

Analyzing the Politics of PD – reflections on participation in the CITH-project

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For the PDC2014 workshop on Analyzing the Politics of PD, I have chosen to answer the below questions raised in the call. But first some background information about the project on which I base my position paper.

Co-Constructing IT and Healthcare (CITH-project) was carried out by an interdisciplinary group of cardiologists, computer scientists, and sociologists through the participation of more than 50 ICD patients and some of their relatives, and more than 15 clinicians. We focus on the treatment and care for chronic heart failure patients and on what it would take to obtain better-informed patients and clinicians and to support them in periods between visits at clinics.

An ICD is an advanced pacemaker designed and individually programmed to pace and, if needed, to give an electric shock to restore the heart's normal rhythm. The device also records data about arrhythmic events and related parameters with the purpose of monitoring the patient's condition in order for cardiologists to decide if particular interventions are needed.

The care for ICD patients involves multiple actors, who are part of a distributed and heterogeneous network. However, here we focus only on patients, relatives, lab technicians, and cardiologists. The main part of the care takes place in three settings: a university hospital's heart centre, patients' homes, and local hospitals. The implantation and device follow-ups are conducted at the heart centre. Currently, the majority of ICD patients are enrolled in remote monitoring. This means that ICD data are sent from patients' homes to the Heart Centre every three months, or when an arrhythmic event has happened.

Further, patients have to visit the Heart Centre once every second year for an in-clinic device follow-up. Whether it is an in-clinic or a remote follow-up, a lab technician and a cardiologist interpret the data. Sometimes they need to consult the patient's electronic medical record, a special ICD paper record, or ask the patient for more information in order to evaluate the patient's condition. When problems are detected, the patient is either referred to the local hospital if adjustments of medication is needed, or called in to have the device adjusted. Most patients are briefly informed that everything looks fine and told when to come in next time. Regular medication management is also part of the lifelong treatment

of such patients, and every three to twelve months, patients go for ambulatory visits at their local hospital for this purpose.

The overall purpose of the project was to find ways for better-informed clinicians and patients, and to find ways that would support more active participation of patients in their own care processes.

We developed an e-health service, i.e. IT applications and the associated new work processes performed by patients and clinicians. We applied an explorative, experimental, and interventionist strategy within an overall iterative and participatory approach.

1) How participatory was problem setting or problem definition in a PD project? How did participatory designers arrange for the users to be able to contribute to choices (of problems to be addressed, of possible solutions)? Which methods were used and how successful were these methods?

4) How important were the users in the 'seeing'/evaluating part of design moves? Did their 'seeing' conflict with the 'seeing' of the designers?

6) How participatory is the design result in the sense of increasing the 'power to' of users? Can users recognize their influence in the design result?

The overall research problem was formulated in the research application by the researchers (cardiologists, computer scientists, and sociologists): "How to conceptualize, model and build IT for distributed, heterogeneous networks of patients and health professionals."

Instead patients, relatives and clinicians participated in defining the specific problems, challenges and opportunities that we choose to work on. This took place through interviews, observations, workshops, design games, and prototyping. Initially, prototyping was conducted in isolation from the daily practices of patients, relatives, and clinicians, but through the iterations the prototype matured enough for us to cautiously try them out in the real life practices of patients and clinicians.

This means that prospective users - through their input and reactions to the design moves that were probably mostly taken by the IT design researchers - did take part in the decision-making as to the IT applications functionality and ways of interaction, as well as to the content of work processes and the division of labor among patients and clinicians.

Ex1: Success: During the evaluation of one version of the prototype, a lab-technician felt that it would be too time consuming and too cumbersome to give a proper response to a patient based on her interpretation of information from the ICD and on what the patient had reported through the prototype. The IT design researcher *sees* that and suggests a *design move*: "How about using your mobile to record a message and send it to the patient through the system?" The lab technician tries this out and they both *see* that it worked fine. Latter the patient expressed satisfaction too.

Ex2: Failure: Patients were willing to prepare for consultations using an IT application that included for instance a questionnaire based on categories defined by clinicians, a way to update the patient's medication list, and the option to raise questions and concerns a patient would like to attend to at the consultation or via the system. Clinicians found it helpful that patients have provided information through the system before the consultations. However, some patients were very disappointed and gave up on the system, as - in their experience - some of the clinicians did not pay attention to their questions and concerns.

This was due to the fact that the researchers did not manage to arrange for adequate participation of another stakeholder - the IT-developers - often neglected in the PD-literature. So while users were adequately participating in analysis, prototyping technical and organizational solutions, they were totally excluded from the technical implementation of the prototypes, which they subsequently evaluated. The problem was that the IT company that signed up for the project "suddenly" decided to outsource the technical implementation to India, and no contact was possible with the Indian team. This meant that much of the mutual understanding developed among users and the IT design researchers was lost. And the understanding that the IT design researchers had developed with the IT company's Danish team was not stable enough for an outsourcing strategy.

3) Did the users contribute to implementing or materializing choices? What types of skills were they encouraged to mobilize? How did the users' contributions affect the technical part of the implementation?

Users were not involved in the technical part of the implementation. Instead, both clinicians and patients contributed to the organizational implementation, as they each were eager to perform their part of the work practices that together with the IT application made up the solutions. But as indicated in ex2 above, the eagerness disappeared in cases where patients did not get the cooperation they had looked for.

The design encouraged patients to mobilize their skills as chronic heart failure patients. And both parties need to adjust to written communication, indicating that we never expected the system to be relevant for all patients in all phases of their illness trajectory.