A Case Study of Data-Enabled Design for Cardiac Telemonitoring

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ABSTRACT

Data-enabled design (DED) is a novel design methodology that is gaining momentum given the growing availability and maturity of IoT technologies. Experiences with this method are limited, for which it is interesting to study how different design teams apply and appropriate the method in different contexts. Our case concerns the design of a smartwatch app and an online dashboard to facilitate self-monitoring in cardiac health to prevent heart failure. We report on the design and evaluation of contextual experiences with the overall system, offering an accessible foundation for future iterative improvements. Our case demonstrates how the DED method can facilitate the participation of stakeholders and especially end-users, in co-designing within a heavily regulated and technologically rich context.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in ubiquitous and mobile computing**; **Interaction design process and methods**; • **Software and its engineering** → *Software creation and management*.

KEYWORDS

Data-enabled design, Cardiac telemonitoring, eHealth, mHealth

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1 INTRODUCTION

In recent times, both eHealth (electronic health: healthcare services that use digital systems for health services and information management) and mHealth (mobile health: smart portable devices like smartphones or smartwatches as an eHealth solution) have become prominent components of healthcare [20]. Such services should be developed in close collaboration with healthcare professionals and patients [20]. In traditional user-centered design processes, patients are involved either as informants in the early stages of a design process or as test participants for prototypes of varying fidelity. Inquiry techniques applied early in such design approaches tap into the experiences and attitudes of study participants that do not reflect directly on the potential of the technologies examined. On the other hand, consulting test users when the system is mature enough for them to try it, means that major design decisions are already settled and the influence of participants is limited to what are essentially local optimizations. This tension is well-known in the field of interaction design and is a central methodological concern for the field [6]. Various methods attempt to overcome it by, e.g., optimizing the input that can be obtained by low-fidelity prototypes [5] or introducing working prototypes [24] early in the design process. We use data-enabled design [2] which relies on the deployment of various probes for data collection and management early in the design process, allowing informants to experience the data collection and management capabilities of a designed ecosystem early on, and to provide effective input early in the design process.

We present a case study in applying DED to explore the design space of self-tracking technologies to support the treatment of existing heart failure patients through medication adaptation. In the following sections, we describe the design and development of a smartwatch app and an online dashboard, i.e., an adaptive data canvas serving as a self-monitoring system for cardiac patients. A data canvas refers to the entanglement of hardware and software or the digital space where the data is collected, organized, and analyzed to support the design process [2]. Simultaneously, our approach reflects on necessary adaptations to the setup and execution of the data-enabled design framework to fit the context of the research and helps picture the effectiveness and confidence level of the design.

2 TELEMONITORING FOR HEART FAILURE PATIENTS

Telemonitoring systems are a combination of self-monitoring with remote reviewing that partially shifts patient care out of clinical settings into the patient's home where physiological data about symptoms are transmitted to the healthcare professional for review via communication technologies, giving the patient enhanced autonomy and control of their health [11]. Previous research on the effects of telemonitoring or intervention methods for heart failure has demonstrated notable improvements in outcome measures (e.g., quality of life, decreased hospitalizations, and a decreased mortality rate [7, 15]). However, other studies showed inconclusive evidence of the potential reduction in healthcare burden through telemonitoring [22, 29].

The *value* of a telemonitoring system is associated with adherence and user experience (UX). For example, if the system requires a lot of attention but is very easy to use, it can be perceived as less costly to the user. On the other hand, adherence is a direct consequence of perceived value; if the cost of the system outweighs the benefits, adherence rates are likely to drop [10].

Self-efficacy in heart failure patients is typically low. The psychological impact of (potential) heart failure often causes patients to lose confidence in their cardiovascular system. Patients become afraid of (re)occurrences, often paired with the fear of exerting themselves [1, 4, 25]. Subsequently, they are hesitant to *push* a weakened cardiovascular system [4].

3 DATA-ENABLED DESIGN

DED is a design methodology for creating intelligent ecosystems which are dynamic compositions of interrelated products, services, and people [21]. Insights regarding user needs and opportunities for design interventions are gained by utilizing a combination of quantitative sensor data and qualitative feedback data to inspire design iterations [3, 16, 28]. DED uses data as creative material by probing for user behavior through reflection [2]. It is an iterative mixed methods approach where qualitative insights define the context for interpreting quantitative data, e.g., by explaining observations, understanding meanings and motivations behind behaviors, etc. Furthermore, qualitative insights may guide the quantitative data collection, as new insights and discoveries prompt new questions for the investigators.

The DED approach is roughly a two-step process [2, 27]: **1)** The *contextual step* aims for a contextualized understanding of user behavior through qualitative and quantitative data. Quantitative data is a combination of telemonitoring data and data gathered from sensors and qualitative data is gathered by interviewing participants. This process relies on a technical infrastructure (data canvas) where data is collected, visualized, and inspected by researchers and informants in co-design activities. **2)** In the *informed step* the deployed system is adapted through a cycle of design interventions from the gathered quantitative and qualitative data. These interventions are supported by the deployed technical infrastructure which has to be flexible and dynamic.

4 A DATA CANVAS FOR TELEMONITORING HEART-FAILURE PATIENTS

The DED framework introduces a dynamic set of tools, called the data canvas [2] that supports collecting contextual and behavioral data and deploying design interventions. The data canvas in this study was populated with data that helps clinicians track the condition of heart failure patients. The data was collected through several off-the-shelf CE-certified IoT devices: a Bluetooth receiver, digital scale, pulse oximeter, blood pressure monitor (Fig. 1), and a (Samsung Galaxy Active 2) smartwatch (Fig. 2).

In this study, despite previous works that utilized wearables as a black-box medium for data collection (e.g., [9]), we further leveraged the smartwatches for direct interaction with the user who wears it, as it provides ample support for self-monitoring through custom apps [13]. Indeed the smartwatch also enabled the collection of data through its embedded sensors. Lastly, our data canvas includes a web-based dashboard that offers visual representations of collected data (through telemonitoring devices) to each participant. We introduced the dashboard in the contextual step rather than in the informed step as suggested by the framework [2], potentially helping with understanding the user context and having an overview of quantitative data collected through the IoT devices. Data is stored in GameBus, a GDPR-compliant mHealth platform developed to support the design, implementation, and evaluation of gamified health campaigns [26].

Designers should initiate design interventions by remotely adapting the functionality and presentation of the canvas on the fly. Remote adaptation enables the exploration of several iterations at a time, within the boundaries of the data canvas. Specifically, Samsung smartwatches can be configured and adapted remotely, without the need for any user interaction [23]. Our data canvas was designed to allow scaling up the number of individual users and allows integration of any design explorations into the final outcome of the design process. Although scalability and by proxy standardization are not addressed by the DED framework, they seem particularly relevant for a telemonitoring scenario in eHealth. For example, the connection between the Bluetooth receiver (that collects data from measurement devices and sends them to GameBus) and the WiFi network is essential. Thus, a preconfigured WiFi extender was provided with the IoT devices, making the system plug-and-play which reduces the burden of participation.

The smartwatch app is developed in Javascript for Tizen OS 5.5 [8]. The smartwatch supports third-party software apps and has a display of 360 x 360 pixels on a 1.4-inch circular screen. The app was built upon Experiencer [12], a smartwatch app that facilitates experience sampling research studies [14]. Experiencer offers a variety of core functionalities including an authentication system, an internal storage management system, automatic data transmission, and a notification system. Despite the high accuracy of the touchscreen of the smartwatch, its small screen can still easily cause accidental touch inputs (e.g., when trying to tap smaller buttons), especially for older users. Therefore, every interactive element is spaced apart and is accompanied by haptic feedback (short vibration) upon touch.

Contrary to the *traditional* DED framework [27], several functionalities were introduced to the app before the start contextual phase. The smartwatch is not just a collector and transmitter of quantitative data or a design intervention platform but also allows for confirming and viewing the latest measurements, entering

Figure 2: Accompanying smartwatch with our custom app showing the cardiogram functionality

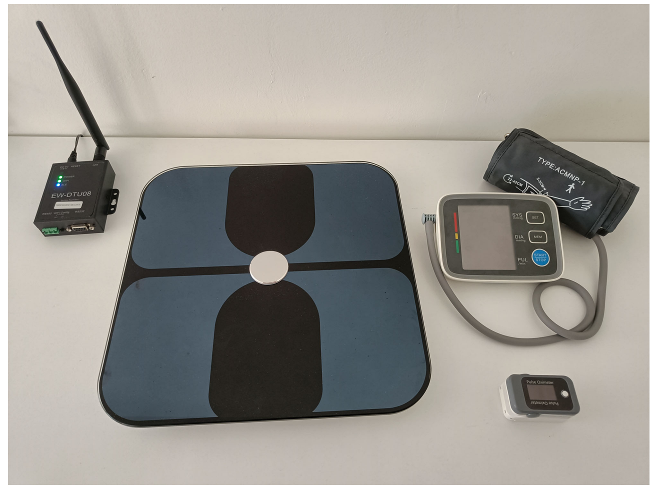

Figure 1: Assemblage of the IoT devices given to users (left: Bluetooth receiver, middle: digital scale, top right: blood pressure monitor, bottom right: pulse oximeter)

weight measurements manually, self-reporting symptoms, and receiving daily reminder notifications.

Notifications are a common method for boosting adherence [18]. The biggest factors in notification design are frequency, content, and time [13]. We set the frequency of notifications to once a day as this is sufficient for the specific health scenario we were working on. The content is either a reminder or a compliment based on whether a measurement exists in the database, created on the day of the reminder. Moreover, the local data and configurations on the app are periodically updated in the presence of stable Wi-Fi which enables working (partially) offline, every interaction with functions and program exceptions is logged.

The web-based dashboards (i.e., for users and researchers) were created using Metabase, an open-source business intelligence tool that allows the creation and automatic updating of graphs and tables from database entries [17]. For security purposes, the Metabase was self-hosted on our own EU-based server. For each user, a personal dashboard is generated containing only their own data. Access to the dashboard is managed with a personal unique token. The researcher dashboard (similar to patients’) contains data of all users as well as data from the data probes built within the data canvas. The subsequent section outlines the contextual and informed phases employed in our study. In contrast to the traditional DED approach [2], we initiated intervention design early on during the contextual phase to capitalize on the available infrastructure and expedite the iterative process. By preparing the data canvas for field deployment, data collection, and exploration were facilitated during this phase. This approach fostered ample room for exploration, development, and effectively linking qualitative feedback with quantitative events, seamlessly blending the two phases together. As such, we use the term data probe as a deployed device, tool, prototype, or program element that collects data and is part of the data canvas in both phases.

5 DATA-ENABLED DESIGN WITH HEART FAILURE PATIENTS

The data canvas was deployed in a field study that aimed **1)** to evaluate the UX of the telemonitoring system, **2)** to collect quantitative and qualitative data to make valuable design interventions, and **3)** to evaluate the DED framework approach. As aimed to design a system for heart failure patients aged 60+ and to avoid ethical hurdles and procedures of running tests with patients, we recruited participants without a heart condition. Five participants were recruited, but $N = 4$ (P1, P2, P3, and P4) participated in the experiment. Their ages ranged from 58 to 76 ($M = 65.5, SD = 6.6$) and each participant had a unique distinct relation to cardiovascular health (e.g., risk of heart failure from diabetes (P1) or heart failure in their social circle (P2, P3)). P2 and P3 lived in the same household. None of the participants were using technology to track data about their cardiac health. P1 had been using a personal smartwatch for some time already. Since none of the participants suffered from heart disease or heart failure, a major emphasis would specifically be put on the evaluation of the system as a prevention method.

Each participant was visited at home to receive the self-tracking IoT devices, a smartwatch with our app preinstalled, and a unique personal token to access their personal dashboard. Participants were informed about the purpose and nature of the experiment and were asked to sign a consent form. Participants were instructed to use the system for two weeks as they saw fit and to relay any feedback about the system to the designer via the dashboard or through text.

Online interviews were planned seven days into the study to explore first experiences with the system and to discuss any other observations and remarks by participants. In-person interviews were planned at the end of the two weeks to discuss any design interventions and to evaluate the overall experience of each participant.

5.1 Contextual phase

Over the course of seven days, participants used the telemonitoring setup in any way they saw fit. They interacted with the smartwatch app a total of 342 times, used the IoT devices 126 times, and sent 57 feedback messages. During the first couple of days, a significant portion of participant feedback indicated their struggle with understanding the measurement procedure. Quantitative data showed that participants would try to explore the system themselves to possibly determine where something went wrong and whether it was their fault or of the system, e.g., by repeatedly refreshing the interface related to the measurements to see if it would update.

> *"I'm getting a bit frustrated; I notice that measurements aren't being remembered [on the dashboard] even though I just measured. I tried measuring upstairs and downstairs [closer to the Bluetooth receiver]. (...) I can see values on the smartwatch, but I don't know if those are from just now or yesterday." – P2*

The quantitative data revealed that reported frustrations were sometimes caused by the devices themselves failing to transmit data to the server, while in other cases participants simply forgot to confirm their measurement submission. Participants initially saw the dashboard as a tool to confirm whether measurements were properly recorded. However, after a few days, qualitative feedback started to shift towards seeking personal insights and suggestions for improvements in relation to the dashboard.

> *"Why can I only see my average [measurement values] for each day? I'm more interested in seeing all measurements separately so I can compare them." – P1*

During the midterm interviews, the combination of real-time quantitative data and qualitative feedback had already shaped a fairly accurate picture of what participants were struggling with. The interview provided a deeper insight into why participants were using the system in the way that they were.

> *"It's slowly becoming a daily rhythm. I needed some time to [start], but I am more and more confident in my use [of the system] so I have switched to only looking at my measurements when I want to." – P2*

The dashboard proved to be a valuable point of discussion. The data it presented was personal and factual so participants could relate strongly to its contents. They remarked in different ways how having direct access to their personal data gave them a feeling of awareness about their bodies. For example, P2 who was prone to heart disease mentioned that the dashboard was already a great tool for staying aware of their condition. While some had bought self-tracking devices (i.e., fitness bands, and blood pressure monitors) they appreciated making it *their own* by not just measuring regularly in the morning as rhythm over a long time, but also occasionally throughout the rest of the day out of curiosity and for exploration. In conclusion, findings from the contextual phase supported the importance of awareness and insight and suggested that users possess an intrinsic personal interest in *exploring their own heart.*

5.2 Informed phase

As became clear during the midterm interviews, participants appreciated data visualization but felt it lacked personalization and was thus not perceived as personally meaningful. During the informed phase, several design interventions were implemented and deployed remotely, based on experiential feedback and quantitative data. Some interventions could not be deployed and experienced in the field setting due to limitations. For example, some interventions could not be developed in due time and were presented to participants using the Wizard of Oz methodology [19].

The first set of design interventions could be remotely deployed at the start of the informed phase, including a more informative management interface on the smartwatch app, changes to the data visualization on the dashboard, and the ability to track heart rate using the physiological sensors of the smartwatch. Participants responded favorably towards these adaptations, confirming that it was now easier to distinguish and thus compare measurements. This was also confirmed by logged data which showed a significant drop in repetitive management interface checks.

> *"It grows my awareness, like how your weight can fluctuate quite substantially in relation to what you are eating and drinking. It is actually kind of obvious, but still." – P2*

A second set of interventions was deployed three days into the informed phase. They were designed using data from the contextual phase in combination with findings from the midterm interview and aimed to tackle the elements of context and meaningful personal data (Fig. 3). An interesting behavioral observation after deploying this second set was how some participants changed the formulation of feedback messages related to measurements.

Figure 3: Iterative dashboard showing average weight in relation to BMI (top left), average saturation level in relation to 'healthy' value (bottom left), blood pressure measurements in relation to 'healthy' value (top right), and individual weight data (bottom middle, right).

Initially, participants reported unexpected measurements in relation to their previous measurements (i.e., higher, lower), but later feedback showed signs of more informed exploration. Furthermore, it caused participants to adapt their behavior based on their own personal data. For example, the P4 who observed high blood pressure would always measure only in the morning but measured an extra time in the evening on the day of that particular measurement.

5.3 Results

Over the course of the informed phase, participants interacted with specific smartwatch functions a total of 316 times and used the IoT tracking devices 130 times. All participants mentioned that they found it quite easy to learn and handle, despite three participants having never used a smartwatch before. P1, P2, and P4 mentioned that receiving a notification complimenting them after successful measurements made them feel accomplished and reassured that they were doing well. The effect of the notification as a reminder was smaller since participants were measuring consistently. None of the participants had trouble filling in the questionnaire on the smartwatch and they occasionally did so throughout the day when they felt like it. P3 stopped filling in the questionnaire for a week since they experienced no symptoms. In general, participants found it very easy and low effort to report their symptoms using the questionnaire on the smartwatch app.

The measurement-related interfaces were reported to be mostly used for confirmation purposes and occasionally out of curiosity. Participants appreciated seeing the details of each measurement, but P1, P2, and P3 mentioned that they would appreciate an extra function to confirm device measurements retroactively if they had missed the confirmation popup. The delete and manual entry functions were useful, but difficult due to the small screen of the smartwatch. Therefore, this function was preferred to be used as a last resort. The procedure of confirming measurements using the smartwatch received mixed feedback. Participants that live with other people in the same household appreciated they could ensure measurements were their own. Participants living alone did not appreciate the confirmation process and preferred to retroactively handle wrong measurements through the app or dashboard. Participants responded enthusiastically about the implemented design interventions and how these made it easier to determine personal cardiac status. They liked seeing how their heart was doing in comparison to normalized expectations. Participants would often refer to specific insights during the interview, which indicated they had gained a heightened awareness of their personal cardiovascular health. Moreover, P1 and P3 indicated an interest in further exploration of their heart rates as a result of noticing a vast difference between their heart rate measurements through the oximeter. Accordingly, we expanded the smartwatch app by adding a heart rate monitor (Fig. 2). Subsequently, following received feedback, a live graph (cardiogram) was added so participants could monitor their fluctuations visually. Overall, participants found the heart rate monitor to be a great indicator of what is dynamically happening in their cardiovascular system as opposed to the snapshot measurements with the IoT devices.

Furthermore, the insights led to some participants expressing intentions to change their behavior, e.g., P1 remarked how their BMI was surprisingly "in the green" and how they were going to try and "keep it there", while another participant P2 noticed low blood pressure and would "keep an eye on it and otherwise call their doctor". P1, P2, and P3 were enthusiastic about the ability to explore relations between their cardiovascular health, personal behavior, and mental health. This enthusiasm was reported to partially stem from the information panels, but also from noticing fluctuations.

> *"The BMI color gradient looks nice and feels stimulating to 'stay in the green', it helps to see where you're currently standing. What I also liked was seeing how [my measurements] fluctuate over this period. I think it is important to show these fluctuations over a long time though." – P4*

A clear distinction could be made between participants who had existing conditions related to heart disease and participants who did not. The former indicated that being able to measure with a lower frequency (e.g., bi-weekly) would still be really nice with this system to spot potential negative trends over time. They also appreciated the possibility of substantially increasing their measuring intensity as soon as they spotted such a trend or if they felt physically or mentally off. The latter indicated less interest in longitudinal personal use, where one participant even went as far as to say they preferred not to monitor themselves preventively as they had experienced enough health conditions in their life already. Therefore, they preferred not to be repeatedly confronted with their personal health data unless absolutely necessary. Interestingly, sometime after the conclusion of the experiment, two participants with a higher risk of heart disease requested to receive a transcription of their blood pressure data to discuss with a medical expert. More generally, when faced with a health issue like heart disease, a patient should feel confident in the medical expert that is responsible for monitoring and/or treating them. After all, the medical expert is trusted to know and do what is best for the patient. If the personal connection is partially replaced by a telemonitoring system, part of that *human touch* is lost. Thus, the developers of telemonitoring technology should strive to compensate for this loss by boosting self-confidence. In the context of a telemonitoring system, system confidence, i.e., confidence in using the system as intended and confidence in the system being reliable, is an integral part of the UX design.

6 DISCUSSION

In this section, we step back to examine the specific implementation of the DED approach in our case and reflect on lessons that can guide designers following this approach in different contexts. We note some differences between the original data-enabled framework [27] and its execution in this paper. The study presented here was a methodological exploration of a relatively short duration, embedded in a larger project with the aim to develop and test self-monitoring technologies. This meant that a clear project scope enveloped the design space and technological infrastructure was already in place regarding the remote monitoring of patient health parameters. This infrastructure considerably lowered the threshold for engaging in DED. Still, considerable effort was directed toward developing the data canvas. This meant not just designing a fully working field-ready prototype that participants could experience, but also making the prototype **1)** remotely adaptive, **2)** capable of recording, storing, and transmitting real data in real-time, **3)** open to a wide range of design interventions and **4)** track, store and offer exploration of the data as a design material. A benefit of developing the data canvas with these requirements is that they would be beneficial for future studies and design iterations. Depending on the time and resources for such iterations, this investment in infrastructure to support the design process will offer different returns.

Given the availability of the infrastructure but also in order to inject pace into the iterative process, we started the designing of interventions early on during the contextual phase. The data canvas was made adaptive and field-ready before starting the deployment and thus data could be collected and explored during the contextual phase. This gave more room to explore and develop and helped a lot in matching qualitative feedback to quantitative events, blending two phases into one another. Applying the DED approach in different contexts will need to be similarly speeded up, adjusting the transition between the contextual and the informed steps in project-specific ways. Methodologically, there is a tension between exploring whether the currently available data is not yet sufficient (e.g., does it need more data probes to get valuable data?), or designing and developing adaptations to the system based on findings as they were. While this tension is arguably present in any design process, the time scales are compressed in DED and the costs of changes to design concepts are higher given that they are affected while a field test is running, with all the costs this brings about.

To reflect on the effectiveness of the DED approach in supporting the specific project, we consider the quantity and quality of the design interventions made. The use of real experience data from a field setting as design material lent realism to the design process. Looking back, the blending of the phases discussed above combined with the early deployment of the data canvas resulted in a generally broader but less in-depth exploration. None of the participants had used a telemonitoring system before nor did they have a first-hand understanding of self-monitoring their cardiac health. So, participants took relatively long to learn and explore what the system does rather than ideating what the system can do. In practice, the aforementioned expectations and framework adoptions caused the balance between the contextual phase and the informed phase to heavily lean towards the latter. As a result, even though the data canvas was very much capable of producing rich quantitative and qualitative data and produced some generative insights, less elaborated contextual exploration likely led to less radical design interventions. The methodological choice that users of the DED framework are called to make is whether the benefits of running a seamless uninterrupted field experiment outweigh the opportunity cost of not exploring the design space broadly during the contextual phase. One of the biggest challenges facing designers using the DED is to decide what design opportunities are important to explore and how much effort to invest in each. For the present case, we feel that future design iterations would call for a richer contextual phase, with more emphasis on design opportunities that stem from or facilitate personalized experiences.

An additional challenge emerges from the benefits of having participants experience the system as naturally as possible. In this research, participants were informed at the start of the experiment that the system could change, but not how or when. Interventions were therefore noticed and experienced as naturally as possible to stimulate exploration for personal reasons. In hindsight, this turned out to be an effective way to collect rich personal feedback about design interventions. In addition, a great unexpected benefit of the quantitative data probes was that they provided contextual insights beyond their intended relations (i.e., one probe → one function). For example, a significant delay between the timestamp of a data probe of an app interaction and the timestamp of that entry being transmitted to the database by the smartwatch could be interpreted as having occurred outside the house. Such factors help contextualize system usage in a natural setting. Yet another challenge relates to the limitations in time and capacity. Most design opportunities that were found during the experiment could be developed and deployed as design interventions so participants could experience them. The opportunities that could not be implemented in time were instead presented to participants in a Wizard of Oz style. However, participants cannot fully experience them and data used for Wizard of Oz data visualization is often not real or at least not real-time. Furthermore, these design explorations were not supported by data probes, so using them for subsequent iterations during the informed phase was not possible. Wizard of Oz was useful for exploring concepts difficult to realize but it does not integrate well with the DED approach.

Lastly, two limitations of this research are worth mentioning: **1)** the element of reactivity, which almost inevitably influences how test participants use and experience a deployed experimental system, and **2)** for the design of telemonitoring systems for heart failure patients, the inclusion of patients in the design process is essential. However, the current study and evaluation are necessary steps for overcoming the ethical challenges of capturing medical data and involving patients, for which a clear benefit to patients and a positive UX are practically necessary.

7 CONCLUSION

This paper reports a case study on the application of the DED approach for designing telemonitoring apps for heart failure patients. Earlier applications of the method have largely been by the originators of this approach [21, 27, 28]. In our case, DED was adopted as the favored approach for a design exploration embedded within a larger project, rather than as the overarching framework for the project as a whole. In this design exploration, we deviated from the original method mostly in moving faster toward deployment and data collection in the field. Future case studies should further explore the trade-off that arises from investing effort early in deploying working probes and the way they tend to focus the design exploration. The benefit provided to our project was that real-world insight entered the design exploration and improvements to the telemonitoring system resulted directly from our exploration to address user needs not anticipated at the start. A limitation experienced in this study was that it was difficult to resolve the tension between generally applicable improvements and personal adaptations and priorities for each user. We argue that the remotely adaptive, scalable, and dynamic nature of the data canvas supporting DED makes it a foundation for future design iterations that explore this tension more deeply. Future cases exploring this tension could provide methodological guidance regarding the application of data-enabled design in a research context but also a practical means for designing personalization and adaptations in ecosystems of connected devices.

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