Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents

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A B S T R A C T

Purpose: We investigate why clinicians experience problems interpreting implantable cardioverter-defibrillator (ICD) data when the patient is absent, and we explore how to re-introduce patients into the socio-technical setup of telemonitored interpretation practices.

Method: An action research study with a design interventionist perspective was conducted to investigate the telemonitoring arrangement for chronic heart patients with ICDs and to identify the nature of the collaborative practices involved in ICD data interpretation. We diagnose the main challenges involved in collaborative interpretation practices. These insights were used to re-design the socio-technical setup of the telemonitoring practices by designing and building a web-based, patient-centric, collaborative application, myRecord, to re-introduce the patients as active participants into the telemonitoring setup. Finally, we introduce myRecord at Copenhagen University Hospital and evaluate the new practices and the collaborative technology related to the transformed role of the patients.

Results: The interpretation of ICD data is a collaborative practice engaging clinicians and patients and involving three separate collaborative processes: interpretation of numbers; interpretation of general condition; and patient’s interpretation of own condition and ICD data. In a collocated setup, these three interpretation processes are entangled and seamlessly inter-related. However, in the current telemonitoring setup, only the interpretation of numbers process is fully supported, neglecting the two other processes, and, in particular, the role of the patient. By re-introducing patients into the socio-technical setup of telemonitoring through myRecord, our design acknowledges the collaborative nature of the interpretation process. However, re-introducing patients transforms their role, and leads to new transformed telemonitoring practices, different from both the current telemonitoring setup as well as from the collocated setup.

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1. Introduction

Health care is an inherently collaborative effort where multiple healthcare practitioners and patients collaborate in practices of diagnosing and treating health problems. Because of the collaborative nature of healthcare work, the technologies we design and bring to the setting should be thought of as collaborative technologies supporting collaborative work. Computer Supported Cooperative Work (CSCW) research is the "endeavor to understand the nature and requirements of cooperative work with the objective of designing computer-based technologies for cooperative work arrangements" [1, p. 11]. CSCW researchers have been investigating the collaborative practices within health care for two decades [2], yet the changing nature of health care, combined with new technological opportunities, continues to extend this research field and bring new challenges [3]. Implantable cardioverter-defibrillators (ICDs) are one of the new technologies changing healthcare practices for patients with heart problems. An ICD is an advanced pacemaker that can be implanted in patients at risk for sudden cardiac death due to ventricular fibrillation. It is designed to deliver electric shocks to restore the normal heart rhythm. The ICD also records data about detected arrhythmic events as well as selected overall conditions of the body. For example, some ICDs can provide information about rising fluid levels approximately 14 days before ordinary methods would detect the indications. The purpose of collecting these ICD data is to continuously monitor the chronic condition and to support decisions about whether or not particular interventions (e.g., change in medication or re-programming of the ICD) should be initiated.

Monitoring ICD data is basically a practice of collaborative interpretation where multiple healthcare practitioners and the patient together investigate the data, identify possible issues, and decide whether to take action. The monitoring activity traditionally took place collocated, where the patient traveled to the healthcare facility and advanced machinery read the ICD device, the output from which then formed the basis for data interpretation. However, in recent years ICD technology has started to include telemonitoring opportunities. Telemonitoring has transformed the practices of interpretation and use of ICD data, and some of the current ICD telemonitoring systems allow the patient to be located globally while being monitored locally.

We know that technology transforms practices in unanticipated ways [4]. However, because ICD telemonitoring technology is fairly new, its effects on the activity of data interpretation have not yet been documented. While investigating the telemonitoring practices, we quickly realized that one consequence of telemonitoring was that the patient became absent from the interpretation practices, which was identified as problematic for the clinicians. Thus, in this paper we investigate why clinicians experience problems interpreting ICD data when the patient is absent, and we explore how patients could be re-introduced into the socio-technical setup of telemonitored interpretation practices.

Applying action research [5], we initially found that ICD data interpretation in the collocated setup was, in fact, a collaborative practice between the clinicians and the patient, that it comprised three seamlessly entangled processes, and that the current socio-technical telemonitoring setup only supported one of these processes, neglecting the role of the patient. Next, we designed an add-on patient-centric web-application, myRecord, with the aim of re-introducing the patient into the data interpretation process. The new socio-technical setup was then evaluated by both the healthcare practitioners and the patients. In this way we went through a full action research cycle of understanding, intervening, and evaluating [6], and, finally, we reflected on the transformed role of the patient.

The paper is structured as follows. First, we present previous work on patients as active participants in telemonitoring practices and interpretation. Then, we present the action research methodology including data sources and methods of analysis. Further, we show the results in three parts: understanding the interpretation work, intervening through design, and evaluating the intervention. This is followed by a discussion and, finally, we offer a conclusion.

1.1. Previous work: collaborative effort in telemonitoring

Collaboration occurs when multiple people are mutually dependent in their work, and it “is constituted by the interdependence of multiple actors who, in their individual activities, in changing the state of their individual field of work, also change the state of the field of work of others and who thus interact through changing the state of a common field of work” [7, p. 4]. The interaction between healthcare professionals and patients in the process of monitoring chronic illnesses is a long-term, collaborative effort. However, most research on telemonitoring tends to neglect the collaborative aspect and instead focuses on how treatment can be more cost efficient [8,9], or how monitoring might reduce the risk of mortality among heart failure patients [10–13]. Moreover, research on
how IT might improve the communication and information access within home telemonitoring is sparse [14]. While we do appreciate the mainstream research in telemonitoring, we believe a vital element of telemonitoring is being ignored: the collaborative effort.

Few researchers [15,16] appreciate the collaborative engagement in telemonitoring practices and few have investigated the inevitable transformation in the cooperative work caused by new technologies. Kaplan and Fitzgerald [16] investigate remote intensive telehealth care and provide interesting observations, but they explore the collaborative practices between dispersed healthcare practitioners and not the monitoring of patients. Bardram et al. [15] found that telemonitoring technologies transformed the practices by changing the division of work between the physician and the patient, placing new work tasks on the physician in terms of time and effort used to monitor, and that the communication patterns were transformed from a contextual, rich conversation to asynchronous messages [15]. New technologies transform medical practice, and studies have pointed to how the integration of new technologies leads to redistribution rather than reduction of work [e.g., 17].

Patients are an essential part of the collaborative engagement in the telemonitoring context, and it has been argued that patients are able to act as diagnostic agents in such setups [18]. Being a diagnostic agent, essential work is redistributed from the healthcare professionals to the patient, and often this new type of work disappears from the formal descriptions of telemedicine [18]. Oudshoorn introduces the concept of ‘diagnostic agent’ to capture the invisible work done by patients in telemonitoring. She argues that “[p]atients are not just users of a new technology that requires instrumental skills, but should be considered as agents that have to perform all manner of articulation work required to make these new healthcare services work.” [18, p. 276]. She builds the concept on empirical work of heart patients, who are equipped with a new technology – an ECG recorder. The responsibility of selecting the right moment to make an ECG is delegated to the patient. Becoming a diagnostic agent thereby depends on self-learning and trust in their own ability to make the right choices [Ibid.]. When patients become “absent,” their condition is separated from the context of their bodies, and the “condition” becomes represented through particular forms of representation such as images and graphs [19]. This means that the healthcare practitioners must rely solely on representation to make sense of the context, which is a huge change from the practice in collocated settings.

Previous design-oriented research on telemonitoring practices suggests different web-based solutions for telemonitoring, where the patient and the healthcare practitioners, through one portal, can reach the clinical data collected in the patient’s home as well as the patient record [e.g., 20]. However, while these kinds of studies are mainly technically oriented, typically referring to laboratory installations, they do not take into account all of the organizational issues related to the real-life context that is included in our study. Even though previous design-oriented telemonitoring research tends to focus only on the technical aspects of the telemonitoring process, there is a trend in medical informatics [e.g., 21,22–24] toward more patient-centered approaches and the design

of computer supported cooperative systems [14, p. 570]. Our work is part of this trend.

1.2. Research setting: the CITH research project

The study presented here is part of the larger research project, Co-constructing IT and Healthcare (CITH). In this project, we explore communication and collaboration across institutional and professional boundaries in heterogeneous settings within healthcare. The CITH project analyzes existing collaborative practices among heterogeneous actors who manage patients with an ICD. The project aims at “designing, developing, and evaluating IT applications and services supporting the work of both healthcare professionals and patients” [25]. The authors are part of an interdisciplinary group with backgrounds in Cardiology, Health Informatics, Computer Science, and Sociology. We have also engaged ICD patients as active participants in defining the aim of the project as well as in its analyses, design, and evaluation activities.

1.2.1. The organizational context

The care for ICD patients involves multiple participants, including patients, relatives, general practitioners, lab technicians, bioanalysts, heart specialists, device specialists, nurses, clerks, social workers, etc. The main work takes place in three settings: the Heart Centre at Copenhagen University Hospital, patients’ homes, and local hospitals. The ICD patients from Denmark, Greenland, and the Faeroe Islands that are connected to the Heart Centre have the implantation and the device follow-ups conducted in Copenhagen even though some of these patients live far away. Patients not on the telemonitoring system travel quite far to get a device follow-up. It takes place every three months and consists of monitoring the ICD and taking action when it does not work correctly, or when it has to be re-programmed according to the patient’s changing condition. An increasing number of ICD patients have a telemonitoring setup at home that is able to read and send the status of the ICD to the Heart Centre. The local hospital’s responsibility is to stabilize the patient by checking and adjusting the medical treatment. This takes place during ambulatory visits every three months. However, the part of the CITH project presented here concentrates on the collaborative interpretation work performed by the healthcare professionals at the Heart Centre and by the patients.

2. Method

2.1. Action research

The relevance of expanding the medical informatics field toward a multi-disciplinary approach has been put forward convincingly [26]. Qualitative methodologies for the design and evaluation of technologies in healthcare are entering the field of healthcare informatics [22]. The methodology applied in this paper follows this tradition, emphasizing user-centric designs, and, in particular, we apply action research [6]. Action research comprises two iterative interrelated stages: diagnostics and therapeutics. The diagnostic stage involves a
joint analysis between the practitioners and the researchers of an experienced problematic situation, while the therapeutic stage involves the introduction of changes combined with an analysis of the effects of these changes [5]. In our case, the starting point was the clinicians’ statement that during ICD data interpretation practices they experienced that the absent patient was problematic; thus we initiated an in-depth qualitative investigation of the ICD interpretation practices. These investigations formed the diagnostic stage. Understanding why the absent patient was experienced as problematic, we then initiated the therapeutic stage of the research. Here we investigated, in joint collaboration with both the clinicians and patients, how it might be possible to re-introduce the patient into the socio-technical setup of telemonitored interpretation practices. This intervention took form as a combined design of both changed work practices and a new add-on technical application. Finally, we evaluated the intervention and the possible effects and consequences of such a transformed socio-technical setup. Action research seeks to contribute both to the practical concerns of a particular problem (the absent patient) and to the goals of scientific research (understanding the collaborative practices of ICD interpretation while designing collaborative technologies) by taking initiatives toward a joint venture between researchers and practitioners [27]. The joint effort was thus guided by the joint research question: Why do clinicians experience problems interpreting ICD data when the patient is absent, and how can patients be re-introduced into the socio-technical setup of telemonitored interpretation practices?

Action research within information systems and CSCW is well established, and even though there are multiple action research approaches, the fundamental activities and issues are similar [28-30]. In our work, the action cycle is divided into three main activities: (1) understanding interpretation work, (2) intervening through design, and (3) evaluating the intervention (see Fig. 1).

Understanding interpretation work is the part of our study that focuses on diagnosing the problematic issues experienced by the healthcare practitioners during ICD data interpretation in the telemonitoring setup. This process includes qualitative data collection, where we combine observations of work practices with interviews, identify the use of coordinative artefacts by various participants in particular situations, and reflect upon these findings together with our empirical partners.

Intervening through design is the second part of our study, where, based on the understanding achieved in the first part of the study, we initiate design activities together with the empirical partners. These activities include workshops with both patients and clinicians where together we develop mock-ups that are then turned into a web-based prototype. Evaluating is the third and final part of our study, where the designed prototype is placed within the actual practical situation of telemonitoring along with newly designed organizational practices. Evaluation includes activities such as educating the patients and clinicians about the transformed practices, as well as collecting data about the intervention and the consequences of the intervention. Because of the cyclic nature of action research, data analysis was continuously conducted in an iterative manner throughout the entire project. Results from, for example, observations and interview activities (understanding) were used in the initial prototype design (intervening), and then evaluated and discussed with patients and clinicians during workshops (evaluating). Thus, while the whole project enters one main action cycle guided by the research question, the main action cycle consisted of a large number of small action cycles, each entering the ring of understanding, intervening, and evaluating. Considering the criteria for action research, it is essential to understand that an action researcher cannot be a disinterested observer, but must act in practice to solve the experienced problematic situation while simultaneously observing oneself acting [32]. Thus, one of the key aspects of action research is intervention while collecting data about the intervention. Theory in action research is the analytical frame by which you investigate the domain. In our case the theoretical basis comprises the socio-technical approach, which stipulates that new technical systems cannot be understood as simply technical artefacts but should be understood in the context of use. We apply this theoretical approach when we examine the practices of interpretation as well as develop new designs supporting these practices. Theory in action research is also part of the results, so while we seek to solve the practical problem of collaborative ICD data interpretation, we also develop a theoretical framework of how to understand the practices of collaborative interpretation practices. In this way our theory about the domain is constructed during our investigations. Table 1 contains an overview of the data collection and activities forming the action research study. The setting of the intervention was designed as follows. Prior to the intervention, the socio-technical setup of telemonitoring at the Heart Centre consisted mainly of the telemonitoring system. Here, the bioanalyst can access various representations of patients’ ICD data. With the intervention we implemented a new socio-technical system, myRecord. myRecord is an ‘add-on’ web-application installed on patients’ PCs that runs separately from the telemonitoring system. The intervention spanned two days where 23 patients took part in the study.

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1 Action research typically involves cycles of: problem identification, planning interventions, executing actions, observing the outcome, reflecting upon the results, while simultaneously collecting data about the situations and the interventions [31].
Table 1 – Data collection and activities forming the action research study.

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
<th>Proportion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Included in the study</td>
<td>Involved in the co-construction of myRecord</td>
<td>4 cardiologists 7 bioanalysts 2 secretaries 23 patients (myRecord users)</td>
</tr>
<tr>
<td>Observations of work practices</td>
<td>Heart Centre: collocated ICD interpretation</td>
<td>8 patients (1 video documented)</td>
</tr>
<tr>
<td></td>
<td>Heart Centre: distributed ICD interpretation</td>
<td>9 × 4h observations (126 telemonitored patients)</td>
</tr>
<tr>
<td></td>
<td>Patients’ homes: daily practices</td>
<td>7 patients</td>
</tr>
<tr>
<td></td>
<td>Heart Centre: use of computer systems (lab systems, research applications, ICD register, patients records, ICD data)</td>
<td>5 × 4h observations</td>
</tr>
<tr>
<td></td>
<td>Local hospital: use of computer systems (lab systems, research applications, ICD register, patient records)</td>
<td>2 × 4h observations</td>
</tr>
<tr>
<td></td>
<td>Local hospital: patient follow-up</td>
<td>12 patients (video documented)</td>
</tr>
<tr>
<td>Formal interviews</td>
<td>Clinician interviews</td>
<td>8 w/cardiologists 2 w/bioanalysts 2 w/secretaries 1 group interview w/vendor</td>
</tr>
<tr>
<td>Informal interviews</td>
<td>Patient interviews</td>
<td>12 w/patient and relative 1 w/vendor consultant 5 w/bioanalysts 6 w/cardiologists 26 w/patients 3 w/secretaries</td>
</tr>
<tr>
<td>Workshops</td>
<td>Patient workshops</td>
<td>4 × 3h workshops (3 video documented)</td>
</tr>
<tr>
<td></td>
<td>Bioanalyst workshop</td>
<td>1 × 2 h 5 bioanalysts 2 researchers (video documented)</td>
</tr>
<tr>
<td></td>
<td>Clinician workshops (Heart Centre and local hospital cardiologists)</td>
<td>4 × 2 h 2–4 cardiologists 3–5 researchers 2 h</td>
</tr>
<tr>
<td></td>
<td>Demonstration of prototype for vendor</td>
<td>2 IT vendor consultants 3 × 8h workshops</td>
</tr>
<tr>
<td></td>
<td>Internal design workshops</td>
<td>Collection of all types of documents: lists, plans, letters, forms, etc.</td>
</tr>
<tr>
<td>Document and artefact analysis</td>
<td>Heart Centre and local hospital</td>
<td></td>
</tr>
<tr>
<td>Prototyping</td>
<td>Sketching, prototyping and building new designs</td>
<td>7 months – 4 iterations 1 part-time developer (387 h)</td>
</tr>
<tr>
<td>Intervention</td>
<td>Heart Centre: action research interventions</td>
<td>2 days of 3h 1 bioanalyst 1 cardiologist myRecord used by 23 patients in 4 weeks (video documented)</td>
</tr>
</tbody>
</table>

3. Results

3.1. Understanding interpretation work

Interpretation work is the work done by participants when exploring and explaining the meaning of particular observations while presenting the results in understandable terms. Interpretation work of ICD data is thus the work where clinicians explore the numbers and graphs collected by the ICD device. These numbers and graphs are represented by the ICD monitoring system, and clinicians explain these data in understandable terms for both the patient and other healthcare professionals. In this context, understandable terms refer
to what kind of action the patient and the clinicians should take based on the ICD data. Basically, the interpretation work can have six different outcomes: (1) re-programming the ICD device, (2) changes to the medication, (3) additional heart surgery (e.g., ablation), (4) replacement of the ICD device (e.g., battery replacement), (5) instructing patients (e.g., on how to act as an ICD patient), and (6) no actions needed. Thus, the main purpose of ICD data interpretation is to determine the appropriate action. Depending on which type of ICD a particular patient has, the data available for interpretation differs. However, all bursts, irregular heart rhythms, etc. are captured with date and time, enabling the creation of various time-accurate representations such as graphs and tables.

In the organizational setup we have investigated, the ICD data are available only at the Heart Centre. The interpretation work at the Heart Centre exists as two practices: collocated collaboration and distributed collaboration. In the collocated setting, the patient, the bioanalyst, and the cardiologist are all located at the Heart Centre, whereas in the distributed setting, the patient becomes geographically distant because of the telemonitoring setup.

3.1.1. Collocation: interpretation of ICD data

We are located at the Heart Centre, and an older lady is being examined. The bioanalyst asks the patient: “How are you feeling, and what kind of medication do you take?” The patient and the bioanalyst talk about the medication—the lady takes four different types of medication. Another bioanalyst reads the screen of the ICD telemonitoring system, while the patient holds the ‘stick’ (reader) near the heart. “What time is this? There are marks—February 9th, April 20th, and April 29th.” The patient says that she had not felt anything. She cannot remember these dates. Then the patient remembers: “Oh…by the way, I did wake up screaming a few weeks ago, but I did not feel it.” The bioanalyst says to the other bioanalyst: “How many ATPs—one on three and then electric charge, VTs” all of them—we need to call a cardiologist.” The bioanalyst turns to the patient and explains: “You had 3 VTs with ATP and electric charge on all of them. They were all during night time, maybe that’s why you did not notice. Maybe you had some bad dreams?” [...] After many examinations and discussions they summarize: “Well, we can say that the machine works as supposed to; however, the question remains: should we do anything?” To the patient they say: “Our cardiologist needs to check your medication.” The cardiologist leaves to consult another cardiologist concerning the medication. Just before the patient leaves the Heart Centre, one of the bioanalysts tells the lady that if she experiences anything again (such as nightmares) she should call them up. (Observation notes, May 2009)

The above snapshot illustrates the crucial activities that are part of the collocated interpretation practice. First, it is evident that although the Heart Centre’s label for the interpretation practice is device follow-up and thus focuses on the device, the engagement with the patient is not solely concentrated on the ICD data (i.e., the numbers, tables, graphs, and percentages read by the ICD monitoring machine). The ICD data, as represented on the screen on the device, is interpreted by the two bioanalysts. However, this interpretation of the ICD data is highly supported by the bioanalyst’s interpretation of the general condition of the patient, which, in many cases, is related to the medication list. The bioanalyst does not have electronic access to the medication lists, so this information is carried by the patient, who typically would bring out a piece of printed paper with the medication information. In all cases observed in the Heart Centre during device follow-up, the patient is asked: “How are you, and what medication do you take?” and the answer to these two questions provides the healthcare professionals essential and valuable information about how they should interpret the ICD data. It should be noted that the way patients answer these questions also affects the interpretation. For instance, if the patient is short of breath while answering, this is taken into account. During an informal interview with two bioanalysts, they explained that the patient’s overall condition highly influenced their interpretation:

In cases where a patient expressed his or her overall condition as feeling good, then even “bad” data is taken less seriously, while in cases where the patients respond they feel bad, the healthcare professionals will take “good” data more seriously and go deeper into the interpretation. (Informal interview with two bioanalysts, October 2009)

Thus, in cases where the ICD reports OK, but the patient expresses feeling bad, lack of sleep, lack of breath, etc., the bioanalyst will not simply turn the patient away. Instead, they take the complaints of the patient seriously and take action. Secondly, the snapshot also points to another essential activity providing crucial information important for the practice of interpreting ICD data, namely the patient’s own interpretation of the ICD data. In the example, the healthcare professionals ask the patient about specific dates where the ICD had reported events. First, the patient cannot remember these dates, but then suddenly she remembers waking up screaming in the middle of the night. This explanation helps to make sense of the data, and the healthcare professionals interpret the experience of screaming as “bad dreams” related to the events marked in the ICD data, reading that the device had calculated risks of heart failure and then delivered a jolt of electricity to the heart a number of times.

So while device follow-up in collocated settings is about (1) interpreting the ICD data read by the ICD monitoring system and represented on the screen and printouts, the process of interpretation also includes information about the (2) patient’s general condition as well as (3) the patient’s interpretation of his or her own condition and ICD data. These interlinked processes of interpretation all together form the foundation for what actions would be appropriate in particular situations. Should they change the medication, should they re-program the device, or is the existing treatment accurate?

Summarizing, there are three main processes of interpretation going on during device follow-up in the collocated setting:

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2 Anti-Tachycardia Pacing (ATP) is a fast-pacing treatment for ventricular tachycardia (VT).

3 Ventricular tachycardia (VT) means fast heart rhythm and is potentially life-threatening because it may lead to sudden death.

4 Ventricular fibrillation (VF) is an uncoordinated contraction of the cardiac muscle of the ventricles in the heart. It is a medical emergency requiring immediate interventions due to high risk of sudden cardiac death.
the interpretation of numbers provided by ICD device data (as in graphs, diagrams, and percentages); the conversation with the patient about the general condition; and the patient's own experiences and thus interpretation of his or her own condition and ICD data.

3.1.2. Distribution: interpretation of ICD data

The system has detected two patients “with events”; however, the bioanalyst quickly browses through the information provided on these, but there is nothing of note. The browsing consists of opening the information on the screen, examining the values of certain data while examining the curves and graphs—is it stable or not? (Observation, May 2009)

The bioanalyst prints out the schedule for the day and sits by the computer screen logging onto the telemonitoring system. The telemonitoring system has pre-sorted the patients according to the system’s algorithm. Thus, all of the patients that the algorithm has sorted as possible candidates for further examinations will be labelled as patients with “events.” However, all of the patients with an event are quickly dismissed as “no action needed” by the bioanalyst, and, interestingly, it is among the remaining patients that the bioanalyst identifies the patients that need further examinations.

The interesting observation here is the issue of sorting the patients. The telemonitoring system has done a pre-assessment of the data automatically and has placed the patients with registered events at the top of the list of patients. Here it is essential that the bioanalyst, after quickly browsing the ICD data from these particular patients, determines that the ICD data on these patients does not lead to particular concerns. Instead, the observation shows that investigating the ICD data sent by the telemonitoring system when sorting and selecting requires professional evaluation by a healthcare professional.

More patients have sent their ICD data, and the bioanalyst has sorted the patients, finding two that she decides to discuss with a cardiologist. The cardiologist sits next to the bioanalyst and they investigate the computer screen in front of them. “Look here [pointing to the screen]—it falls. It looks irregular and there are long periods. Then it becomes faster . . . 320 . . . then back.” They discuss back and forth while trying to interpret the data. They are interrupted during their interpretation. First the bioanalyst is called away to the examination room, and then the cardiologist is called away to the operating room. The computer is left alone. The cardiologist returns. She browses through all of the data. The bioanalyst returns. “Here is one episode, are there more? It breaks . . . then the next episode, where it ramps . . . then it burst.” The bioanalyst is supporting the cardiologist in reading the numbers and measurement. They talk about changing the medications. The patient had three incidents since March—they could ask the local hospital. […] The cardiologist decides to telephone the patient, asking him to contact the local hospital.” (Observation, May, 2009)

The snapshot above illustrates the processes involved in interpreting ICD data when the patient and the healthcare professionals are geographically distributed and telemonitoring technology is applied. We see that the interpretation of the patient’s condition based on the ICD data requires profoundly varying amounts of work from the healthcare professionals. In some situations the condition of the patient is routinely and reliably determined based solely on the incoming data from the ICD. The healthcare professionals need no additional information to take proper action, and therefore no contextual information describing the patient in further detail is called upon. However, in other cases, the bioanalyst selects particular patients, who she decides to discuss with the cardiologist.

In the cases where the ICD data indicate problematic situations influencing the life of the patient, the geographical distance between the healthcare professionals and the patient complicate the interpretation practice. In the snapshot, we see how the bioanalyst and the cardiologist together interpret the ICD data through discussions and arguments. During the selected episode, the two healthcare professionals debate whether to change the medication of the patient; however, they lack access to the existing medication of the patient. The updated information about medication is in the local hospitals treating the patient. Exchange of medication information is clearly an issue for the people involved in the monitoring and treatment of patients with ICDs. In most cases, the exchange of information is done with the patient as a medium, transporting a folded piece of paper with the current medication record between healthcare professionals. In the case of telemonitoring, it is clearly problematic that the healthcare professionals do not have access to medication information, and in the episode reported here, they decide to telephone the local hospital for the information. However, further in the episode, it also becomes clear that they do not have access to change the medication. Changing medication is, in collocated settings, done by the cardiologist writing a prescription for the changed medication and handing this piece of paper to the patient. This is not possible in the telemonitoring situations. Given this complexity, the episode ends with the cardiologist deciding to telephone the patient and asking the patient to contact the local hospital. Here it is clear that the responsibility for taking initiative based on the interpretation of the data is distributed to the patient. In addition, this results in the patient receiving the complex task of explaining to the local hospital why he or she is contacting the local hospital. What was the issue with the ICD data, since the patient is contacting the hospital?

We see here how the entangled interpretation processes become detached from each other in the telemonitoring situation. In the collocated setting there were naturally attached connections between the numbers, the general condition, and the patient's interpretation; the distributed setting is distinctly different in the way that the collaborative effort from the patient is missing, thus the two interpretation processes concerning the general condition and the patient interpretation disappear, increasing the complexity in interpreting the ICD data for the healthcare professionals.

3.1.3. Implications for design: interpretation involves three entangled processes

In our empirical study, we found three main processes involved in the practice of interpreting ICD data. First, interpreting ICD data involves processes where healthcare professionals direct their attention toward the actual numbers, figures, tables, graphs, percentages, and diagrams
represented on a computer screen or printed out on paper. We will label this process interpretation of numbers. Second, we found that interpreting ICD data involves processes where healthcare professionals direct their attention toward the patient's general condition by asking the patient questions such as “how are you?” and “what kind of medication do you take?” In this practice, the patient collaborates by presenting the paper version of the medication list in the collocated situation. We will label this process interpretation of general condition. Finally, we found that interpreting ICD data involves processes where the healthcare professionals direct their attention toward the patient's own interpretation of both the condition and the interpretation of the ICD data. This process we label patient's own interpretation of condition and ICD data.

In the collocated setting, these three processes are entangled into one coherent practice of interpretation conducted as a collaborative activity between multiple healthcare professionals and the patient. Moreover, in many of the empirical observations, the patient family—or others accompanying the patient to the Heart Centre—were also included in the practice of interpreting data. Thus, interpreting ICD data is clearly a collaborative activity requiring highly specialized expertise in reading and interpreting the data as well as access to additional information about the patient.

In the distributed setting, the three processes of interpretation were not entangled and did not inform each other. Instead, it was clear that the existing telemonitoring system only supported one of the three processes, namely the interpretation of numbers. While the interpretation of numbers was adequate in all the cases where no action was required, it proved problematic in more complex cases. To solve these incidents, much detective work was required by the healthcare professionals. It also emerged from our empirical observations that not only did the lack of access to interpret the general condition and to the patient's own interpretation increase the complexity of the interpretation practices, it also shifted the responsibility for acting on the problematic condition detected by the healthcare professionals' interpretation of the ICD data.

The effort required for interpretation and investigation in the telemonitoring setting varies between cases, but in general, two types of patient groups were detected. The largest group of patients, Group A, comprises cases where the bioanalyst decides that the ICD data are sufficient as information to determine the appropriate action. The smaller group, Group B, are patients where the bioanalyst decides that the ICD data are deficient as information to determine the appropriate action, thus additional information is required.

For the Group A patients, each “visit” takes less time than if the patient was physically present. The more complicated cases, however, take much detective work to solve. Thus, patients in Group B are the group of patients that take by far the most resources in the telemonitoring setting.

Based on the above study of the work practices involved in the interpretation of ICD data, we found that our design should re-introduce the patient into the collaborative interpretation practice in the distributed setting in order to re-convene the two interpretation processes that disappeared with the telemonitoring setup: patient’s general condition and patient's interpretation of own condition and ICD data. Moreover, the design should support the interpretation work, especially in the cases of patients in Group B, which are the most resource-demanding cases of interpretation.

3.2. Intervening through design

Informed by the implications for design, myRecord was designed and built as an add-on, patient-centric web-application with the intention to actively re-engage the patient in the process of interpretation, and, in particular, the processes of patient’s general condition and patient's interpretation of own condition and ICD data.

With myRecord, we enable patients to flag attention, write in free text, and select medical categories to communicate their experienced symptoms. Patients can also create and approve their own detailed list of medicine, which then becomes available to the remote healthcare professionals. The bioanalysts and cardiologists can dictate messages and provide additional ICD data as a reply to the patients' comments and ICD transmission. In this way it supports asynchronous dialogue where patients' interpretation gets re-introduced though text and medical categories, while the healthcare professionals can respond by audio and text. With the design, we attempt to transform the current telemonitoring setup into a shared practice of interpretation, which employs the patient’s own individual interpretation. By implementing myRecord into the distributed practice of interpretation, we intervene to explore and experiment with a re-organized telemonitoring practice. In the following we present the modules of myRecord that are designed to support collaborative interpretation work.

3.2.1. myRecord's modules

There are two modules of myRecord that support the interpretation of general condition and patient's interpretation of own condition and ICD data (see Fig. 2):

- Medicine List – a patient-generated, detailed, web-based list of medicine, which is editable and approvable by the patient.
- ICD Readings – a list of all scheduled ICD readings. Each reading includes a component where the patient can enter three levels of contextual information: (1) flag attention, (2) raise questions and describe experiences in free text, and (3) communicate symptoms using medical categories. Additionally, each patient can access the healthcare professionals’ reply as audio, text, as well as a limited amount of ICD data values.

3.2.2. The Medicine List

With the Medicine List, patients can create a digital version of their medicine list, which most patients already have in memory or carry around on a piece of paper. It is designed

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5 myRecord is a prototype of a patient-centric web-application that includes multiple features. To mention some, there is a module entitled ‘LogBook,’ which is designed for patients to keep an online diary, record symptoms, and write and organize their anamnesis. Another module, ‘Profile,’ enables patients to manage contacts, preferences, and personal information. A third module, ‘Consultations,’ is designed for patients to prepare for consultations, thereby qualifying both cardiologist and patients for a better dialogue.
3.2.3. ICD Readings – three levels of contextual information

ICD Readings is designed specifically to support a collaborative interpretation process for both patients and healthcare professionals. It holds a list of all previous and future scheduled ICD readings where each reading links to a page that has two components. One component, “Comment Your Reading,” is designed to let the patient enter contextual information on three levels after having made the transmission, whereas the other component, “See Reply,” is designed to let patients access the healthcare professionals’ reply as audio, text, as well as a few selected ICD data values. The “Comment Your Reading” component consists of three nested levels of contextual information. Initially, the patient is asked: “Has your situation worsened or are there significant changes since the last reading?” The patient then chooses either to communicate that everything is OK by clicking the button “Save and Send” or that the situation has changed, wherein expanded possibilities for explanation are revealed. We label this the first level of contextual information since the patient has the option to “Flag Attention” and thereby, with little effort, express that he or she is aware of something in relation to the ICD reading that needs the attention of a healthcare professional. At the second level of contextual information, the patient can describe their experience in free text. This option provides patients with the opportunity to use individual wording, expressions, and ways of formulating their interpretation of their own condition and ICD data. The last step is the third level of contextual information. It consists of three text fields where the patient can enter their morning weight, blood pressure, and heart rate. It also includes nine sets of checkboxes where the patient can select medical symptom categories such as “chest pains,” “shortness of breath,” or “fainting” and whether it appears during heavy or light physical exercise, no physical exercise, etc.
The final component presents the healthcare professionals’ reply to the reading, i.e., the result of the healthcare professionals’ interpretation. The component is two-fold, showing both a standard reply on the reading (i.e., everything is fine, please contact us, etc.) and selected values from the ICD reading. The selected values are “battery level,” “detailed information on episodes” (if any), including date, time, and type (pacing or shock), and a statement on the “status of the electrodes.” The statement on battery level falls into three categories: at least five years left, at least two years left, and at least three months left. The last category indicates that a replacement of the battery should be scheduled within the following couple of months (the battery is replaced by renewing the whole ICD). Moreover, the healthcare professionals can, as mentioned, dictate a personal audio reply that is automatically transcribed and presented textually within this component.

3.3. Evaluating the intervention

The intervention was carried out over a period of four weeks and included 23 ICD patients. All patients were scheduled for an extra ICD transmission with the telemonitoring setup, and 21 managed to use myRecord to engage in the new collaborative practice of interpretation. One patient was unable to carry out the task because of a re-scheduled vacation and another excluded himself from the study by neither making a transmission nor using myRecord. Out of the 21 patients, 18 were initially classified as Group A and the remaining 3 as Group B. Out of the 18 patients, 10 confirmed the classification as Group A. However, 8 of the initially classified Group A patients ended up as classified Group B patients. We tested myRecord at the Heart Centre by observing transformations of the current distributed interpretation practice by requiring the healthcare professionals to take the patients’ recordings into account after their initial interpretation of the ICD data. In this way we were able to observe how the patients’ recordings changed the current telemonitoring practice. The observations of the healthcare professionals’ use of myRecord took place over two days at the Heart Centre.

3.3.1. Hidden Group B patients revealed

Nearly half of all patients from the experiment (10 of 21) were classified by the bioanalyst as Group A patients (“nothing to note” or “everything looks fine” and therefore resulting in a “no action is needed” reply). In these cases, the bioanalyst based her interpretation solely on the transmitted ICD data, thus only on the interpretation of numbers process. Every patient in this group also used myRecord to signal whether or not their situation had changed. They therefore completed the use of myRecord with no messages and no pre-answered questions for the healthcare professionals. During the experiment, this relatively small piece of patient-produced information (flagging no attention) proved to work as an additional confirming statement that reassured the bioanalyst of her original conclusion. Thus, the patients’ statement on their own condition (no news to report) together with the bioanalyst’s original interpretation based on the numbers formed a simple collaborative interpretation practice. The bioanalyst could, with added confidence, continue her work based on a more informed and qualified decision.

In the cases where the patient “flagged attention,” it also impacted the work of the bioanalyst. In cases where the bioanalyst initially concludes “no action needed” based on the device data alone, she immediately decides differently when confronted with the patient’s written remarks in myRecord. One example is a patient who writes: “I sometimes feel tender in the area where the ICD sits. It might just be me whining, but it feels as if it’s the electrode [the lead connecting the ICD to the ventricle of the heart] that’s attached to the vein. It pinches me” (man, age 56). The patient’s remarks and the indication that it might have to do with the lead causes the bioanalyst to respond by dictating a message to him, where she explains, “from your comment I can see you are having some problems with your pocket [the implanted ICD is hidden in a little pocket-like breach in the chest]. We are always concerned about the condition of the ICD and the leads, and you feel a little sore. We might talk about moving it a little” (bioanalyst’s dictation, April 2010). This scenario illustrates how information from the patient describing an aspect of his own condition triggers and helps the healthcare professional to provide the patient with a calming answer, and it also provides an opportunity to teach the patient how to manage and react to important symptoms. Moreover, we see that the use of myRecord spurs a collaborative effort between the patients and the healthcare professionals.

In another case the bioanalyst initially classifies a woman (age 62) into Group A, but changes her mind based on the patient’s information from myRecord. The patient documented in myRecord that she had experienced a “fluid alarm” on two specific dates. The bioanalyst quickly locates the date within the numbers and graphs and reiterates the values in her system to conclude the patient is right. As a reply to the woman’s experience, the bioanalyst makes an elaborate dictation, explaining how the patient should stay alert the coming week by tracking her weight and contact her GP if the situation changes.

The three examples illustrate how the patient’s own interpretation of condition and ICD data, mediated by myRecord, can have important consequences for the practice of interpretation. The patients’ decision-making and ability to formulate their experiences provide the basis for establishing a remote collaborative process of interpretation.

3.3.2. Sufficient contextual information

In the evaluation of myRecord, we found that several patients made use of the healthcare professionals’ pre-made symptom categories as a means of communicating their experienced symptoms. When patients use the symptom categories they collaborate by making sufficient contextual information available for the bioanalyst and the cardiologist so they can make an informed decision.

In one case the bioanalyst classifies a patient into Group A based on device data. The patient writes: “under physical training at RH Monday [date] in the period around 3.15pm–3.45pm – several near-syncopes and palpitation” (man, age 61). Here the patient describes loss of consciousness and abnormal heartbeats. The patient also asks questions about the ICD data at particular times. This information makes the bioanalyst re-examine the device data, conclude that nothing is recorded, and explain that the patient’s experience is not visible in the transmitted data. She then revisits his recordings in myRecord.
and finds the patient’s selection of two medical categories (level 3): “Heartbeats – Yes, under high physical activity” and “Near faint – Yes, under high physical activity” (man, age 61).

This information changes the bioanalyst’s previous decision. She navigates to the values in the patient’s device data, which describe what zones the patient’s ICD is programmed to monitor. She uses the patient’s textual description and selected categories to conclude that the monitor zone is not set up to record the patient’s experienced event. She calls a physician for support and collects the device paper record. When the physician arrives, they use both levels of the patient’s contextual information and compare it with the device data and information from the device paper record. They conclude and dictate two messages where they explain that his device is not programmed to monitor what he experiences, and they recommend that he make an appointment at the Heart Centre in order to adjust the monitor zone. As such, the patient’s work of questioning and informing the bioanalyst and the cardiologist rightly impact the result of the interpretation process. The patient succeeded in providing sufficient contextual information to support the healthcare professionals’ work of re-interpreting the device data.

3.3.3. ICD data made understandable

In the case of a woman (age 56) classified by the bioanalyst into Group A, the bioanalyst selects the device data to be presented in myRecord and notes that a replacement of the battery might soon be required. She communicates this by selecting the label “minimum 3 months left” in myRecord. The bioanalyst decides to use myRecord to dictate a message where she explains in more detail the reason behind the label and how the patient is to manage the situation “when the device starts beeping.” The bioanalyst dictates, “We can tell from your ICD that you’ll soon start beeping. It may be within the next six months to a year or even 1.5 years. But because the value of the battery decreases in stages, we cannot say exactly when it will be. You should just be aware that when it ‘beeps,’ you should call us. Then there are three months left on the battery before we need it changed” (bioanalyst’s dictation, April 2010). The situation is interesting for two reasons. Prior to the introduction of the new telemonitoring practice, patients were (in the collocated setup) informed about the level of battery left on their device, and, in the case of “3 months left,” they were given guidance and explanation similar to the above example. However, in the new practice, the Heart Centre do not to inform patients on their battery level because, as the bioanalyst explains, “it’s simply not doable for us if we were to phone every patient upon every ICD scan, just to inform them on their level of battery. They already know that they should call us if their device starts beeping” (Informal interview with bioanalyst, April 2010). The bioanalyst knows from previous experience that labelling batteries “at least three months left” often causes anxiety and confusion for some patients. But the distributed nature of the telemonitoring practice has forced them to skip informing patients about batteries to avoid overhead work. The case illustrates how the new design holds the opportunity to re-introduce important but otherwise disregarded elements of the interpretation process. Specifically we see how the dictation feature in myRecord serves additional purposes, for example, as a feasible and convenient way to communicate important messages while still preserving the benefits of asynchronous verbal communication. Patients are thereby helped in interpreting their own condition by ICD data being made (more) understandable.

3.3.4. Support for patient’s own interpretation

During the evaluation we found that some patients used myRecord to support their own work of interpretation and self-diagnosis. Instead of simply commenting on experiences to aid the bioanalyst’s reading of device data, some patients used myRecord to ask the bioanalyst to provide device data to them.

In one case a man (age 60) flags attention and asks how much his ICD has paced since last transmission. The bioanalyst responds by dictating an answer where she includes the value and that it is her interpretation that the ICD probably paces at night. Another patient writes: “Have NOT heard ALARM the last two mornings (after continuous alarm in 51 days)– is it correct? (Or have I become more deaf and/or battery flat?)” (man, age 62). The bioanalyst revisits the ICD data and responds by dictating a message where she confirms that the alarm has been off the past two days and calms him by telling him not to worry.

In another situation the bioanalyst found an episode in the ICD data. The patient (man, age 65) also flagged attention and described his experience and the date of the episode (using both the free text and the medical symptom categories). However, the event in the ICD data is different, and the bioanalyst decides to record a message where she recommends that he make an appointment with the Heart Centre to get his ICD re-programmed with an extra feature. The reply included the date and time of the recorded episode. We later learned that the patient himself correlated the time of the recorded episode with an incident where he was asked to “give it all you got” in a cardiac stress test in another research project. He later informed us: “This is therefore a situation where I gave myself physically to the fullest. [The physician] said that I could safely exercise. The question is now: Can I?” (man, age 65’s logbook entry in myRecord, April 2010). In this way the bioanalyst’s reply supports his own interpretation and makes him actively question his treatment and the physician’s advice.

3.3.5. Use of Medicine List

The paper-based medicine list was an intricate part of the interpretation practice in the collocated setup. The patient would carry the folded piece of paper with the medicine information to the Heart Center and this information would be included in the interpretation process. In the telemonitoring setup the healthcare professionals lack access to the medication list. In myRecord we designed for patients to create, update, and approve an online shareable Medicine List with the ambition to test whether this list could support the healthcare professionals in their interpretation practices. Surprisingly, we found that the bioanalyst purposefully disregarded the Medicine List doing the evaluation. In one case, a patient (woman, age 60) was initially classified in Group A, but in myRecord she flagged attention. In the free text field she explains that her medicine was changed by her local physician. She also provides a full list of her current medication. The bioanalyst does not even glance at the Medicine List but immediately records a audio message: “[.] Hi [the woman’s name],
it’s about the comment you wrote in myRecord about your medication. I can only say yes/OK for it, since we do not interfere with what they do in research [another medical research project].” (bioanalyst, dictation in myRecord, April 2010). In this way, the bioanalyst explains the responsibility related to medication changes and does not use the information in the list. During the intervention the bioanalyst explains about the use of medication informations:

“So, our problem right here is that, we type all [medication information from the patient’s medication list] into a [medicine management system] and then we go to the ICD Registry [national online ICD/pacemaker information] and type it again. (…) If the patient is physically present we always ask: ‘what medication do you take?’ The problem is that we don’t [type in medication information] in the [telemonitoring setup], because we can’t telephone each patient and ask about their medication. We [bioanalysts in the telemonitoring setup] don’t use [medication information] for anything; it is only for physicians that might need [the information]” (bioanalyst, observation, April 2010).

Here, the bioanalyst explains how the telemonitoring setup changed the practice surrounding medication, by re-organizing practices to disregard medication information because of the lack of access to this type of information. The absent patient caused absent medication information, thus forced the bioanalysts to skip the task of updating the national ICD registry. We found that in the telemonitoring setup, it was only the cardiologists who were interested in medication information, where in the collocated setup it included the bioanalysts. However, in a few cases where the healthcare professionals had access to medication information using myRecord, we did not see any cases where the cardiologist asked for the medication list. However, this might be due to the previously changed practices caused by the telemonitoring setup, where the cardiologist had learned to do without such information, since these are no longer available. More studies are required to determine whether medication information is essential or not during telemonitored interpretation practices.

4. Discussion

In our study, in the same way as Bardram et al. [15], we investigate the transformed practices caused by telemonitoring, and as Bardram et al., we see how the rich collocated conversations between the patient and the healthcare practitioners were reduced; not to asynchronous messaging as Bardram et al. found, but to one-way communication of sending bodily device data and getting a short reply. The previous collaborative process of interpretation in the collocated setting was reduced to data transmission. However, whereas the latter study [15] found that the patient became more involved in the interpretation of the data, our study showed the opposite. Namely, our study showed that the patient became passively disengaged and more distant from the data interpretation process. This disengagement due to the socio-technical setup of telemonitoring affected the ICD data interpretation practice by neglecting the patient’s vital role in general, and in particular, the patient’s own interpretation of the general condition and the ICD data. Interestingly, we found that that the disengaged patient was problematic for the healthcare practitioners, because they lacked essential information for interpreting the data, in particular, for the Group B patients, where the available device data was not sufficient to determine the appropriate action. Our design intervention was designed specifically to deal with this problem, bringing additional contextual information to the healthcare practitioners supporting the ICD data interpretation and re-introducing the patient as a collaborative partner. In the evaluation of the design intervention, we found that myRecord did provide additional useful contextual information enabling the decision for appropriate action for the Group B patients. In this way our design did make the work of interpretation more collaborative; however, we question if this re-designed practice (where the patient contributes with additional information) can be labelled as collaboration or as mere transmission of more data?

If we look at the three different levels in which the patient can provide the additional contextual information within myRecord, one could argue that simply flagging attention or filling out the medical categories are practices where the patient simply delivers more data and not an act of collaboration. Collaboration requires that the actors are mutually dependent in their work [1], thus the question is whether the patients and the healthcare practitioners are mutually dependent on each others’ actions? Given that the healthcare practitioners were able to conduct their work before the introduction of myRecord without any involvement of the patient beyond providing the bodily data, one could argue that the patient and the healthcare practitioner were not mutually dependent in their work prior to myRecord. However, with the introduction of myRecord, when the patients flag attention, they change the state of their individual work (their involvement in the data interpretation is not simply providing bodily data). The question, then, is whether this individual activity (flagging attention) also changes the state of the work for the healthcare practitioners and thus the common field of work? During the evaluation of myRecord we saw how patients originally categorized as belonging to Group A (sufficient information) were re-categorized to patient Group B (deficient information) by the bioanalyst as a result of flagging attention, as was the case with the ten patients who chose not to flag attention. This points to how even a small amount of information can change the state of the common field of work. The collaborative aspect of the common field of work (the ICD data interpretation) is thus re-introduced by our design intervention. However, it was also clear that the patient’s active role in the new transformed collaborative practice comes in different forms depending on the level of involvement the patient chooses.

At the lowest level of involvement the patient simply flags attention, which is used by the healthcare practitioners to re-evaluate whether their initial categorization of the patient is accurate. Then, at the second level, the patients have the opportunity to express, using their own language, what they think might be relevant for the ICD data interpretation practice, and at the third level, the patients volunteer their own diagnosis of their condition, applying the standardized medical categories. There is no question that all of these levels of involvement change the state of the common field of work, therefore they are all part of the collaborative practice. How-
ever, we saw how the collaborative practice took different forms.

We saw that, in the case of Group B patients (where the ICD device data are insufficient to make a decision), the additional contextual information provided by the third level of information (the standardized medical categories) was sufficient for the healthcare practitioners to make a decision, as in the case of the patient (man, age 61) who used the medical symptom categories. In this way, the collaborative interpretation practice ends quickly with a decision of appropriate action. While this form of collaboration was intended by our design, we also detected two other intriguing forms of collaborative activities caused by our design: inclusion work and self-diagnostic work.

Inclusion work is work that healthcare professionals do when educating the patient outside of training sessions, such as comforting and reassuring patients about their abilities to master new technology, thereby turning potential non-users into users [18, p. 280]. Inclusion work for ICD patients involves telling the patients how to react to different alarms set off by the ICD, for example fluid or battery alarms. In the collocated setting, inclusion work is an embedded part of the collaborative interpretation that unfolds in joined conversations with the patients at the Heart Centre. However, in the distributed telemonitoring setting prior to the introduction of myRecord, inclusion work disappeared from the ordinary activities. With the introduction of myRecord, we unexpectedly found that inclusion work was re-introduced, for example, in terms of explaining ICD battery state. Here, based on her experiences with patients’ misunderstandings, the healthcare practitioner translated the ICD battery state, “at least three months,” into understandable language for the patient within an audio recording using myRecord.

Self-diagnostic work is the work involved when the patient is actively engaged with the diagnostic work usually done primarily by the physicians. This type of work serves to distinguish and identify how particular bodily experiences can be interpreted. When the patients are asked to apply the standardized medical categories within myRecord to determine the current condition of their health, they are asked to take part in the diagnostic work. We saw that patients took this task seriously. Besides providing additional contextual information, they also played an active role using myRecord and asked the healthcare practitioners direct questions, for example, to confirm their own interpretation of a stopped alarm or to use the ICD data to question physicians’ recommendations.

We argue that the socio-technical setup of myRecord re-introduces the critical role of the patient, thus bringing back the collaborative aspect of ICD data interpretation practices. The consequence of this re-introduction is that the patient is situated as a diagnostic agent and the two processes, interpretation of general condition and patient’s own interpretation of condition and ICD data, which were otherwise lost in the distributed setting, reappear in the telemonitoring setting through the design intervention with myRecord. By intervening, we probe into ways of re-positioning the patient as a reliable and valuable diagnostic agent, thereby challenging the dominant logic of care [33] while still maintaining the benefits of remote monitoring in terms of saving time for patients and healthcare professionals. Patients are re-introduced as technologically empowered actors with increased expectations toward taking part in their own treatment. The patients become actively engaged and are expected to take on an increased workload to realize the full potential of the new design. The evaluation showed that the majority of the patients were willing to take on that workload, especially in situations where they saw that as a strategy for receiving more elaborate feedback from the healthcare professionals’ interpretation. Patient-generated content makes for a new practice that renders patients more responsible, and consequently more disciplined actors [34], with increased expectations of active membership attached. At the same time, however, it raises questions still not fully answered, neither in our study nor in the literature, about the responsibility and practicalities of healthcare practitioners to act upon critical symptoms provided through designs like myRecord in a timely manner.

5. Conclusion

Earlier studies [18] show that including the patient in telemonitoring practices is vital; however, the patient needs time and effort to become a skilled, active, and responsible participant able to engage in the interpretation process. When the patient is reduced to representations such as images and graphs, the essential cooperative potential between the healthcare practitioner and patient when interpreting the ICD data collocated disappears. The invisible work of the patient involved in interpreting practices is missing. While the reduced representation might be adequate in some situations, it seriously “disables” the data interpretation process in situations of uncertainty. Here the patient’s active role as diagnostic agent is needed so that the representation becomes adequate “to speak” for the patient [19]. We designed myRecord to re-introduce the patient in the interpretation process by providing the patient the opportunity to add contextual information to the partial representations captured and measured by the ICD-monitoring system.

New technologies involved in the monitoring and treatment of chronic heart patients with ICDs make it possible to transform the previously local practices of interpreting ICD data into a globally distributed activity where the patient and healthcare professionals are geographically distributed. However, before embracing these new opportunities, we must examine the existing local practices of interpreting ICD data, ensuring that the new technologies enable rather than constrain these practices. Based on our observational study, we conceptualize the ICD data interpretation practice as three entangled processes: (1) interpretation of numbers, (2) interpretation of patient’s general condition, and (3) the patient’s own interpretation of general condition and ICD data. Moreover, we found that the current telemonitoring system only supports the first process of interpretation, leaving out the two others.

Our socio-technical design intervention re-introduces the patient and takes the collaborative aspect of the interpretation practice seriously. We saw how our design intervention managed to include the two otherwise lost processes of ICD data interpretation, as well as how the patients went from passive bodily device data sources to active diagnostic agents. We believe that this approach to increase the participation of the patients in telemonitoring situations forms the future for
Summary points
What was known before the study:

• Telemonitoring transforms healthcare practices in unanticipated ways
• With the increased use of modern ICDs (implantable cardioverter-defibrillator) the practice of telemonitoring emerges.
• In order to understand how telemonitoring practices influence the interpretation of ICD data, we need to investigate practices in both collocated and distributed settings.

What the study has added to the body of knowledge:

• An illustration of the socio-technical transformation of work practices during the interpretation practices of ICD telemonitoring.
• An understanding of the three essential entangled interpretation processes involved in ICD telemonitoring.
• Illumination of how two of these processes are neglected in the current telemonitoring setup
• How to design for patients as diagnostic agents in collaborative telemonitoring interpretation
• Insights into how the design of a collaborative socio-technical information technology can turn patients from passive sources of bodily device data into active diagnostic agents.

Improving telemonitoring practices. Previous studies of what gets lost in the design of telemedicine point to the invisible, however essential, work of combining various information artefacts into a coherent whole [18,19]. In our design intervention, we try to bring back the invisible work done by the patients during ICD data interpretation, thus making seriously what was otherwise lost in telemonitoring.

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