patients with 4 or more co-morbidities was five times higher than patients with no LTC. Care for patients with LTC is often characterized fragmented, ineffective, and disconnected. Information and communication technology (ICT) is one of the important factors that supports patients with LTC and reduce the cost. However, there is little attention on how to considering the patients’ individual needs, values, preferences and care goals into the digitally driven care settings.

In this workshop, we will discuss barriers and enablers in relation to the integration of personal goals of patients with LTC into digitalized care plans based on what is important to the patient. We invite healthcare professionals and medical informatics researchers to the poster at which we will discuss and analyze our own examples from experience and elaborate typical barriers and enablers. Service design methods will be used to facilitate the discussion and support participants to articulate their own opinions and concepts.

We expect that the identified barriers and enablers during the discussion might be valuable input for the design and deployment of patient-tailored care plans in the digital era which can contribute to empowering patients with LTC and enhancing their quality of life.

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Diagnostic Games: A Way to Doctors’ Engagement in Digital Transformation of Healthcare

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**Keywords.** Gamification, doctors engagement, big data

Future 4P-medicine is based on the analysis of huge data sets, which creates the risk of turning a doctor into an "appendage" of ICT systems. But the doctor is an unrivaled integrator of large data flows, and it is important to learn how to use his experience in ICT systems, relying on its formalization.

One of the approaches - the "method of adequate formalization" - was developed in the last century by the team of the world famous mathematician I. Gelfand. The main tool of this method is "diagnostic games" (DG). With the help of DG, interesting results were obtained, but it was very laborious and did not receive proper distribution. Modern ICT can revive it.

The method is based on modeling real clinical situations. Diagnoses allow the doctor to be placed in a situation using a controlled flow of information for decision making. DGs were used to formulate formal problems in medicine and to develop for each task a system of generalized concepts that allow formulating problems and presenting formal solutions in a form understandable to the physician.

The DG method can be turned into an ICT product based on openEHR technology. It is proposed to create a network technology, which can be used simultaneously by many doctors.

The networked DG system will engage doctors in the process of digital transformation of health care, which is no less important than engaging patients in health management.

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Improving Access to Care in Rural Africa Through the Use of Telemedicine: Using a mHealth System as a Case Study

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Keywords. Developing countries, LTC, telemedicine, Diabetes, mHealth

1. Introduction

Access to care in developing countries is limited. With increasing availability of mobile internet access, mHealth systems have the potential to help elevate this.

2. Method

To investigate if telemedicine can improve access to care in rural Africa, a mixed-methods field study and feasibility analysis with a mobile phone-based telemedical system for diabetes patients was conducted at Mbingo Baptist Hospital in Cameroon.

3. Results

The study had 10 participants and post-study overall experience rating by the patients was average on 9.5 (1-10 Likert scale). Handling issues were observed during the study. The cost of diabetes care supplies and mobile internet was very high.

4. Discussion and Conclusion

The field study has shown that the system is technically feasible and can improve access to care, despite certain handling issues but at high cost. mHealth systems for diabetes care are technically feasible in developing countries, but are currently not feasible for economic reasons.

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Mobile Microservice Architecture for Patients Self-Care

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Keywords: Health self-care, service oriented architecture, bluetooth

The proposed health self-care IT system consists of the mobile based microservices built on the principles of Service Oriented Architecture. The turning of the traditional backend-frontend architecture upside-down leads to simplicity in developing the basic services for patients’ sensors data collection and in developing value add health self-care services on the top of the basic services. This development is enabled by the current computing, communication, LTE, and storage capacities of the state-of-the-art mobile phones. The state-of-the-art mobile phones have an extensive set of various sensors and possibilities to extend to Bluetooth based sensors. Especially in the context of the health self-care, various microservices can be created for the each of the factors that are asked to be measured e.g. steps taken. Each basic service communicates the with other services by employing RESTful web service architecture.

One of the advantages of this systems is that there is no need for any cloud based storages as the data is many times sensitive in health care. The other clear benefit is the real time or near real time follow of the condition of the patient remotely. Also, the microservice architecture allows developing various services rather independently as the interfaces are well defined.

This type of an architecture leads to the simplified patient user interface fitting for Parkinson patients. The basic principles of the system have been tested on an Android based mobile phone acting as a server and a laptop acting as a client. Various other configuration has also been investigated.

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Validating Reported Cause of Death Using a Population-Based Integrated Electronic Health Record

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\textbf{Keywords.} Cause of death, EMR, electronic medical record

1. Objective

To validate reported underlying cause of death using an electronic medical record (EMR) in a fully integrated payer/provider system.

2. Material and methods

The individual-level underlying cause of death was obtained from the Israeli Ministry of Health for deaths during 2009-2012 for 82,298 Clalit Health Service Members. A final cohort was constructed of 37,723 members whose death occurred within a hospital and had continuous membership prior to death. The correlation between the reported cause of death and supporting documentation of the disease in the EMR was calculated for each year by the top ten reported causes of death (malignancies, heart disease, cerebrovascular disease, diabetes, kidney disease, septicemia, accidents, chronic lower respiratory disease, dementia, and pneumonia and influenza).

3. Results

The overall correlation was 87.21%. The lowest correlation was for septicemia (54.77%) and the highest correlation was for malignancies (94.89%). There were minimal differences during the four-year follow up period. Alternative documented diagnoses were analysed to explore justification for the low levels of correlation.

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4. Discussion

A fully integrated payer/provider system can study the correlation between physician-reported underlying cause of death and complete electronic medical records. We have found a wide range in consistency in the correlation, with a consistent bias toward certain conditions. Average index-admission length of stay has not increased. Effects have diminished after 2014.

5. Conclusion

Physician-reported underlying cause of death is frequently consistent with evidence from the comprehensive medical record. However, certain causes of death (septicemia, accidents, dementia) are not and should be interpreted with caution.
Reducing Readmission Rates: Evidence from a Large Intervention in Israel

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Keywords: readmission, evidence, healthcare utilization

1. Introduction

Starting 2012, the largest Israeli HMO has initiated a program to reduce hospital readmission rates. For all admitted patients aged 65 and older, readmission risk was predicted using prior healthcare utilization and provided upon admission to care continuity nurses, which allowed them to prioritize resources toward patients with high risk of being readmitted.

2. Objective

Retrospective evaluation of this intervention

3. Method

A sample of 171,541 admissions to inpatient wards across 27 hospitals during 2009-2016 and subsequent readmissions to any hospital. Difference-in-difference estimation, comparing readmission rates before and after the intervention and between patients aged 65-70, for whom readmission risk scores were calculated, and a comparison group of patients aged 60-64, for whom no such scores were calculated and who were therefore not directly affected by the intervention.

4. Results

Over its first two years, the intervention reduced 30-day readmission rates by 6.2\% (p < 0.01) among the 65-70 age group relative to the 60-64 age group. The reduction

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was largest among patients with the highest readmission risk scores. Corresponding 60- and 90-day readmission rates also declined by 6.6% and 7.8%, respectively (p < 0.01). Average index-admission length of stay has not increased. Effects have diminished after 2014.

5. Conclusion

Evidence demonstrates that informing providers about predicted readmission risk in real time can improve allocation of care continuity efforts and reduce hospital readmissions. Maintaining such efforts on an ongoing basis is important to sustain their impact.
Abstract. The smart information management system (SIMS) is concerned with the organization of anonymous patient records in a big data and their extraction in order to provide needful real-time intelligence. The purpose of the present study is to highlight the design and the implementation of the smart information management system. We emphasis, in one hand, the organization of a big data in flat file in simulation of nosql database, and in the other hand, the extraction of information based on lookup table and cache mechanism. The SIMS in the health big data aims the identification of new therapies and approaches to delivering care.

Keywords. Smart information management, health big data, flat file, lookup table, caching.

1. Introduction

The smart information management system (SIMS) is concerned with the organization of anonymous patient records in a big data and their extraction in order to provide needful real-time intelligence. The purpose of the present study is to highlight the design and the implementation of the smart information management system. We emphasis, in one hand, the organization of a big data in flat file in simulation of nosql database, and in the other hand, the extraction of information based on lookup table and cache mechanism.

2. Methods

The SIMS includes the following process: organization and extraction of information. The organization of information allows the acquisition and the storage of information. The collection of data is represented by an \( n \)-dimensional vector and an entry in the collection of data is one dimension corresponding to \( m \) distinct attributes of a patient record. Since the collection of data is organized in small subset. A subset stores information according to belonging criteria such as “a similar patient’s case”. These are called parameters of identification. The extraction of information passes through three steps: querying, searching and answering. Single term or list of term leads to an immediate query of the collection of data. To produce smart information, the search exploits parameters of identification. At least, the result of search is qualitative and quantitative. The SIMS is designed to take advantage of cloud computing architecture. The health big data is built to contain the collection of data. It handled special flat files that simulate nosql database techniques for a practical management. This structured set
has the following structural factors: file name, cluster type-key and metadata. The flat files correspond to clusters containing the data that meet the belonging criteria and are clearly identified. Each flat file is composed by a file name, cluster type-key and a record. Search is done by the cluster type-key first and by others specific keywords following the needs of the user. Data record unloaded from flat files of big data can be stored in table and cached in memory.

3. Results

As an implication of technology solution to problem of fighting malaria, we developed a web-based medical decision support system under the project called Optimization of Malaria Treatments: http://www.maesoft1.co/projects.html. On consultation time, the SIMS allows to the healthcare giver to query about relevant information related to diagnosis and treatment of similar cases stored in the health big data. The candidate queries, for searching in the big data relevant information, can be a profile information and the signs/symptoms information, and can be expressed in single term “adult”, “high-fever” or a list of terms “female, adult, pregnant, high fever, hyperpyrexia”. The search engine could pick up from the big data all similar cases that have occurrence of both the candidate queries. The search engine returns a list of data sources such as “<1, female, adult, pregnant, 75 to 80 kg, Democratic Republic of Congo, resident, high fever, gastro intestinal complications, Giemsa-Stained Blood Smears, B50.0 Plasmodium falciparum malaria with cerebral complications, quinine, stabilized>; <2, female, adult, pregnant, 65 to 70 kg, Cameroon, resident, high fever, hyperpyrexia, Giemsa-Stained Blood Smears, B50.0 Plasmodium falciparum malaria with cerebral complications, quinine, stabilized>; …” and others information like percentage expressing the benefit-risk of decisions taken for those cases.

4. Discussion

The health big data is built from submitted data by users’ subscriber (healthcare givers) of different regions of the world concerned by malaria. There is one instance of case’s patient record on submission. There is also one instance of anonymous patient record selected to be stored in a specific cluster. The present project is at the prototype phase. The training data used are data collected for the needs of the evaluation. One of the primary constraints on performance of the SIMS, using big data and flat file techniques, is the numbers of files and their records to read. This constraint is resolved by means of look up table and caching queries.

5. Conclusion

Most of health caregivers are interested to system that process a large number of available information and that allow expressive queries and efficient answering. Thus, managing health big data by the SIMS can help to visualize scenarios, to extent intelligence, to make more informed decisions and to address complex issues. The SIMS in the health big data aims also the identification of new therapies and approaches to delivering care.
The Presentation of Personalized Medical Information, and Its Impact on Health-Related Choices

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Keywords. Decision making, meaningful information, efficient use of resources

1. Introduction

Healthcare systems in Europe, the United States and Israel emphasize informed choice in decision-making, and heightened patients’ involvement in self-managing acute and chronic conditions. Such shift in responsibilities and initiative must be founded on meaningful information that engages the patients. Consequently, redesigning information in a way that would precipitate efficient use of medical resources, cut costs, and improve the quality of care becomes a major concern in an age of overburdened healthcare systems.

2. Objective

Our objective was to examine how different presentations of the same clinical information result in different evaluations of the health condition’s severity, and inspire different courses of action. Methodology: During 2016, the research team developed an on-line questionnaire comprising 10 hypothetical medical decision making scenarios.

3. Hypothesis

A) There will be a positive relationship between perceived severity and the action taken. B) Participants were asked to assess the perceived level of severity for each scenario. Severity of the condition described in the scenario ranged from 1="very low", to 5="very high. Participants were also given the option of 6="do not know". We hypothesize that the higher the level of "not know", the more active people will tend to be in seeking physician’s counsel, and searching for information. C) Scenarios were divided into three types of information presentation: numerical, graphic, and verbal. We hypothesized that the three will differ in clarity, and that these differences will precipitate a preference for different courses of action. We present findings collected from 298 participants who participated in the study.

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Empowering Patients with Healthcare: Evaluation of Patient Room Configuration

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Keywords: Healthcare design, evaluation, patient room, future scenario

One of the most significant changes in hospitals design in recent decades, which reflects advances in patient centered care, is the transformation of patient rooms. The basic component of the modern hospital has shifted from multi-patient rooms; transforming the concept of the “Nightingale” open ward to private rooms in inpatient units. While following the change in patient room standards in hospitals in the United States and Europe, Israeli hospitals have been striving to deal with high rates of over-occupancy in the winter, lack of medical personnel, and insufficient funding. Although many studies have evaluated the advantages and disadvantages of single-patient rooms versus multi-patient rooms; i.e. infection rates, length of stay, medical errors, sense of isolation and patient safety; only a few have evaluated the correlation of the patient room configuration with the overall design and performance of the inpatient unit.

A case study of the Sammy Ofer Heart Building at the Tel Aviv Medical Center, Israel, demonstrates the need to evaluate current inpatient unit layout of patient rooms (following the Israel Ministry of Health guidelines) and to compare it to future options for configuration change.

Simulating ‘what-if’ scenarios, such as over-occupancy rates or new medical procedures, illustrates how each design option could support future change. This method of evaluation of future scenarios could promote design optimization, collaboration among inter-disciplinary members of the project team and enhance knowledgeable decision-making during the design process and throughout the life-cycle of the hospital.

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The Practice of Patient Centered Care: Empowering and Engaging Patients in the Digital Era
R. Engelbrecht et al. (Eds.)
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