



Alignment of concerns

Andersen, Tariq Osman; Bansler, Jørgen P.; Kensing, Finn; Moll, Jonas; Nielsen, Karen Dam

Published in:

2014 47th Hawaii International Conference on System Sciences (HICSS)

DOI:

[10.1109/HICSS.2014.327](https://doi.org/10.1109/HICSS.2014.327)

Publication date:

2014

Document Version

Publisher's PDF, also known as Version of record

Citation for published version (APA):

Andersen, T. O., Bansler, J. P., Kensing, F., Moll, J., & Nielsen, K. D. (2014). Alignment of concerns: a design rationale for patient participation in eHealth. In 2014 47th Hawaii International Conference on System Sciences (HICSS) (pp. 2587-2596). IEEE. DOI: 10.1109/HICSS.2014.327

Alignment of Concerns: A Design Rationale for Patient Participation in eHealth

Tariq Andersen¹, Jørgen Bansler¹, Finn Kensing², Jonas Moll¹, Karen Dam Nielsen³

¹Dept. of Computer Science, ²Center for IT-Innovation, ³Dept. of Public Health

University of Copenhagen, Denmark

tariq@diku.dk, bansler@diku.dk, kensing@citi.ku.dk, jonas@jermiin.dk, kadn@sund.ku.dk

Abstract

The emergence of patient-centered eHealth systems introduces new challenges, where patients come to play an increasingly important role. Realizing the promises requires an in-depth understanding of not only the technology, but also the needs of both clinicians and patients. However, insights from medical phenomenology bring forth how physicians and patients focus on different aspects of illness and that they often have starkly divergent concerns. This has important implications for the design of eHealth systems that seek to engage patients as active participants. We emphasize the crucial importance of acknowledging these fundamental differences between patients' and physicians' everyday projects and we illustrate it by three case examples from a participatory design project of constructing a personal health record for chronic heart patients and their clinicians. We summarize our suggestion as a design rationale for successful eHealth, termed 'alignment of concerns'.

1. Introduction

The recent emergence of patient-centered eHealth services, such as *telehomecare* and *personal health records (PHR)*, mark a new stage in the ongoing development and rollout of healthcare IT. In contrast to previous systems, such as *hospital information systems* and *electronic medical records*, which primarily targeted clinicians and hospital administrators, these new applications also seek to involve patients as active users.

There are great excitement and high hopes for patient-centered eHealth services. They are expected to enable patient empowerment and self-management as well as improve quality and efficiency of care [14,17,29]. At present, however, most of these

benefits are largely hypothetical and the clinical effectiveness and cost-effectiveness of these solutions have not been demonstrated [3,10]. In addition, several authors warn that patient-centered eHealth services may have detrimental effects on the physician-patient relationship and that they in some cases may force patients to take on tasks and responsibilities that they do not feel capable of dealing with [8,10,22,23].

This state of affairs is not surprising. The inclusion of patients as users of eHealth services introduces a whole new class of challenges for health informatics. Patients have quite different concerns and needs than physicians and other health professionals and these concerns and needs must be satisfactorily addressed if patient-centered eHealth services are to be successful. However, it seems that researchers and designers, in general, do not truly understand the scope and complexity of this task.

To address this issue, we look into how patients' perceptions of illness differ from physicians' and explore the implications for the design of patient-centered eHealth services. In doing so, we draw on insights from medical phenomenology as well as on our own experiences from designing an eHealth application for patients with chronic heart disease. We argue that *alignment of the concerns of the patients with those of the physicians* is a prerequisite for the successful design and implementation of patient-centered eHealth services. This does not imply that patients and physicians need to have identical perspectives on illness and treatment, but rather that their respective concerns and needs must be recognized and reconciled. Otherwise, there is a high risk that either patients or physicians will be dissatisfied with and thus reluctant to adopt these new eHealth services. We end the paper by presenting a design rationale that focuses on how such alignment can be achieved.

1.1. eHealth introduces new challenges

Early research and development of health IT focused on so-called hospital information systems (HIS), which were limited to single wards or hospitals. Users consisted mainly of administrators, physicians and other health professionals [5,13]. With the emergence of health informatics in the 90s, the scope broadened to include systems spanning multiple hospitals, global information infrastructures, and strategic information management [27]. But the users were still primarily hospital staff and administrators.

However, over the last decade, patients have come to play an increasingly important role in their own treatment and care, and under the umbrella of *eHealth* researchers and designers have begun to extend the network of users to include patients (and their relatives) [1]. Examples of eHealth services that target patients include patient-provider portals (e-mail, eVisits, ePrescriptions, and eScheduling), telehomecare platforms [17] and PHRs [4,18]. Furthermore, there is currently a rapid growth in consumer-oriented health websites, mobile applications, and social software that enable patients to engage in self-management and exchange experiences and advices to better cope with day-to-day personal health issues [12].

It is still too early to tell where this new technological trend leads, but it will without doubt hugely impact the future of healthcare [4,10,23].

1.2. Patient participation in eHealth

It is generally expected that patient-centered eHealth services will facilitate patient participation, self-management, and empowerment [3,10].

Such services, it is suggested, can for instance become a “supplement to existing relationships and forms of care” [10], which improves behavioral outcomes through tailored communication and increased interactivity [22]. It is also suggested, that eHealth has the potential for “creating favorable circumstances for improvements or strengthening patient participation”. For example, PHR’s and various health sites may make patients better informed and empowered [18] and thereby possibly better equipped for “self-management” [14] and “shared decision-making” [22]. eHealth can also function as a lever for engaging health professionals in working together with patients and stimulate discourses on “patient centered care” [30].

However, early experiences with patient-centered eHealth services also point to many challenges and unintended consequences that should be taken into

consideration in the design of future applications and services.

Dedding et al. [10] warn, for instance, that these services may “disturb” physician-patient relations and lead to more “sick work” for the patients. They therefore advice that “more attention should be paid to the redistribution of tasks and responsibility to patients” [10]. Another unintended consequence may be added responsibilities and extra costs for providers [10]. Physicians may also feel that their position is threatened or undermined by the new technologies. Chen et al. [8], for example, highlight the challenges of eVisits, where patients and physicians communicate online, and question whether physicians can build trust and engage in diagnosis without being able to interview, observe, and examine the patient in-person. Similarly, Oudshoorn [23] describes how health professionals working with telecare need to learn new skills such as how to create “intimacy at a distance.” She also describes how telecare can have the unintended consequence of shifting responsibility onto patients so that self-care is forced upon them whether they like it or not. In a similar vein, Langstrup [19] describes the negative effects of telehomecare and how “family members become, willingly or unwillingly, parts of the chronic care infrastructure.”

So, delivering on the promise of patient-centered eHealth requires an in-depth understanding of not only the technology but also the needs and concerns of all relevant actors including, in particular, physicians and patients.

2. Divergent meanings of illness and disease

An understanding of the fundamental difference between the perspectives and goals of patients and physicians, we suggest, is key to the successful design of eHealth systems.

As S. Kay Toombs [32] has pointed out in her seminal book on the meaning of illness, there is a “decisive gap” between the way illness is experienced by the patient and the way in which physicians conceptualize disease in biomedical terms such as symptoms, diagnoses, pathology, treatment, and prognosis. “Consequently, rather than representing a shared ‘reality’ between them, illness represents in effect two quite distinct ‘realities’” [32]. Patients experience *illness* as a unique, personal event that transforms their bodily awareness and disrupts their everyday practices, roles and relationships with others [7,25]. 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 [21,32]. This crucial difference is rarely acknowledged in the literature on eHealth.

A reason for the apparent lack of attention to the gap between the perceptions of patients and physicians may be that it is obscured by the migration of scientific and technical medical terms, such as “congestive heart failure” and “pacemaker,” into ordinary, everyday language. The use of common terms suggests that physician and patient are talking about the same things, but as Hunter [15] has emphasized, “often only the physical signs and their diagnostic labels are the same; the understanding and the concerns are entirely different” (p. 14). In fact, the difference in perspectives is typically so deep-seated that it results in a “systematic distortion” of meaning in the patient-physician encounter [31]. The reason is that the difference is “grounded in the fundamental distinction between the lived experience of illness and its conceptualization as a disease state” [32] and thus goes far beyond differing levels of knowledge about illness and disease (with the physician being regarded as the most knowledgeable).

First, the physician and the patient focus on different aspects of illness. The patient encounters his illness as an immediate lived experience. It manifests itself as pain or other physical problems that disrupts his normal functioning and demands his attention. The categories he uses to make sense of it are “primarily concerned with everyday life and functioning” and often imbued with social and cultural meanings (p. 12). Serious illness, and in particular serious chronic illness, does not just affect the body. It can affect one’s whole life, one’s relationships with others, and how one sees oneself [24]. Patients suffer because their illness constrains their agency and because it creates anxiety and fear, but they also suffer because “they feel isolated from others, because they feel alone” [6]. The physician, in contrast, is trained to “see” the patient’s illness within a prescribed conceptual framework (the biomedical model of medicine), as a typical example of a disease. He conceptualizes the illness in terms of abstract scientific constructs and in doing so he focuses primarily on “objective facts” such as physical signs, clinical findings, and laboratory data [21,32].

Second, the physician and the patient are engaged in different “projects” and, as a consequence, they have different criteria of relevance. The goal of the physician is to diagnose the patient’s condition (i.e., to fit the particular case into a general taxonomy of

diseases) and provide reliable and effective treatment in accordance with accepted practice standards, clinical guidelines, protocols, and so forth [21]. On the surface, this goal seems to match the patient’s needs. However, as Toombs [32] has stressed, “the patient’s goals relate to the qualitative immediacy of his illness. They represent an attempt to integrate the experience into daily life” (p. 18). The overriding goal of the patient is to come to terms with his changed situation and develop effective coping strategies that allow him to curb his anxiety and re-establish a meaningful life [7,24,25]. One consequence of these differences in priorities is that patients and physicians disagree on what is relevant and what is not: “*Since the ‘problem at hand’ is defined differently by patient and physician, according to goals that relate to their separate worlds, they do not share a system of relevance with respect to these goals.*” [32]

In other words, physicians and patients generally have very different concerns about treatment options and priorities, medication side effects, symptom management, impact on daily life and relationships, identity and self-esteem, course of the disease, fear of death, and so forth. Patients with chronic diseases may, for instance, choose to “preserve aspects of their identity or habitus at the cost of symptom management” [25].

The fact that physicians and patients focus on different aspects of illness and that they often have starkly divergent concerns and priorities regarding treatment and “disease management” has important implications for the design of patient-centered eHealth services. Such services will only be a success if both physicians and patients see the benefits and are ready to make them work. Therefore, the design must carefully address and seek to reconcile the needs of both groups so that the outcome will be a system, which everybody finds useful and important. Or, to put it succinctly, the identification and alignment of concerns between physicians and patients is a prerequisite for successful design.

As a final remark, it should be noted that patients, of course, are different and to some extent have different needs and concerns dependent upon their life history and present life situation. Similarly, there might be significant differences among physicians as well as between physicians and other health professionals. However, we do not go further into this issue with this paper.

3. Setting, approach, and prototype

The study presented here is part of the research project *Co-Constructing IT and Healthcare*¹ carried out by an interdisciplinary group of cardiologists, computer scientists, and sociologists.

We focus on the treatment and care of chronic heart failure patients and on what it would take to obtain better-informed clinicians and to support patients in periods between visits to healthcare providers. We have developed innovative IT support and new ways of organizing treatment and care for patients who are willing and capable of becoming (more) active participants in their own care processes.

Heart failure patients at risk of sudden cardiac death due to ventricular fibrillation may have an Implantable Cardioverter Defibrillator (ICD). This device is an advanced pacemaker designed and individually programmed 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 participants, but here we focus on patients, relatives, lab technicians, and cardiologists. The main part of their work takes place in three settings: the Heart Centre at Copenhagen University Hospital, patients' homes, and local hospitals. ICD patients from Denmark, Greenland, and the Faeroe Islands who are connected to the Heart Centre have the implantation and device follow-ups conducted there. Currently, the majority of ICD patients are monitored remotely. This means that ICD data are sent from patients' homes to the Heart Centre every three months, or when an arrhythmic event occurs. Patients have to visit the Heart Centre once every second year for a device follow-up. Whether it is an in-clinic or a remote follow-up, a lab technician, assisted by a cardiologist, interprets the data. Sometimes they need to consult the patient's record, a special ICD paper record, or ask the patient for more information in order to evaluate the patient's condition. Based on this, the patient is briefly informed, referred to the local hospital, called in for a battery change or to have the device adjusted. Medication management is also part of the lifelong treatment of such patients. Thus, every three months, patients go for ambulatory visits at their local hospital to have the medication followed up on and adjusted if needed.

¹ See www.cith.dk for details.

² For a detailed description see [2], where the amount and type of activities and participating users are accounted for.

3.1. Research approach²

An increasing number of authors suggest to engage users in the design of eHealth systems [11,26] and participatory design has proven instrumental for this purpose [2,9]. Following this relatively new tradition we have applied an explorative, experimental, and interventionist strategy within an overall iterative and participatory approach. Participatory design [28] entails that prospective users take part in the design process for the combined purpose of having a say and engaging in mutual learning with designers [16]. We have engaged clinicians, ICD patients, and relatives as active participants in defining the aim of the project as well as in analyses, design, and evaluation. In total ~50 patients and relatives, ~10 clinicians, and 4 hospitals and clinics have participated. The participatory design techniques used include interviews, observations, artefact and document analysis, workshops, design games, and prototyping [28]. Such activities allow for developing an in-depth understanding of current practices and of the needs and concerns of the prospective users. This is in contrast to traditional approaches relying on expert strategies involving users only as informants in interviews, focus groups, and testing of intermediate and final results.

Hence, we sat out to explore existing practices at the three settings: The Heart Centre, patients' homes, and local hospitals. We found that patients engage various strategies for handling the many types of information they receive. Moreover, both patients and clinicians find their information resources insufficient and fragmented and they each struggle to obtain the meaningful type of information during consultations. The cases exemplify this.

3.2. myRecord

We started to experiment with prototypes of what later became myRecord. It is a type of PHR with the overall purpose to assist the heterogeneous network of actors in supporting the patient in disease management and to allow for intervention in due time, before a potentially critical situation escalates. myRecord facilitates communication between health professionals and patients. It is designed to change patient-clinician relations and empower patients who are willing and capable of taking more responsibility for monitoring their own condition and for preparing for consultations.

² For a detailed description see [2], where the amount and type of activities and participating users are accounted for.

With this paper, we focus on the features that support preparation for remote follow-ups and in-clinic consultations, be they for device or medical follow-up. However, myRecord also offers other features such as a calendar to keep track of appointments, easy access to guidelines, information on potential harmful interactions between prescribed medications, a logbook to mark symptoms and note diary entries related to the disease, and a community/network to allow for communication with other ICD patients.

Patients are prompted to complete a preparation form prior to a consultation. This includes updating and confirming their medication list, and using their own vocabulary they can pose questions about experienced problems or concerns. Further, using symptom categories defined based on NYHA classification scheme (New York Heart Association) patients are asked to report on their health status.

Thus, the rationale has been to further the potential positive and to counteract the negative consequences briefly described in Section 1.2 and further developed in e.g. [8,10,23]. The replacement of most of the face-to-face device follow-ups however were already achieved and, at large, appreciated by patients and clinicians by the telemonitoring system to which myRecord is an add-on. As the project evolved we (re)designed a set of services supporting the work of clinicians, patients, and relatives. We introduced new tasks, roles, and new ways for them to cooperate, e.g. we experimented with a dictation feature where lab technicians could easily dictate an individual reply as a supplement to the standard letter that the current system supports. Based on such experiments we adjusted the prototype, the tasks, and the roles, but we also learned about new issues of the current practices. In this way, we deliberately iterated between analysis and design activities. At first the experiments were conducted in isolation from the daily practices of patients, relatives, and clinicians, but through seven iterations the prototype matured enough for us to cautiously intervene by trying it out in real life settings.

4. Three empirical cases: IT-support for patient participation

With this section, we bring forth three empirical cases to illustrate how the *divergent meanings of illness and disease* play out in three characteristic situations of designing and testing IT-support for active patient participation in eHealth. There is a progression with each case, starting from a relatively simple example of a contradictory patient-physician

relation to the final case where the relational aspects are more entangled. For each case we discuss how it illustrates a key challenge in the process of aligning concerns.

Our goal is to illustrate how the differences that underpin the understanding and conceptualization of symptoms and disease between patients and health professionals come to signify central aspects of patient-physician relations and thus the use of eHealth.

4.1. Case #1 – Concepts and meaning differ

With this case, we bring forth the difference in how illness is experienced by patients and how clinicians conceptualize disease and how this differentiation then comes to designate what is perceived as important and meaningful to each part.

Louis is 51 years of age and has had his ICD for only a year, after suffering a sudden heart attack. The experiences of becoming a heart patient and an ICD-patient in his case melt into each other. Louis suffers from various symptoms related to the heart disease itself, the device, and the medication as well as recovering from the heart attack. Besides this, Louis feels anxious and depressed which he partly ascribes to the trauma of experiencing his own mortality and partly to the lack of continuity of care and the lack of coherence of the information he receives from health professionals and institutions.

Because of this, Louis is enthusiastic about the prospect for new ways and means of communicating with clinicians and engages very actively in the use of myRecord. He makes several notes on symptoms with the logbook feature (ranging from feeling tired, loss of breath, swollen legs, anxiety, and impotence) and is eager to utilize the preparation module prior to his upcoming in-clinic follow-up. Besides this, he explores the network feature to connect and share experiences with other patients. He praises the potential of the system and explicitly links his positive assessment of its value to his position as a new patient with a great need to feel secure and “in control” and to be able to raise urgent questions and seek continual professional guidance.

Having completed the preparation via myRecord where he has written an extensive prose text about his symptoms and concerns, Louis has high expectations for the upcoming consultation at the clinic. However, afterwards he is greatly disappointed, as he did not feel that the clinician responded to all the concrete concerns he had raised nor attended to his situation at large:

“I was prepared for the consultation. And that thing regarding vitamin D, he didn’t mention it. He

didn't say anything to me. And regarding the legs, it was me who insisted, insisted, insisted [...] So, I was disappointed with the consultation, really.” (Final interview with Louis, February 2013)

The cardiologist on the other hand felt that he was able to react to the patient's *primary* concern (which he perceived to be the experience of dizziness and loss of breath and which he links to a possible regulation of medication) and then leave the rest unspoken, since it was not something for him to act on:

“Because he was allowed to write about it and he had made that list, I could just say to him; ‘I can see you’ve written something about this and that. This is the main thing for you,’ and we could then go straight to that topic without having to start all over. So, I think it’s a good way to manage the contact.” (Final interview with cardiologist, local hospital, February 2013)

The cardiologist further indicates that he thinks the very act by Louis of writing down his concerns would make him feel better. And that Louis would further “feel heard” by knowing that the cardiologist had read through his preparation.

This case illustrates how the clinician and patient have conflicting perspectives on 1) which concerns are meaningful in the sense of important and relevant for the consultation, and 2) what constitutes proper (re)action. The cardiologist perceives his role as to manage the consultation in the most productive and meaningful way, which in respect to the cardiologist is to ensure that his most important concerns are attended to. Besides this, he acts as a passive listener through myRecord as an act that will indirectly satisfy the patient. The patient, however, feels quite differently and finds much of the follow-up meaningless, stating that in order to be meaningful to him his efforts must result in a “real” (re)action at “the other end.”

From the case, we also learn that even though a concern is meaningful to one party, does not mean it becomes meaningful for the other to attend to. This is also a matter of what is allowed (or not allowed) to be put to the front both by patients and clinicians.

4.2. Case #2 – On action and feasibility

With this case, we take the matter of proper reaction a bit further by illustrating the second challenge that plays an important part in the process of aligning concerns. Namely, that it is not enough for a concern to be meaningful – it needs to be *actionable* as well.

In a distributed care scheme clinical concerns are formally, and often also practically, distributed. This

means that even if a certain concern of a patient may be of great clinical relevance (e.g. critical side-effects of medication) it will only be relevant for *certain* clinicians. When patients then write questions and state concerns in a system like myRecord, where a certain clinician is the receiver, the patient must be able to assess what is relevant to whom. In other words, the patient must at some level understand the infrastructure of the distributed care scheme, or the IT-system should indicate or assist in this.

Ben (aged 60) is preparing for the upcoming in-clinic device follow-up at the Heart Centre by filling out the step-by-step preparation form in myRecord. When he reaches the section where he can state his most important questions for the clinician he writes that he is very concerned with his blood pressure because he finds himself increasingly exhausted at work when performing his daily tasks. His job is very important to him and he is eager to find a solution so that he can keep working. Ben therefore asks to have it monitored over the course of a day at work. He also poses a question about some over-the-counter-drugs he has been advised to take by a friend. He then finishes the rest of the preparation form and sends it off digitally to the clinic.

During the consultation at the out-patient clinic, the lab technician and the cardiologist quickly browse through Ben's preparation form on their computer screen, while they ask him about his general well-being, his medication and specific symptoms related to the ICD. Ben then asks about the possibility of having his blood pressure monitored and brings forth a referral letter for a local hospital he has received from his general practitioner. The cardiologist briefly answers that it is not something she can get into, and that he will have to take it up with the local hospital.

Afterwards Ben states how he was “*disappointed about the fact that they hadn't read it through carefully. It just goes helter-skelter, you know. [...] They don't talk about over-the-counter drugs or anything. Then it's just ridiculous to write about it.*” (Final interview with Ben, February 2013)

Now that Ben with great effort had prepared so well using myRecord, he was expecting the clinicians to be prepared too and address his concerns. But he felt that the clinician had not prepared properly and that their lack of interest and action in relation to his concern about this blood pressure and over-the-counter-drugs made his preparation meaningless.

The cardiologist on the other hand, stated how she, while being with the patient, was able to “*browse through what he had written,*” and that the preparation form “*worked well.*” Although she admitted to not having read it beforehand. (Final

interview with cardiologist, The Heart Centre, February 2013)

The cardiologist was not bothered by the fact that she was presented with a concern of the patient that she was not able to act on for organizational reasons, but rather she found it useful to be able to quickly browse through the patient's concerns and screen out those she did not have to pay attention to.

In this case we learn that although the concern raised was both *meaningful* to the patient and the clinician and in fact also *clinically* actionable, it was not *organizationally feasible*. One party, the cardiologist, is pleased with the myRecord system and not bothered by being confronted with a concern that she is not able to take action on. But the patient, on the hand, finds the encounter demoralizing and disappointing due to what he perceived as an unsatisfactory "absence of action."

The case thus illustrates how some patients are neither able to assess what could become a concern to *certain* clinicians, nor to accept that the concerns they have articulated are not responded to and acted on by the clinicians. Subsequently, using this version of myRecord entailed great disappointment for the patient in this case and led him to lose his motivation for further use. This supports our claim that motivation for use rests on the existence of aligned concerns and of the system's ability to support these. In this case it fails to do so as it fails to account for, or compensate for, the distribution of care by facilitating a 'match' between the concern of the patient and the concern, in the sense of *ability to act*, of the clinician in question.

4.3. Case #3 – Alignment of concerns with myRecord

While the two previous cases illustrate how myRecord was unsuccessful in supporting meaningful patient participation in some situations, the following case presents how other features of the system used in other situations provided for enhanced collaboration. In remote monitoring, patients are excluded from engaging with clinicians, both parties thus rely primarily on data recorded by the ICD device, which is transmitted for interpretation to lab technicians and cardiologists at the Heart Centre. Patients can therefore no longer ask questions regarding the ICD and raise concerns such as potentially relevant symptoms in the time between the remaining in-clinic follow-ups every second or third year. In design interventions with different version of myRecord we experimented with ways to fulfill the needs of both patients and clinicians by enabling patients to qualify transmissions with their

own experiences and by enabling lab technicians and cardiologists to respond in effective ways.

Consider the case of Irene who is 57 years of age. She is born with a 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. Irene feels that her health is "fragile", as she says, and she has lately been seeing a psychologist, which has improved her well-being.

During 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" by writing:

"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 arises, it makes me feel quite insecure, partly because I get dizzy, partly because I'm afraid of what it is." (entry in myRecord, November, 2010). Irene approves her medication 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: *"Registered episodes have been: 01.10., 11.10., 31.10., 05.11. (at 8.40 and approx. 12.15 to 13)."*

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 reviews Irene's medication list and what she writes, the lab technician decides to re-visit the recorded data and the device settings. A reason for this is that sometimes patients experience similar symptoms as Irene describes and the clinicians then need to make sure that the device settings are set properly. The lab technician, although, interprets that this is not the case and decides to continue with her standard procedure and send the brief standard letter to Irene affirming; "the system looks fine." However, provided with the possibility of easily dictating an individual reply to patients in myRecord, the lab technician 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 Heart Centre [...] I can understand that you feel uncomfortable and I have therefore checked the episodes you are mentioning. But the device has not recorded atrial fibrillation. So, when nothing is registered in the zones that we've 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 medication [...]"(lab technician's reply in myRecord, November, 2010).

This case shows how myRecord supported the patient, Irene, in raising concerns in a format which proved useful for the health professional when reassuring the settings of the device. The symptoms (and thus concerns) described by Irene were of particular interest for the clinician in the process of ICD monitoring (device settings need to match symptom experiences and zones for monitoring need to be set accordingly). Hence, it enabled the lab technician to decide on proper action with improved confidence, improving her decision-making in remote monitoring. Moreover, the possibility provided by myRecord of easily making a voice-dictated and individualized reply (automatically transcribed), enabled the lab technician in accommodating the concern of the patient. In the language of eHealth, 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 heartbeats) with the clinician's 'project' of ensuring high quality telemonitoring (device settings are set properly and the patient is notified in a comforting way).

5. Design rationale:

Alignment of concerns

MacLean et al. [20] were among the first to introduce the notion of *design rationale* in relation to the design of IT systems. Their idea was to deliver not just the system, but also "the argument behind the artifact" [20]. Following this idea, we propose a design rationale for eHealth services that are intended to involve patients as active participants (like myRecord). The design rationale is grounded in insights from medical phenomenology [31,32] and in analytical reflections from the participatory design research of myRecord. We formulate a design rationale for eHealth which we term *alignment of concerns*. The rationale accentuates the importance of making eHealth systems that reconcile (by aligning) divergent needs, interests, or concerns of patients and clinicians. It recognizes the decisive gap in how patients and clinicians conceptualize illness and disease and suggests the importance of working towards designing eHealth systems that specifically seek to reconcile these, often divergent, concerns. Below, we describe the design rationale and present it as composed of three primary properties that are

essential in the process of identifying and subsequently aligning concerns, and which need to be in place for patient participating eHealth systems to work. The properties are *meaningfulness*, *actionability*, and *organizational feasibility*.

5.1. Meaningfulness

The initial property designates how a concern of one party (e.g. the patient) only can become a concern for the other (e.g. the clinician) if it is found 'meaningful' by being acknowledged either as clinically topical or relevant to the treatment and care process. With case 1 and 2, we illustrate this by showing how concerns that are meaningful to Louis and Ben are not necessarily considered meaningful to the 'project' of clinicians. A meaningful concern is, however, no static entity. For instance, patients may experience that taking on 'clinical home work' using eHealth systems such as myRecord may result in more informed and more detailed answers that aid her/his own task of coping with the everyday challenges of illness. That is, if patients begin to provide clinicians with the information, which they need in order to proceed in improved ways, clinicians may begin to consider the patient's concern as relevant and in turn start supporting the patient's needs. Still, concerns only align if they are found to be meaningful to both the patient and the clinician.

5.2. Actionability

In all the cases, we pointed to a second aspect of what makes a certain concern relevant. Namely, that it is 'actionable'. Meaningful concerns arise as topical and/or clinically relevant for both parties only when it is possible to take action upon the concern. In other words, the concern needs to be actionable to come into consideration.

In the third case, myRecord facilitated the patient's articulation of a concern, which proved relevant for both parties (providing important symptoms not reflected in the ICD data). That is, the patient and the clinician succeeded, by support of the eHealth system, to make her concern actionable to the clinician. By giving the lab technician the opportunity to quickly and easily respond verbally to the patient with a comforting message, a certain kind of action (an action of care, we might call it) was made possible. In other words, the lab technician's (re)action made it meaningful for the patient to raise her concerns.

5.3. Organizational feasibility

A concern may be meaningful in the sense of relevant and actionable, but impossible to handle by the clinician receiving it (e.g. due to divisions in medical specialties and/or professional and organizational boundaries). With the second case we showed how a lack of knowledge about the infrastructure and distribution of care let the patient to raise concerns that were simply outside the scope of what the clinician could take action on. While the system succeeded in assisting the clinician in handling such a concern, by allowing her to quickly disregard it, the patient was not assisted in directing the *right concern* to the *right clinician*. As a result, the patient found his efforts and the system meaningless. Hence, concerns raised with an eHealth system need to be ‘organizationally feasible’. The concern has to be actionable by the receiving clinician or the system should support the clinician in re-delegating action to the appropriate actor.

6. Concluding discussion

We started by recognizing the shift from hospital information systems to eHealth and emphasized the new challenges that arise when extending the healthcare network to include patients as active, participating users. Informed by insights from medical phenomenology we accentuated how patients experience, live with, and focus on strategies to cope with illness in everyday life as opposed to how physicians understand disease according to medical knowledge and how physicians focus on objective facts and are guided by clinical goals of diagnosis and treatment. Together with case examples we demonstrated the importance of patients’ and clinicians’ different concerns and the need for appropriate alignment of these. That is, when designing eHealth systems to support collaboration between patients and clinicians it is particularly important to identify the concerns that are meaningful to patients and in turn which can be made (clinically) actionable and organizationally feasible to clinicians.

We emphasize the consequences of introducing eHealth into existing care networks and how it complicates the care, but also introduce opportunities for new forms of care where active patient participation improves clinical decision-making and the quality of healthcare. Our cases show how these endeavors can work together. Introducing a PHR for ICD patients and the involved professionals turned out to reproduce, and even underpin, existing challenges of empowering patients to engage more actively in chronic care. With early versions of

myRecord, the decisive gap between patients and clinicians was made more tension-filled and dissatisfactory for at least one part, often the patient. In these examples the system neither tapped into nor succeeded to support the alignment of concerns between patient and clinician. More specifically, myRecord failed due to a persistent mismatch between the respective patients’ and clinicians’ perception of what constitutes a topical and meaningful concern and subsequently appropriate action. With the final case, however, we show how the system succeeded in aligning concerns by facilitating a translation of the patients’ concerns into meaningful issues *and* making them organizationally and clinically actionable.

These somewhat contradictory outcomes underpin both the necessity of developing solid and empirically grounded design rationales for eHealth, as we believe to put forth with this paper, and the precaution not to perceive such design rationales as ensuring successful eHealth solutions. In practice, although the alignment of concerns between patients and clinicians may be supported by a certain eHealth system, the technology itself is never the only piece of the puzzle that needs attention. Patients’ perceptions, competences, and repertoires differ, just as do clinicians’, and the particular interpersonal relations play a crucial role in the possibility of aligning concerns. Thus, eHealth does not just affect existing patient-clinician relations, by disturbing or improving existing relations, but these relations also in turn affects how well eHealth may perform as a meaningful tool for collaboration.

We therefore advise to employ the design rationale *alignment of concerns* not only as a resource for the constructive reconfiguration of relations by means of technology, but also as a resource for being attentive to existing relations and practices that might already contain favorable conditions for the alignment of concerns and seek to support these.

Echoing research that suggests participatory design (and co-design) as a way ahead [9,11,26], we recommend to engage in participative design activities that employ an explorative, experimental, and interventionist strategy. As described above, we believe the participatory approach is a powerful resource in designing eHealth systems where actors do not share the same criteria of relevance and where the reconciliation of concerns benefits from being collaboratively identified and negotiated.

7. References

- [1] Ahern, D., Phalen, J.M., and Eaton, C.B. The role of eHealth in patient engagement and quality improvement. *eHealth solutions for healthcare disparities*. Springer New York, (2008), 75–92.
- [2] Andersen, T., Bjørn, P., Kensing, F., and Moll, J. Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents. *Int. J. of Med. Info.* 80, 8 (2011), e112–e126.
- [3] Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbin, K.A., and Straus, S.E. Personal health records: a scoping review. *JAMIA* 18, 4 (2011), 515–522.
- [4] Baird, A., North, F., and Raghu, T.S. Personal Health Records (PHR) and the future of the physician-patient relationship. iConference. ACM. (2011), 281-288.
- [5] Bath, P.A. Health informatics: current issues and challenges. *J. of Info. Science* 34, 4 (2008), 501–518.
- [6] Biro, D. An Anatomy of Illness. *Journal of Medical Humanities*, 33, 1 (2012), 41-54.
- [7] Charon, R. To Build a Case: Medical Histories as Traditions in Conflict. *Literature and Medicine*, 11, 1 (1992), 115-132.
- [8] Chen, Y., Cheng, K., Tang, C., and Siek, K.A. Is my doctor listening to me? CHI'13, ACM, pp. 2419-26, (2013).
- [9] Clemensen, J., Larsen, S.B., Kyng, M., and Kirkevold, M. Participatory Design in Health Sciences. *Qualitative Health Research*, 17, 1 (2007), 122-130.
- [10] Dedding, C., van Doorn, R., Winkler, L., and Reis, R. How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients. *Social Science & Medicine* 72, 1 (2011), 49–53.
- [11] Hardisty, A.R., Peirce, S.C., Preece, A., et al. Bridging two translation gaps: A new informatics research agenda for telemonitoring of chronic disease. *International Journal of Medical Informatics* 80, 10 (2011), 734–744.
- [12] Hartzler, A. and Pratt, W. Managing the Personal Side of Health: How Patient Expertise Differs from the Expertise of Clinicians. *Journal of Medical Internet Research*, 13, 3 (2011), e62.
- [13] Haux, R. Medical informatics: Past, present, future. *International Journal of Medical Informatics* 79, 9 (2010), 599–610.
- [14] Holman, H. and Lorig, K. Patient self-management: a key to effectiveness and efficiency in care of chronic disease. *Public Health Reports* 119, 3 2004, 239-243.
- [15] Hunter, K.M. Doctors' Stories: The Narrative Structure of Medical Knowledge. (1991).
- [16] Kensing, F. and Greenbaum, J. Heritage: Having a Say. In J. Simonsen and T. Robertson, eds., *Routledge International Handbook of Participatory Design*. Routledge. (2013).
- [17] Koch, S. Home telehealth—Current state and future trends. *International Journal of Medical Informatics* 75, 8 (2006), 565–576.
- [18] Lafky, D.B. and Horan, T.A. Prospective personal health record use among different user groups: results of a multi-wave study. (2008), 233–233.
- [19] Langstrup, H. Chronic care infrastructures and the home. *Sociology of Health & Illness*, (2013).
- [20] MacLean, A., Young, R.M., and Moran, T.P. Design rationale: the argument behind the artifact. 20, SI (1989), 247–252.
- [21] Montgomery, K. *How Doctors Think*. Oxford University Press, (2005).
- [22] Neuhauser, L. and Kreps, G.L. Rethinking communication in the e-health era. *Journal of Health Psychology* 8, 1 (2003), 7–23.
- [23] Oudshoorn, N. *Telecare Technologies and the Transformation of Healthcare*. Palgrave Macmillan, Basingstoke, (2011).
- [24] Öhman, M., Söderberg, S., and Lundman, B. Hovering Between Suffering and Enduring: The Meaning of Living With Serious Chronic Illness. *Qualitative Health Research*, 13, 4 (2003), 528-542.
- [25] Pickard, S. Knowing as practice: Self-care in the case of chronic multi-morbidities. *Social Theory & Health* 10, 2, (2012).
- [26] Pilemalm, S. and Timpka, T. Third generation participatory design in health informatics—Making user participation applicable to large-scale information system projects. *Journal of Biomed. Inf.* 41, 2 (2008), 327–339.
- [27] Shepherd, M. Challenges in Health Informatics. *HICSS'07 – 40th Annual Hawaii International Conference on Systems Sciences* (2007), 135-145.
- [28] Simonsen, J. and Robertson, T. *Routledge International Handbook of Participatory Design*. Routledge, New York, (2013).
- [29] Street, R.L., Jr, Gordon, H.S., Ward, M.M., Krupat, E., and Kravitz, R.L. Patient participation in medical consultations: why some patients are more involved than others. *Medical care* 43, 10 (2005), 960–969.
- [30] Tang, P.C. and Lansky, D. The Missing Link: Bridging The Patient-Provider Health Information Gap. *Health Affairs* 24, 5 (2005), 1290–1295.
- [31] Toombs, S.K. The Meaning of Illness: A Phenomenological Approach to the Patient-Physician Relationship. *Journal of Medicine and Philosophy*, 12, 3 (1987), 219-240.
- [32] Toombs, S.K. *The Meaning of Illness*. Kluwer Academic Pub, (1993).