Alignment of Concerns
A Design Rationale for E-Health

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Abstract. E-health promises to enable and support active patient participation in chronic care. However, these fairly recent innovations are complicated matters and emphasize significant challenges, such as patients' and clinicians' different ways of conceptualizing disease and illness. Informed by insights from medical phenomenology and our own empirical work in telemonitoring and medical care of heart patients, we propose a design rationale for e-health systems conceptualized as the 'alignment of concerns'.

Challenges to Patient Participation in E-Health

The evolution from 'hospital information systems' to 'e-health' has extended the scope of health informatics and healthcare research in CSCW (Fitzpatrick and Ellingsen 2012). While clinicians and hospital administrators were originally the only 'users', patients and their relatives are now increasingly engaged as new types actors. Reaching active patient participation (Street et al. 2005) and self-management (Holman and Lorig 2004) is considered crucial for tackling the socio-economic challenges of chronic care management and there are high expectations for e.g. telehomecare technologies and personal health records (Koch 2006). Research suggest that e-health will supplement existing forms of care and improve the circumstances for patient participation (Dedding et al. 2011). However, these fairly recent innovations are complicated matters and introduce significant challenges. One key challenge is that patients and health professionals conceptualize and experience disease quite differently, which designers of e-health systems have not fully taken into consideration. With this

paper, we address this challenge by providing a case snippet from a design intervention with a working prototype of patient-centric e-health platform, *myRecord*. In this way, we contribute to the discussions in health informatics by proposing a *design rationale* for e-health, conceptualized as 'alignment of concerns.'

Different Conceptualizations of Illness and Disease

Understanding the fundamental difference between the perspectives and goals of patients and physicians, we suggest, is key to successful design of e-health. In her seminal work on 'the meaning of illness', Toombs (1987) points out that there is a "decisive gap" between the way illness is experienced by patients and the way in which physicians conceptualize disease in biomedical terms, such as symptoms, diagnosis, pathology, treatment and prognosis. Consequently, "rather than representing a shared 'reality' between them, illness represents in effect two quite distinct 'realities'" (Toombs 1987, 219). Patients experience *illness* as a unique, personal event that transforms their bodily awareness and disrupts their everyday practices, roles and relationships with others (Pickard and Rogers 2012). Physicians understand *disease* as an entity in itself, a biological phenomenon that can be categorized as an instance of a known type, for instance as a particular case of "diabetes" or "ischemic heart disease," and treated according to scientifically tested procedures (Montgomery 2006; Toombs 1987). This crucial difference is rarely acknowledged in the literature on e-health. When physicians and patients might discuss the same abstract concern, but as Hunter has emphasized, "often only the physical signs and their diagnostic labels are the same; the understanding and the concerns are entirely different." (1991, 14)

Designing for Alignment of Concerns

We report on a four-year combined participatory design and CSCW project[1] in healthcare, where we have applied numerous design interventions with working prototypes as part of medical consultations and telemonitoring of patients with an ICD (advanced pacemaker) (see Andersen et al. 2011; Mønsted, Reddy, and Bansler 2011). With the following case we illustrate how we succeeded to design and trial a patient-centric e-health platform, *myRecord*, which provided for improved patient participation and what we suggest as *alignment of concerns*. In remote monitoring ICD patients are excluded from engaging with clinicians and

rely solely on data recorded by the ICD device and transmitted for interpretation by lab technicians and cardiologists at the Heart Centre. Compared with in-clinic follow-ups, patients can no longer ask questions about the ICD and raise concerns such as potentially relevant symptom experiences. In design interventions with later versions of myRecord we experimented with ways to fulfill the needs of both patients and clinicians by enabling patients to qualify transmitted data with their own experiences and by enabling lab technicians and cardiologists to respond in effective ways.

Consider the case of Irene who participated on the project. She is 57 years of age and born with congenital heart defect and has therefore been undergoing chronic care since an early age. The implantation of an ICD in 2005 has added to her anxiety, particularly because of inappropriate shocks (erroneous and severe ICD treatment) and her continuous experiences of arrhythmia. In a design intervention in a remote follow-up with myRecord, Irene transmits her ICD device data as usual from home, but this time she also logs into myRecord where she answers the question "how are you feeling" with: *"Up and down – I've experienced being dizzy several times and have had the same feelings as when I got atrial fibrillation [irregular heart beat] in 2008. When the feeling comes, it makes me feel quite insecure, partly because I get dizzy, partly because I am afraid of what it is."* (entry in myRecord, November, 2010).

She approves the medicine list, selects the appropriate medical categories, writes about her worries, and enters the specific dates and times where she has experienced dizziness and symptoms like atrial fibrillation. The following day at the Heart Centre, the lab technician reviews the transmitted data and concludes that there have been no therapies and that no events are recorded. However, when she consults myRecord and discovers Irene's medicine list and what she writes, the lab technician decides to re-visit the recorded data and the device settings. A reason for her doing this, is that sometimes patients experience symptoms, similar to Irene's, and clinicians need to adjust the device settings so that they are set according to what the patient experiences. In this case, the lab technician interprets that this is not the case and decides to continue with the standard procedure and mail Irene a letter affirming that "everything looks fine". However, provided with the possibility of easily dictating an individual reply to patients in myRecord, she decides to take action and comfort Irene by explaining what the data and settings tell her: *"Hi Irene, it's the lab technician at the Heat Centre […] I can understand that you feel uncomfortable and I have therefore checked the episodes you are mentioning. The device has not recorded atrial fibrillation. So, when nothing is registered in the zones that we have set it up to monitor I can assure you that the atrial fibrillation is well controlled and that you do not enter any critical zones […] so it's super great that it works well with your medicine […]"*(lab technician's reply in myRecord, November, 2010).

This case shows how myRecord supports the patient in raising concerns in a format, which proved useful for the lab technician when reassuring device

settings. The symptoms described by Irene were of particular interest for clinicians' ICD monitoring (see Andersen et al. 2011) and enabled the lab technician to decide on proper action with improved confidence. Her decision-making in remote monitoring had improved. Moreover, the possibility of easily making an individualized reply, by voice dictation and automated transcription, provided the lab technician with ways to fulfill the patient's needs. In terms of e-health, myRecord supplemented the existing form of remote follow-ups and created favorable circumstances for active patient participation. To a certain extent, the add-on features in myRecord allowed for the alignment of the patient's 'reality' (feeling anxious about symptoms of irregular heart beats) with the clinician's 'project' of ensuring high quality telemonitoring (device settings are set properly and the patient is notified in a comforting way). This case has implications for e-health design and suggests that a) engaging methods, such as participatory design, can 'reconcile needs' and make interaction meaningful for both patients and clinicians, and b) enable e-health to support the *alignment of concerns*.

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