
Are Electronic Health Records Reaching Out?

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ABSTRACT

Personalized health technology that focuses on helping a user to prevent, monitor, and manage his or her own health conditions is emerging both in research and commercially. It is, however, an open question how this technology will integrate with existing technology like the electronic health record (EHR). This integration is of socio-technical nature; there are several technical questions specifically related to data integration, but more importantly there are a wide range questions on the nature of 'social integration' of the 'work' of both the user and the clinician. In this paper, we discuss some of these questions based on ongoing research in personalized health technology for mental health.

KEYWORDS

Electronic Health Record; EHR, Personal Health Record; PHR; Mobile Health; mHealth; Personal Health Technology; Mental Health

ACM Reference format:

Jakob E. Bardram & Raju Maharjan. 2018. Are Electronic Health Records Reaching Out?. In *Proceedings of Workshop on Next Generation of Electronic Health Records, Copenhagen, Denmark, March 21, 2018*, 6 pages. <https://doi.org/10.1145/nnnnnnn.nnnnnnn>

Workshop on Next Generation of Electronic Health Records, March 21, 2018, Copenhagen, Denmark

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INTRODUCTION

Medical informatics is by now a mature domain. Research into medical/health informatics have been ongoing for many years and there is a growing body of scientific literature on both different types of technologies, applications, as well as studies of the use of medical informatics technology in clinical care. There has been an extensive focus on data management, which has lead to work on how to collect, store, share, and use clinical data, which again has lead to a significant focus on standardization on health data. There is no lack of standards in medical informatics, which include EDIFACT, CEN, DICOM, HL7, IEEE, ISO, and other standards. Finally, there is a wide range of commercial systems available for medical informatics, covering a wide spectrum of systems types ranging from general-purpose EHRs for hospital-wide use, to special-purpose system such as a PACS system used in radiology. Generally speaking, medical informatics is concerned with the use of information in health care by and for *clinicians*.

Due to the major health challenges worldwide – an ageing population and prevalence of chronic diseases – there is, however, a growing interest in the design and use of what we label ‘*personalized health technology*’ [1]. The focus of personalized health technology¹ – in contrast to medical informatics – is to provide technologies primarily for the *patient*² designed for prevention, self-management, self-care, and self-treatment of health related conditions in a broad sense. The core rationale is that this kind of prevention and self-management of health is imperative in addressing the core health challenges of our present-day society.

The call for this workshops state that; “[t]he excitement around data-driven healthcare raises questions about both the kind of EHRs we should aim for in the future, and whether new types of data support the effective provision of healthcare.” In this paper, we argue that there is a need for a new kind of EHR – a personal one – as well as new types of data (and technology) to help the effective provision of healthcare in the future. The discussion is based on our research in mental health.

PERSONAL HEALTH TECHNOLOGY IN MENTAL HEALTH

According to WHO, mental health is the fastest growing chronic disease and is one of the leading causes to disability [10]. Affective disorders (depression and bipolar disorders) account for nearly half of all morbidity and mortality due to mental and substance use disorders [11], and burdens society with the highest health care costs of all psychiatric and neurological disorders [9]. At the same time, there is a significant shortage of trained psychiatrists, psychologists, therapists, and nurses which leads to long waiting lists and a high treatment gab (above 50%) of mental health patients [6].

As such, mental health is suitable for the design of personal health technology, and several research projects including our own MONARCA system have been addressing this challenge [2, 3]. By using this personal smartphone-based healthcare application (Figure 1), the patient is provided with a

¹There are a number of other names and concepts used, including ‘pervasive health technology’, ‘personal health informatics’, and ‘persuasive health technology’, as well as more technologically oriented terms like ‘mobile/wearable health technology’.

²Actually, in this context we no longer talk about a ‘patient’, since this is a term that belongs to the clinical domain in which a person has a diagnosis. In personalized health technology, we often talk about a ‘person’, ‘citizen’, or ‘user’.



Figure 1: The MONARCA system in use.

³<http://www.cachet.dk/research/Research-Projects/PhyPsy-Trial>

⁴One example of this approach is the Danish 'Data for Good' foundation, who seeks to give back the citizen control over own health data. See <http://dataforgoodfoundation.com/>

greater awareness of his or her disease and can exercise a much greater degree of self-care and self-treatment. The system lets the patient self-assess and review a number of health parameters and supports illness management. For example, patients can use the data to determine adherence to medications, investigate illness patterns and identify early warning signs for upcoming affective episodes, or test potentially beneficial behavior changes. Data collected can be used to predict and prevent the relapse of critical episodes. Through monitoring and persuasive feedback, the system helps patients implement effective short-term responses to warning signs and preventive long-term habits. This reduces the need for clinical supervision, treatment, and care, while at the same time empowers the patient in personally dealing with the disease.

However, people with severe mental illness (SMI) die 10-20 years earlier than people without SMI [7] and most of this excess mortality stems from physical diseases [8], which are under-diagnosed and under-treated [5]. These patients are treated across sector borders, and coordinated care between general practice, municipalities and hospital psychiatry is imperative to proper treatment of SMI patients. The ongoing 'PhyPsy Trial' project³ is addressing this problem. Focus is on improving the detection and pharmacological treatment of physical diseases in patients with SMI through a mutually committed and efficient cross-sectorial collaborative team. From a technological point of view, this is to be supported by personalized health technology used by the patient and a shared care platform used by the collaborative team. This will enable what we have called a 'double-loop' treatment setup [4], as illustrated in Figure 2. As such, the personalized health technology needs to be integrated with clinical treatment.

DISCUSSION

The questions initially raised for this workshop were related to (i) the kind of EHRs and (ii) data types needed for future effective provision of healthcare.

The emergence of the personal health record (PHR)

With the emergence of personalized health technologies a new type of health record might be emerging and needed; one which is personally tied to the patient (or 'user') rather than to clinicians. Such a medical record is sometimes called a personal health record (PHR) and is fundamentally different from the EHR approach, which is prevalent today⁴. A PHR is designed for the patient to store and manage personal health data. Legally, data responsibility (or ownership) lies with the patient, while data responsibility in an EHR lies with the clinic or health management organization. Technically, a PHR is purchased, managed, and used by the patient with little technical skills and support, whereas an EHR lives in a robust, trusted, and secure operation environment with extensive technical support.



Figure 2: The double-loop setup in the MONARCA project. The first loop takes place between the patient and the smartphone health application. The second loop takes place between the clinician and the clinical portal. This double-loop setup mediates the relationship between the patient and his or her clinical treatment.

Socio-technical integration of personal and clinical technology and data

The emergence of PHRs raises the question of their relationship to the EHR; what is the relationship between personal health data (and technology, more broadly) collected and used by the patient, and clinical health data collected and used by clinicians? Is there any intersection between the two; will personalized health data be relevant for clinical use, and vice versa? There are definitely different – and even conflicting – views on this:

Personalized health data is valuable in clinical practice – On the one hand, some argue that personalized health technologies may provide a valuable stream of data and insight from patients while not in the clinic. We could call this the ‘telemedicine’ approach; collection of health data

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⁵This is taking place in the newly formed IEEE P1752 standardization initiative, which design data formats and APIs to bridge between mHealth data (from e.g. activity trackers) to clinical data using the HL7 FHIR standard.

from patients at home (e.g. from medical sensors) is highly relevant and useful in clinical diagnosis. For example, in the MONARCA project the collection of self-reported data like mood, stress, sleep, medicine compliance, etc. was a valuable addition to clinical diagnosis and follow-up. Similarly, technologies can be used to extend clinical treatment into the 'home' of the patient, using e.g. videoconferencing. In this view, personalized health technology and a PHR becomes a part of the clinical setup and works as an 'extended arm' to a clinical socio-technical system, including an EHR. From a technical point of view, ongoing work is seeking to design standardized data formats and APIs to help bridge between mHealth data and EHR systems⁵.

Personalized health data is garbage and useless in clinical practice – On the other hand, some argue that this kind of personalized health technology is – and should be – fundamentally different from the clinical socio-technical system. The core purpose and goal of these technologies is to help the 'user' – not the clinician. One argument for this view, is due to the fact that there simply isn't enough clinical resources to meet the increasing health challenges, and technologies (and approaches) for preventive and self-management of e.g. chronic diseases should therefore stand on their own, without the need for clinical integration. For example, diabetes is a chronic disease which, to a large degree, is handled by patients themselves. Similarly, the design goal of the MONARCA system was to help users with a disease insight for better self-management of bipolar disorder. A second argument is that data collected from personalized health technology is too 'messy' and irrelevant for clinical use. For example, collection of daily step counts, calorie expenditure, and sleep from activity trackers might be of very limited utility in the clinic, and biomedical measures like blood pressure, pulse and heart rate variability from non-medical grade equipment might be flawed. Hence, clinicians would argue that such data is bulky, unreliable, and noisy. And this low data quality contradicts the extensive effort in medical informatics which has focused on the standardization of precise and concise medical nomenclatures like SNOMED. In this view, the goal of personalized health technology should therefore not be to bridge between the 'personal' and 'clinical' domain, but to design technologies which helps users in prevention and health management on their own.

In summary, personalized health technology and the personal health record (PHR) are emerging, and it is an open question what relationship will be needed in terms of socio-technical integration with the existing clinical types of systems like the EHR. But under all circumstances, there will be a need for the EHR to 'reach out' to also include the personal space of the patient or user. Exactly how, is an ongoing discussion.

ACKNOWLEDGMENTS

The MONARCA project was funded by the EU 7th Framework Program, contract #248545. The PhyPsy Trial project is funded by the Novo Nordisk Foundation. All viewpoints are the authors and do not represent the viewpoints of the funding agencies.

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