

Functions for Personal Health Records in Sweden – Patient Perspectives

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Introduction

As part of the ongoing shift in health policy, with focus on patient empowerment, the Swedish government prioritizes the patients' access to their medical records. Different models for personal health records (PHR) are suggested.

Studies have shown difficulties for patients when navigating and understanding the information in their records. Electronic health record systems are physician-oriented and do not include patient-oriented functions. One problem with medical records is that they contain a lot of data which is usually kept as unstructured text in narrative form; this information overload needs to be structured and presented in a manner that patients understand. Furthermore, in order for the PHR to be a supporting tool for patients, there is a need to identify which key functions should be implemented to support patients. Usage of PHR is highly dependent on the information offered and that functions available meet patient needs. In Sweden, little research has been conducted regarding PHR functions preferred by patients. This study addresses the research question "Which PHR functions are preferred by patients living in Sweden?".

Materials and Methods

Structured interviews were conducted with five participants (ages 18 to 79) to capture how Swedish patients perceive medical records and the information obtained from healthcare. The thematic analysis of the interview data was used to design an online survey that was available for two months during the summer of 2012. A five-point Likert scale was used to perform a descriptive analysis of the respondents' attitude to 18 statements. Five patient organizations distributed the survey to their members, and the survey was also made available in an online article published by the newspaper Metro. 201 respondents participated in the survey.

Results

Five themes were identified through the interviews:

- overview of the content
- help to understand the content
- help to understand screening results
- communication/interaction with healthcare

- additional functions

Besides these themes, the participants confirmed issues regarding insufficiency and understandability of the information received by healthcare providers.

The typical survey respondent was a middle-aged female who suffered from some kind of illness and had good computer skills. The respondents wanted timelines for a better overview of their illness and medication, help to understand the content in everyday language, and text summaries. Further, they wanted explanations illustrated with pictures and videos, and access to a medical dictionary. Most of all, they would appreciate fact boxes and search engines as functions in the PHR. Also, they wanted the possibility to add information to the medical record. To communicate with caregivers apart from face-to-face meetings, e-mail was preferred. Video calls were deemed least important.

The respondents considered all categories important, almost all the answers were at the level of "strongly agree". However, the statements regarding the possibility to communicate with a chat bot and the possibility to view PHR content in another language had a low agreement level.

Discussion

In this study on preferred functions in PHRs, interview participants confirmed that medical records are hard to understand, due to structure and content, e.g. the extensive use of abbreviations and Latin terms. Existing techniques, such as Natural Language Processing for summarization, presentation in everyday language, usage of different visualization techniques for presenting screening results and different communication means, should be exploited for interactive and user centred PHR. Offering patients a tailored PHR can facilitate achieving high acceptance. This can further create active participation, which in turn may lead to patient empowerment.

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