

Prototyping Patient 2.0

Lately, another kind of electronic health record, often called to as the Personal Health Record (PHR), has received increased attention from both private and public enterprises. Essentially, the PHR is a patient-centric web-application by which patients can access, produce and share health related information. The PHR addresses multiple, sometimes competing, motivations for creating improved patient satisfaction and disease management as well as increased efficiency and patient empowerment (Kaelber et al., 2008). We report on a participatory design research project* where we prototype a PHR as a tool for chronic ill ICD-patients** and their healthcare network. As part of the project, patients co-design PHR functionality and thereby re-shape their own role and practice. By prototyping several versions of PHRs we negotiate a particular Patient 2.0 which is what we present and discuss in the following.

The power of patient-generated content

The PHR-prototype we introduce is a relatively simple web-application but in practice it re-positions patients and consequently challenges healthcare professionals' treatment of them. In one part of the PHR we provided twelve patients the possibility to record symptoms, write their anamnesis and keep an online diary for ten weeks. The produced content provoked strong reactions from healthcare professionals and basic disagreements among patients. When patients record utterances and experiences as text and as selected categories in the PHR, content is transformed from silent expressions into formal and powerful information. It induces design implications on what (patient produced) health content is, who its recipients are, and who and what are to act upon recordings of critical symptoms. Patient-generated content makes for a new practice that renders Patient 2.0 a more responsible and consequently disciplined actor (Berg, 1997) with increased expectations of active membership attached.

Re-positioning the patient as valuable and reliable content provider

Another part of the PHR challenges the remote monitoring setup of sending and interpreting quantitative data from the implanted ICD-device. The remote setup has changed the process of interpretation from being performed locally into a now distributed and asynchronous setup. As shown by Bjørn (2010) this changes the process of interpretation and evaluation of the condition in significant ways. Primarily, the new distributed setup results in a lack of contextual information being available to the healthcare professionals. By prototyping the PHR we probe into ways of re-positioning the patient as a reliable and valuable content provider, while still maintaining the benefits of remote monitoring. Patients are required to keep an authorized list of medication, a personal profile as well to formulate changes in their condition, by which affordances similar to the earlier local process are introduced – mediated by the PHR.

Consequences of introducing the PHR

When the PHR enters the healthcare network, patients are re-introduced as technologically empowered actors with increased expectations towards taking part in their own treatment. The patients become actively engaged but are simultaneously required to take on increased workload to realize the full potential of Patient 2.0, which challenges the logic of care (Mol, 2008).

*The CITH project (Co-constructing IT and Healthcare) is an ongoing 4-year interdisciplinary research project, which investigates while intervenes in the collaborative practices involved in disease management of remote monitored ICD-patients. [www.cith.dk] (Andersen, 2009).

** Chronic heart patients with an ICD (Implantable Cardioverter-Defibrillator), which is an advanced pacemaker.

References

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