

Patient-generated data in the Electronic Health Record: Opportunities and challenges

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Introduction

With this workshop position paper, we wish to present results from the SCAUT research and development project (www.scaut.dk) where we experiment with integrating patient-generated data in remote monitoring of cardiac device patients. We suggest that the future of electronic health record (EHR) needs to take into account the opportunities and challenges of patient-generated data for clinical decision-making and for improved synchronous and asynchronous patient-clinician interaction.



Figure 1. A patient with and implanted ICD using the SCAUT mobile app to describe symptoms and being invited to use a FitBit activity tracker.

From a paternalistic to a patient-centered care model

Patient-centered care models are considered key to improve chronic care. In a historical perspective, diagnosis and treatment was carried out by clinicians *on* patients. Traditional healthcare follows a paternalistic model (Longtin et al., 2010), where the patient is the passive recipient of treatment and the physician is the dominant expert.

Since the 1990's, the traditional care model has been turned upside down. It is increasingly argued that greater improvement of health outcomes can be achieved only through making the on-going collaboration between patient and clinician more effective. Active patient involvement, patient empowerment (Funnell & Anderson, 2003), shared-decision making (Charles, Gafni, & Whelan, 1997) and patient-centered communication are a few examples of new care principles that all inherit a re-organization of healthcare delivery.

Transitioning to 'value-based healthcare' is currently high priority for many governments. This means that patient experience and patient-reported outcome data (PRO) have become ever more important building blocks (T. O. Andersen, Andersen, Kornum, & Larsen, n.d.; Langstrup, 2017) for decision-making. In Denmark, it is high on the political agenda to develop new ways for patients to engage in their own health. More recently, patient-centered initiatives are being rolled out, including personal health records from the nationwide Sundhed.dk and the patient mobile app (myChart) from the capital region's EHR implementation of EPIC.

Patient-generated data

Integrating patient-generated data in the EHR poses new opportunities for better clinical decision-making but it also introduces challenges of various kinds such as new clinical work practices and new responsibilities for patients. Patient-generated data covers a wide range of health-related data that are created, recorded, and gathered by patients, relatives, or other caregivers (Zhu, Colgan, Reddy, & Choe, 2016). With the boom in consumer wearable tracking devices and mobile health apps, patients are also tracking and generating large volumes of personal health data on their own. This data may not be technically integrated but become part of the clinical encounter by patients bringing the data into the clinic themselves (Chung et al., 2016).

Patient-generated data covers a large diversity of data types such as subjective measures like symptom-experiences and medication intake

but also more objective biometric measures like weight and blood pressure or behavior-type data such as steps and sleep.

Opportunities and challenges with patient-generated data in the EHR

The potential usefulness of these data is great as they can provide good measures of the patient's health status, everyday behavior and lifestyle. In the SCAUT R&D project, we are experimenting with using various kinds of patient-generated data to support patient self-management, collaboration and clinical decision-making. For example, in the SCAUT project we have been experimenting with letting patients provide subjective input on data transmissions in remote monitoring of cardiac device patients and, in turn, letting clinicians reply to the input and give patients feedback (T. O. Andersen, Bansler, Kensing, & Moll, 2017). This is currently working very well, and more than 200 patients are using the prototype platform consisting of a patient mobile app and a clinician website.

However, other features such as the Symptom Diary turned out to be more or less useful for patients, but a pain for clinicians since they needed to spend more time on interpreting the patients' reported symptoms. We find that challenges are related to dimensions such as 'who initiates the tracking', 'tracking purpose', 'data storage and ownership', and 'capture mechanisms'.

Currently, we are experimenting with wearable activity trackers (FitBit) to explore the relations between cardiac events, symptoms and patient behavior (sleep, number of steps, and heart rate) but also to see how patients and clinicians may find it useful as part of the EHR. At the time of writing, 19 patients have been on-boarded and we are conducting interviews and preparing for making quick design interventions in the clinic.

Conclusion

With this paper, we suggest taking seriously the transition towards patient-centered care and the technological opportunities (and challenges) with patient-generated data when integrated in the HER. We foresee that a next big change in the design of EHRs are exactly that of holding patient-generated data.

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