

Data Contribution Summaries for Patient Engagement in Multi-Device Health Monitoring Research

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ABSTRACT

The rapid growth in the range of data measures from wearable and stationary sensing devices has led to the adoption of multiple devices in health research. Such multi-device setups present challenges in sustaining patient engagement to capture continuous and high-quality datasets. One approach is to present health data to patients throughout the study but often occurs upon study completion. We report on preliminary insights from a feasibility study (IDEA-FAST) where multiple devices were used by 141 patients in their free-living environments. Interviews with a subset of patients and clinicians highlight challenges and opportunities around participation, data use and interpretation, including understanding compliance and data explainability with patients. We propose that summarising metadata from device usage could foster engagement and scale across a range of technologies regardless of the specific measures or post-processing algorithms provided by devices.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in ubiquitous and mobile computing**.

KEYWORDS

digital health, human-centered design, in-the-wild studies, wearables, sensing devices, patient engagement, human-data interaction

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1 INTRODUCTION

Sensing devices are revolutionising healthcare as they offer unobtrusive ways to record continuous streams of patients' vital and behavioural signs in free-living environments, such as heart rate, brain activity, and physical movement [19, 29]. This is applied across a broad range of use cases, e.g. in the assessment or monitoring of Parkinson's disease symptoms [10, 27], bipolar disorder [13], or sleep assessment [2, 28]. Increasingly, clinical studies are being conducted where multiple sensing devices are used to generate large, multi-modal health datasets that can be used to provide a more refined insight into a range of disease symptoms [16, 21, 23]. The growing numbers of simultaneously used sensing technologies adds additional protocol requirements for patients to engage with that can impact compliance and desires to participate.

One approach to foster engagement is to provide processed data generated by these sensing devices to patients. Recent work has shown how patients feel motivated, rewarded, and included in research studies when they receive personalised reports [3], and that daily feedback on an individual's disease created positive effects on people living with Parkinson's disease [27]. Across this work, sensing data is often analysed to create *health summaries* that can inform personalised, data-driven consultations between clinicians and patients [18, 20]. During such consultations, patients can be asked to contextualise the data to assist the discussion. However, this introduces additional time and effort requirements for both parties [22]. Post-processed data is commonly presented to patients

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weekly (e.g., [3, 5, 27]) or upon study completion [2, 28]. Yet, studies exclusively using end-of-participation health reports miss the opportunity to motivate patients and contextualise their data regularly whilst research participation is ongoing – although engagement is key for large-scale and longitudinal research.

Building on these challenges, we present findings based on a feasibility study (FS) that is conducted in preparation for a clinical observation study in the context of the IDEA-FAST project. Semi-structured interviews were held with 24 patients and 9 clinicians to understand their experiences on-boarding, supporting, and using multiple sensing technologies, and challenges with keeping patients engaged during the study. A formative qualitative analysis of these interviews is presented with a focused reflection on *the use of health data summaries and how data from sensing devices could sustain and engage patients*.

Our findings contribute to future planning of multi-device research projects in digital health and are also of relevance to practical developments in a world of increasingly ubiquitous sensing that hinges on the successful integration of numerous sensing devices.

2 MULTI-DEVICE HEALTH MONITORING

Using multiple sensing devices to provide insights into health conditions is becoming more common with several recent and ongoing projects exploring the use of multi-device sensing for digital health. For example, *RADAR-CNS* uses commercially available devices to study central nervous system disease progression [21, 23], *Mobilise-D* uses smartphones and sensors to examine people's mobility [25], and the *SPHERE* project uses a multi-sensor and multi-modal platform (environmental, video, and wearable sensors) to passively detect health-related behaviours at home [8]. These projects use multiple devices in-the-wild, which can increase the burden for research participants and creates opportunities to explore new ways to sustain engagement. This is exemplified by a recent workshop aiming to address the user experience for multi-device ecosystems rather than the typically researched cross-device interaction techniques [30].

3 IDEA-FAST

Fatigue and sleep disturbances are symptoms of several chronic diseases associated with poor quality of life and increased health-care costs [16]. A large part of measuring patient's health is using self-reported methods that can be prone to recall bias or require extensive effort to complete, e.g., sleep diaries [16]. Building on these challenges, IDEA-FAST is a five and a half year project that aims to determine “digital endpoints” or digital biomarkers through using multiple sensing devices “in-the-wild” to assess fatigue, sleep, and activities of daily living in patients with neurodegenerative diseases (e.g. Huntington's disease) and immune-mediated inflammatory diseases (e.g. rheumatoid arthritis) [16].

IDEA-FAST is composed of three stages: a *pre-feasibility process* where multiple sensing devices were tested by experts and used with convenient subjects to select devices for the subsequent stage as detailed in [15]; a *feasibility study (FS)* where eleven sensing devices were used “in-the-wild” by patients across six disease affliction groups; and a large-scale longitudinal study *clinical observation study (COS)* where a subset of devices from the FS will be used.

The FS aims to identify candidate digital parameters of fatigue and sleep disturbances to be examined in the larger COS. Patients were recruited across four EU and UK study centres and asked to report sleep disturbances and fatigue through surveys, questionnaires, and a digital diary during a four to five week study period [14]. Alongside this, patients are asked to use multiple sensing devices concurrently for four periods of five consecutive days. These devices measured: *physical activity* (e.g., [9, 11, 31]), *physiology* (e.g., VitalPatch [2]), *EEG* (e.g., [1]), *cognition* (e.g. [6]), and *socialisation parameters* (via a smartphone app). Data collected from these sensing technologies will be compared with traditional clinical measures and patient-reported outcomes to understand which digital measures best correlate, and thus which devices should be used in the COS [14].

During the FS, clinicians were responsible for on-boarding and supporting patients, including monitoring device usage, and transferring data from devices. Patients were optionally provided with *summary data reports* generated from device provider's digital platforms (if available) upon completion of a device-use period. As human-computer interaction (HCI) researchers our focus during the FS was to understand the usability, user experience, and acceptability of these sensing devices to inform device selection suggestions, as well as the development of potential support technologies for the COS. In this paper, we present insights gained from preliminary qualitative analysis that examines the *perspectives of patients and clinicians on device usage and data generated from them that could help to sustain patient engagement in multi-device studies*.

4 STUDY DESIGN

Semi-structured interviews were conducted with patients and clinicians following their participation in the IDEA-FAST FS. These interviews aimed to understand the contextual challenges of on-boarding, supporting, and keeping patients engaged during the study, and their experiences with multiple sensing devices.

Out of 24 interviewed patients, 13 were considered healthy (control), eight Parkinson's disease (PD), two inflammatory bowel disease (IBD), and one Huntington's disease (HD); more interviews are being conducted at the time of writing. Interviews lasted 49-minutes on average (SD=19m, min=21m, max=92m) and were conducted within four weeks of patients' participation. Two researchers from one study site conducted all included patient interviews with 75% being held over videoconferencing software or telephone, and the remaining in person. Additionally, nine clinicians from four study sites were interviewed towards the end of the FS that lasted 38-minutes on average (SD=09m, min=26m, max=50m). All patient interviews were conducted in their native languages (i.e., German, English and Dutch), while clinician interviews were conducted in English. All interviews were audio recorded, transcribed, and translated into English if necessary using an automated translation service with spot-checking for translation accuracy as appropriate.

A preliminary qualitative analysis is being conducted by two authors across these datasets. The qualitative analysis of interview data was focused on understanding the challenges of multi-device use as prescribed by the existing study design protocol for both patients (for protocol engagement and device use) and clinicians (for device setup and monitoring of patient engagement), with the

aim of informing technology design to sustain patient engagement. Labels are used to indicate individual patients (P) and clinicians (C).

4.1 Ethics

IDEA-FAST's FS study protocol [14] was registered at the German Clinical Trial Registry (DRKS00021693) and approved by the ethics committee of the Medical Faculty of Kiel University (D 491/20). Patient interviews are pseudonymous for storage and only accessible by data analysts within the consortium. Ethical approval for the clinician (anonymised) interviews reported in this paper (which was outside the scope of the FS protocol) was granted by Newcastle University (7421/2020). Verbal consent was taken as interviews were primarily held over videoconferencing software or telephone.

5 PRELIMINARY FINDINGS

This section outlines preliminary findings focused on the use, interpretation, and experience with health data summaries provided to patients. It examines how data from sensing devices could be used to sustain and engage patients doing longitudinal multi-device studies, and the implications for clinical practice.

5.1 Reflecting on Health Data Summaries

Patients used multiple sensing devices over four periods of five days each where they received daily feedback from some devices, a report following their participation, or no feedback at all, depending on the device. One of the sensing devices that monitored EEG during sleep had an associated smartphone application which *did* provide a report after each night. Some patients described that they were unable to engage with much of these metrics (e.g., sleep stages), as it was often unclear what the data meant, or data reports were unavailable in the provided application as data had not yet been automatically transferred. For other patients, viewing this data was used as a feedback mechanism to understand if the device was configured and recording data correctly as described by one patient:

“It was nice to see how it was going, because with [the app] I could see if it was working and if [...] the [device] battery died or whatever, it was good to keep up with that. So I knew I was doing it right.” (P1)

In this way, the availability of frequent data summaries enabled patients to feel confident that they were adhering to study protocol when they “should”. This meant that while some patients deviated from the agreed upon study protocol, they instead ‘made up’ the difference in skipped device wear days by extending their original use period. While this allows flexibility in study protocol and more convenient participation for patients, feeding back those deviations is critical to understand the overall accuracy of the dataset.

Conversely, some participants requested to discuss and clarify the data with clinicians that were provided by smartphone applications or summary health reports. Clinicians highlighted that collating reports across multiple devices was tedious, and often required collaboration with patients as some devices provided reports via apps on patient's smartphones. Clinicians reported that patients were often interested in sleep-related data so that they could observe and correlate for themselves any discrepancies between their disease conditions and the data. This required clinicians to interpret data and explain concepts (e.g. REM) to help with understanding the

data. Access and availability of data was highlighted as a limiting factor in how insights could be shared to patients:

“[Patients] always want to know and have data, which is then a bit sad when we have to tell them that the sleeping reports are not available [...] we have to tell them we can't because it is all raw data.” (C1)

Discussion around these health reports was seen as a key factor for motivating participation according to clinicians. It was argued that patients' access to their personalised data is required so that they can answer personal questions they have about their health:

“If patients are to be motivated to wear the devices, then they themselves must also benefit from it by getting an answer to questions they have.” (C2)

Across these interviews, patients reflected how they enjoyed seeing the summary health data reports provided by clinicians after they took part in IDEA-FAST. Some patients attributed these reports as motivation for taking part, while others were not interested in the data unless they experienced poor health, e.g., did not sleep well or felt poorly. When presented with a data summary, one patient described that data was missing for some days when they thought that they had worn the device:

“The 2nd time the [report] showed that I would not have worn [device] many times, which was not true. That irritated me a bit as I thought I worn it.” (P2)

The health summary report data provided to this patient labelled missing data as “not worn” and highlighted those days in red. Upon receiving this report, the patient felt “accused” as the missing data did not match with when they had worn the device. Even though some devices provided health summary reports following study participation or in near real-time through smartphone applications, most did not. This was primarily because data transfer occurs offline (manually) after a usage period. Some patients reported feeling anxious with what the sensing devices were recording, and if it was recording data at all. This outlines a limitation with devices where near real-time feedback on usage is not currently provided whilst highlighting the benefits when it is provided.

6 DHAPP: SUMMARISING DEVICE DATA

Central to IDEA-FAST is the process of consistently and continuously collecting sensing data in-the-wild from patients to ensure the technologies are used during intended days and for extended periods. High quality data is required for effective analysis and to create a greater benefit to the research community and patients involved. Our preliminary findings support recent calls for increased access of health data for patients [24], and additionally suggests that not only do patients use this to reflect on indications pertaining to their health and wellbeing, but also to assess their participation in, and contributions to, a study, as well as the functionality of the device(s) in use. Across these findings, the quantity of sensing devices, companion applications, and distinct ways that health data summaries were represented increased the time and effort to participate for both patients and clinicians.

In response, and to explore ways to tackle this challenge, we have designed and developed a mobile application prototype, the *Device Hub Application* (DHAPP) that unifies how patients can monitor

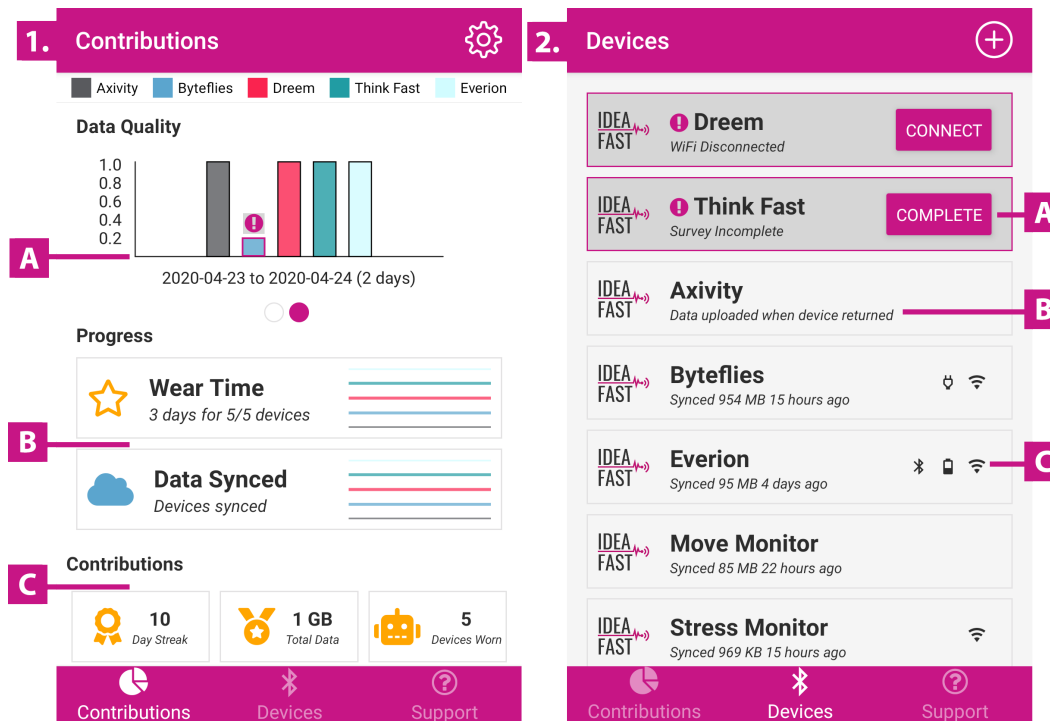


Figure 1: Exploratory designs of the Device Hub Application (DHAPP) that: (1) summarises data contributions from multiple sensing devices; and (2) provides a status overview of data transfer and connectivity of all technologies. The contributions screen provides feedback on data quality (1.A), progress against intended wear periods (1.B) and an aggregation of data contributions (1.C). The devices screen shows potential errors with technologies, e.g., that a daily cognition task is incomplete (2.A), when data was uploaded from a technology (2.B), and its connectivity status (2.C).

the usage of multiple sensing device during ongoing studies, which is available on GitHub [17]. Prior work highlights how patients feel motivated when they receive data, which often occurs at the end of a study period. The DHAPP summarises metadata from device usage that assumes regular access to (or control over) the raw data. This approach scales across multiple devices regardless of the specific measures provided by devices and the post-processing algorithms that are typically performed to create health reports.

Currently, DHAPP has four design features to assist patients in understanding device use, operation, and engagement with the research protocol: (1) *data volume* that provides a summary of participation over time; (2) *data quality* that notifies patients if data contributed falls below a threshold (Figure 1.1.A); (3) *data transfer and connectivity* that provides a status overview of all technologies in use (Figure 1.2.A-C); and (4) access to *training resources* for each device, i.e., documentation. This initial design explores playful gamified approaches to further engage patients at an individual level, such as streaks [7, 26]. However, our findings highlight that consideration is needed when representing ‘missing’ data so that patients are motivated to take action to contextualise why this occurs to reduce misunderstandings in the reported data.

7 SUSTAINING PATIENT ENGAGEMENT

Research studies are increasingly using multiple sensing devices to provide objective measures of a range of disease symptoms, e.g.,

[8, 23, 25]. Such multi-device health monitoring research creates barriers for participants due to the required configurations and adherence to use multiple devices. This paper has outlined preliminary qualitative findings from an ongoing multi-device study and highlights desires from patients to have (near) real-time access to data from such devices to support their study protocol compliance efforts. Building on these findings, we propose that summarising metadata from device usage is independent of sensing devices, its data, or derived health metrics, and offer a design solution for this as realised through the DHAPP.

The recognition for patients to have access to their own data [24] raises tensions around the responsibility of researchers during such long-term studies and how data can be meaningfully represented to patients during their participation in the study. A recent review of personal informatics literature suggests a need to address barriers to creating action from data captured [12]. In multi-device health monitoring studies action could take the form of participants monitoring that data is actively being contributed. Combining meaningful information across multiple data streams remains challenging. Our proposed concept of data contribution summaries help address this through an intermediary layer between raw and post-processed data that could enhance engagement.

The workshop [4] offers an opportunity to discuss ongoing challenges that we have experienced in supporting multi-device research, how our data contribution summaries concept could be extended to other contexts, and to understand how other approaches have been applied to engage patients through data.

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