

# Affect and Emotions in Patient Data Work

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## ABSTRACT

In this position paper we use insights from an on-going qualitative study of 27 ICD patients using self-tracking technologies (a Fitbit device) to raise awareness about the emotional and affective dimensions of patients' data work. We find that self-tracking data can help reduce affective uncertainty but also introduce negative emotions. We situate the study within affect-oriented approaches to HCI and interaction design to outline important themes needed to consider when designing for self-care and wellbeing.

## Author Keywords

Data Work; Patient Work; Emotional Experiences

## INTRODUCTION

Chronic illness influences all parts of life. For heart patients, self-care is about managing symptoms and treatment as well as tackling lifestyle changes, dealing with fluctuations in illness, and coping with uncertainty about the future. In CSCW and HCI, studies of self-care and the design of technologies have long privileged a medical perspective and analysis tend to be grounded in the theoretical frame of "work" [6,11]. The emotional side of care and the feelings attached to interacting with self-care technologies has largely been overlooked. The informal, situated, and personal side of self-care is, however, more relevant than ever. The market of consumer healthcare technologies is booming, and telecare systems are increasingly becoming part of chronic care. This entails entirely different self-care activities where data work seems to cut across many of the new forms of interaction.

With this position paper, we wish to draw attention to the emotional and affective dimensions of patient data work and begin a discussion on what this means for the design of self-care technologies. In the following, we provide a brief background of affective and emotional concerns in HCI and CSCW around self-care technologies, present developments

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from affective computing and give a glimpse into an ongoing study with 27 heart patients who have been invited to wear a Fitbit activity tracker.



**Figure 1: A heart patient from the SCAUT project trying out a Fitbit activity tracker. She engages in data work that has emotional effects when relating to her illness.**

## BACKGROUND

### Self-Care Technologies and Patient Data Work

Self-care technologies provide opportunities for patients to learn and reflect about their illness, get support for taking action, and communicate with formal and informal careers as well as other patients[11]. There are many examples, but to mention a few, there is the well-known blood glucose meter that enables diabetes patients to monitor and control their glucose level (through numbers) and there is the Mosenso smartphone app that enables bipolar patients to engage in self-assessment and collaborate with clinicians (through patient-generated data) [2].

Common to many self-care technologies is that they are based on patients creating, viewing and/or sharing health-related data. In this way, patient data work is inscribed in most self-care technologies and they require new skills and responsibilities. Yet, they also imply psychological consequences of living with health data and have an emotional and affective impact on patients.

### Affective and Emotional Concerns in HCI and CSCW

In a recent paper, Kaziunas et al. [6] argue for paying more attention to how personal data becomes a powerful way for people to experience life and call for alternative data narratives that reflect a multiplicity of emotional concerns. They describe how emotions and mixed feelings such as anxiety, stress, empathy, and freedom are tightly bound to self-tracking in chronic care. Others like Chen et al. [3] found

that patients feel empowered and create a closer relationship with their primary care physician through online messaging and Jacobs et al. [5] describe how data sharing preferences are tightly bound to emotional issues such as loneliness. Andersen et al. [1] suggests that designing self-care technologies is a matter of making it possible for patients to feel connected to the clinic, receive information in an empathic way, and ensure data and health information is easily comprehensible.

### **Affective Computing**

Emotional and affective concerns have although been of growing importance in HCI and interaction design during the last two decades. Whereas a range of researchers have argued strongly for taking emotions seriously when thinking about computers and design, there is also a great diversity in how to conceptualize these concerns. Rosalind Picard's seminal "Affective Computing" from 1997 [12] set out an agenda for taking emotions and affect seriously in the design of digital and intelligent systems that should be able to both recognize and express emotions to create more fluent forms of interaction.

Norman developed the idea of Emotional Design [10] where he argues for understanding affective and visceral attachments to product design as a central aspect of a product's success or failure. Picard and Norman's attempt to structure, formalize, and represent emotions and affect as informational units has also been challenged. A range of researchers have advocated rethinking this 'informational' or 'cognitive' understanding of affect, arguing that emotions and affect are in the affective interaction between a user and a system, and not to be found in the code or hardware. These 'interactional' approaches all emphasize the centrality of affect and emotion to understanding the richness and complexity of human experience and consequently the need to explore this in the design of interactive systems. In this body of work, the aim is less to contain affect than it is to unfold a range of different affective relations to be experimented with in the crafting of interactive system for design values such as self-reflection or ambiguity.

### **Affect Theory**

Recently, there has been an interest in introducing to HCI and design findings from affect theory in critical and cultural theory [4,8,9]. Among other things, this body of work focuses on cultivating affect as a constitutional element of all human experience – not just particular genres or areas of design – and should consequently be explored and developed in a number of existing application domains, such as healthcare design [9]. From this perspective, affective and emotional concerns are absolutely central to understanding what it means to be living with a chronic disease where "choices in the present become highly charged affectively with fear for the uncertain future" [7].

In this paper, we use the affective framing to highlight 1) the continuous affective uncertainty that is part of the everyday lives of the heart patients more or less palpably and 2) to

zoom in on the affective aspects of the data-work that heart patients perform in their interaction with self-tracking technologies. In so doing, we want to make the case for taking affect and emotions seriously in the design of healthcare technologies directed at patient self-care.

### **CASE: HEART PATIENT'S DATA WORK**

In the following, we present glimpse into an empirical case of chronic heart patients' data work when engaging in activity tracking using a Fitbit wearable device.

#### **Setting**

The case is part of an ongoing study that is part of a larger research and development project called SCAUT (2014-2018). The project aims to improve communication between clinicians and heart patients with an implanted cardiac device. The project takes place in the cardiac device clinic at Rigshospitalet, University of Copenhagen, Denmark, which is one of the largest cardiac device remote monitoring centres in Europe, following more than 3.000 cardiac device patients.

#### **Recruitment**

For this study, 65 patients with an implanted ICD (implantable cardioverter-defibrillator) from the SCAUT project were invited through e-mail to wear a Fitbit Alta HR activity tracker, which is a wristband that can record and visualise heart rate, sleep and steps. In total, 27 ICD patients signed up and were recruited for the study. When onboarding the participants, they were informed that wearing the activity tracker was unrelated to the treatment at the cardiac device clinic and that the purpose of the sub-study was to explore the relation between activity and heart disease through interviews and, at a later stage, through statistical analysis.

#### **Ethical Approval and Considerations**

We took several measures to respond to the ethical concerns related to the intervention with the Fitbit activity tracker. For example, we provided for voluntary participation through an open invitation with self-signup and communicated with all participants in-between interviews to ensure they were comfortable with wearing the wristband.

#### **Interviews and Analysis**

Data collection was carried out with semi-structured interviews in three overall iterations with different three interview guides. Patients were interviewed individually, sometimes along with relatives, in their homes or in convenient locations like the participant's workplace or hospital office space.

### **EMOTIONS AND FEELINGS IN DATA WORK WITH FITBIT**

We are currently analyzing the interviews and find four overall dimensions of patient data work emerging:

- Data sensing: Patients use the Fitbit activity data to relate to their illness experience in various ways

- **Data knowing:** Patients learn new things about their illness through exercising and through seeing activity data such as steps, sleep, and heart rate data from Fitbit.
- **Data evaluating:** Patients use the data to evaluate their health status by looking at the Fitbit data, which indicates how well their activity reflects normal behavior.
- **Data feeling:** Patients respond to the Fitbit data with emotions and feelings. It is this latter dimension, that we wish to draw attention to in the following.

### Using Data to Cope with Negative Affect

Several of the ICD patients we interviewed, described how the Fitbit device and the heart rate data became a go-to device for coping with severe symptoms.

*"I was sitting by the computer. And it just came, it was just blowing through. I was completely dizzy and confused. I was shaking, and my legs were warm. A very, very uncomfortable feeling. I immediately looked at this one [Fitbit device]. Mostly to see the heart rate. Because I really felt it was pounding. But according to it, there was no problem" (P12).*

This patient describes how the physical experience of rapid heart beats frightens him and affects his emotional state, primarily because it reminds him of the traumatic incidences of getting a shock from his implanted ICD. Looking at the heart rate data on his wearable activity tracker calms him down and thereby overrule the negative affect.

*"It was very, very, very unpleasant. And it reminds me of the trips I had when I got the shocks. When I get them, it's obviously psychological. And I get scared, really scared. But it [Fitbit device] immediately showed my pulse was 62, I think. [...] So there wasn't anything. It made me calm down" (P12).*

### Feelings in Patient Data Work

One ICD patient wanted to use the Fitbit device to counter his depression. He had been seeing a therapist for a while and explained that with an activity tracker he could have a fresh start and begin to exercise more. But it did not turn out that way. Instead, the low step count numbers created increased awareness of not succeeding to exercise enough and it actualized his bad conscience and sparked negative feelings.

*"I get a feeling that I am not good enough. I know I have to exercise and move because of my heart, but it can be impossible for me some days when I am not feeling great" (P17).*

Another patient installs hope of better health when tracking activity data. He wanted to use the continuous tracking of activity data to be able to correlate good habits of exercising and eating healthy with the possibility to avoid irregular heartbeats and being dizzy and sometimes fainting.

*"Try to imagine being able to get a whole year of [fitbit] data on the times where it runs [irregular heart beats]. If you had that and started combining it with changing your behavior and stuff like that. If the running [of the heart] then becomes less frequent during that year, then that would obvious be a signal to hold on to the healthy lifestyle, eating more vegetables or go vegan" (P4).*

### Summary of Implications for Design

Patient data work with self-tracking technologies have emotional and affective consequences for living with a chronic disease.

- Self-tracking data can help reduce affective commotion /uncertainty and counteract the physiological turmoil
- Negative affect of self-tracking data can have a negative effect on people's motivation for behavioural change
- Positive affect of self-tracking data can have a positive effect on people's motivation for behavioural change
- What constitutes data as either positive/negative, affectively speaking, is not inherent to the data, but part of the data-work and the contextual factors determining it.

### OPEN QUESTIONS

Along with recent studies on the psychological consequences of living with health data, we find it important to consider how to design for emotional and affective dimensions in technologies that engage patients in data work. It is a complex undertaking with a range open questions that we would like to engage at the workshop.

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