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Empowerment or Anxiety?

- *Research on Deployment of Online Medical E-health Services In Sweden*

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Introduction

Development and deployment of e-health services and patient access to medical information is currently prioritized all around the world. This is due to increase in healthcare expenditure that is experienced in the industrialized countries. In Sweden, the first attempts to implement an online access to medical records for patients were made already in the 1990s (Ålander et al. 2004). However, the process has only recently accelerated due to necessary changes in legislation and also through the launch of extensive regional and national initiatives. In 2012 a major Swedish lead EU-funded project, SUSTAINS (Support USers To Access INformation and Services), was launched to implement a patient access system in 11 European countries. Earlier experiences of such initiatives have shown that an effective deployment of relevant and successful services needs to be based on a thorough understanding of technical, societal and organisational contexts of these implementations (Vaart, 2012; Hackl, 2011). In spite of the large number of studies in the field, the dynamics of the different factors is not fully understood. In this respect, the SUSTAINS-project represents a unique national and international context of study for researchers to develop urgently needed theoretical and directly applicable knowledge, as well as guidelines for informing future implementations.

This paper will briefly present the DOME project, a major Swedish research initiative, which was founded to exploit the research potential of the SUSTAINS-project and simultaneously to address the broad research needs in the field of e-Health. The aim of DOME is to gather systematic evidence on the national and European wide implementation of online patient access to electronic health records and e-Health services. The article will also highlight some early findings from the project, and make some reflections on the public discussion that was started in Sweden by the implementation of the online service.

The DOME project

DOME is a collaborative research project between Lund University, University of Skövde and Uppsala University (all in Sweden) consisting of researchers representing different fields of scholarship including for example management accounting, information technology, information and knowledge management and medicine. The purpose of the project is to create and disseminate knowledge about implementation and use of e-Health services based on studies of on-going implementation projects. During the initial phase of DOME, the focus of research has been on the SUSTAINS-project and the deployment of e-Health services in the Swedish counties of Uppland and Norrland and comparative research in the regions of Skåne and Västgötaland. Due to the complexity of the research context and the large number of stakeholders across society in the field of e-Health, the practical relevance of the research findings is considered to be critical for the success of the project.

In order to ensure that the research is firmly anchored in the practice, the DOME project has invested much effort in developing an effective network of reference groups. Currently, twentyfive national and regional organisations participate at different levels in the consultative activities. One goal of the reference groups is to help the DOME researchers to identify, understand, and highlight the practical problems and possibilities with e-Health services from different perspectives. Another goal is to feed back the results of the research project to the national development of e-Health services. A specific practical goal of the DOME project is to establish a stable and empirically informed base for the next phase: a national implementation of e-Health services. In this phase, the service models and solutions developed in the SUSTAINS project in the counties of Uppland and Norrland are going to be diffused nationwide. The DOME project perceives the reference groups as an important channel for disseminating its research results and as a valuable resource for performing collaborative work in developing practical guidelines and recommendations for the future, practical, work. In order to make use of the SUSTAINS-project for empirical research the DOME project has initiated a research collaboration with the European partners.

The SUSTAINS project is an EU project with the County Council of Uppsala (LUL) as the coordinator of 16 partners in 11 countries. Norrbotten County Council is another Swedish partner of SUSTAINS that also works with the development of different eHealth services.

Online Access of Medical Records

In the autumn of 2012 LUL gave all patients in the county access to their personal electronic medical records, together with a number of other e-health services, online. LUL is the first county in Sweden to offer this eHealth service.

The online access of medical records enables patients in LUL to access and read their Electronic Health Record (EHR), containing information such as booking of appointment time, medical notes, drug prescriptions, medical lab results, diagnoses, referrals, and the log list with names of medical staff that has accessed the record. For testing purposes a minor launch, limited to employees at the county, was made in August 2012. This test phase was followed by

a complete launch covering all patients in the county of Uppsala. In April 2013 over 18.000 patients out of the population of 200.000 inhabitants had read their EHR in a total of 67.102 sessions.

Empowerment or Anxiety?

The early research studies of the DOME-project has so far focused on implementation of online access to medical records and development of related new e-Health services in the County Council of Uppsala (LUL) in Sweden. This is a central part of the SUSTAINS-project. The pre and post-implementation studies in the county of Uppsala have been complemented with comparative baseline research in other parts of the country. In the next phase, the aim is to follow the implementations in other county councils in Sweden, and in collaboration with international research partners, in other European countries.

Not entirely unexpected, considering the findings published in earlier literature (Ammenwerth et al., 2012), online access of medical records has led to a debate in media. Proponents of the system regard this as a means to change the role of the patient in the healthcare system. The proponents emphasize potentially positive outcomes of patient empowerment. Whereas politicians and managers in the healthcare organizations tend to be primarily positive to the idea of online access to the EHRs, there is a notable divide among the healthcare professionals. Some professionals have been very positive to the initiative, but at the same time many have expressed concerns regarding implementation of the EHR. Even if most critical voices in the public debate have belonged to professionals, findings of the DOME project show that the anxiety is shared also by some patients. At the moment it seems that in general, the opinions of the patients seem to vary the most. Some patients are indeed very positive to the possibilities offered by the EHR and the opportunities to have a say. At the same time, other patients are not sure whether they would benefit at all from consulting their medical records, and some are concerned with the security of the service.

An interesting aspect of the controversy in media is that the proponents as well as the critics of the online access to the EHRs refer to largely similar arguments. They both express a concern for quality of care and security for example. Those in favour of allowing citizens to access their medical records online regard the consequential empowerment of patients and their possibilities to take charge of their health as a central means to improve the quality of care. Informed patients are assumed to be better equipped to make decisions about their healthcare, treatments, and lifestyle. Empowerment has also been suggested to lead to a deeper engagement in personal health care and to a more meaningful implementation of informed consent. The patient's access to the record is also expected to give a higher accuracy of the information in the EHR, since the patient can spot mistakes and make them known to the doctor. In the long run, the changing role of the patients is expected to lead to healthier lives of citizens as well as a more effective use of healthcare resources.

The critics have expressed their concern of, for instance, how some patients might become anxious after reading about preliminary diagnoses without having someone to talk to, or how some individuals might misunderstand the medical record and take actions that even might

compromise their health and safety. Other critical arguments relate to the possibility of an unauthorised or ineligible access to, or misuse of, data. All of these issues are said to have a potentially negative effect on the quality of health care. At the same time, many professionals have expressed their concern of the current implementation process and how the implications of the new system to the occupational safety and work environment of healthcare professionals were neglected. The anticipated problems in working conditions would also, according to them, lead to a poorer quality of care. In order to reduce the risk of patient anxiety it has been suggested, for instance, that doctors should have sufficient time to consult a colleague and complete notes before new entries in records become accessible to patients. There are also patient and staff safety concerns related to providing access to the medical records of some psychiatric patients, which is an issue that was treated also in the earlier literature (Brakoulias, 2013).

At present the initial hypothesis of the DOME project finds strong support; there is great need of multi- and interdisciplinary research on the deployment of eHealth services. In order to develop and understand the current and future processes in e-Health it is necessary to apply a simultaneous consideration of how technical, professional, political and patient related concerns are linked. The DOME research has already shown this to be an important factor for the success of the initiatives. In the next stage of the DOME research the aim is to track the implementations in other county councils in Sweden as well as, in collaboration with international research partners, in other European countries. The DOME researchers are, by the European wide SUSTAINS project and its national deployment projects in Sweden, given a unique opportunity to analyze the contingencies, opportunities, threats and implications related to the development and implementation of online access to EHRs and other eHealth services in projects that are both large in scale and embedded in national and international contexts.

DOME project

More information about the DOME project can be found at <http://www.it.uu.se/research/hci/dome/index.php?lang=1>

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