# Sharing Access to Behavioural and Personal Health Data: Designers' Perspectives on Opportunities and Barriers

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## ABSTRACT

Behavioural and personal health data can be collected from smartphones, wearable and sensors. Besides using this data as a tool for self-reflection and self-management of health issues, it can also be beneficial to share it with others. The purpose of sharing can range from getting peer support to communicating better with clinicians or contributing to scientific research. However, sharing access to behavioural data can disclose sensitive details of the individuals' lives, and it may be challenging to make shared-access systems adopted, accepted and continuously used. In order to better inform the development of future systems, a review of the literature and a focus group were conducted. The findings presented here provide pointers to some essential considerations to be taken into account when proposing systems for behavioural data sharing.

## CCS CONCEPTS

• **Human-centered computing** → **HCI theory, concepts and models**; *Collaborative and social computing devices.*

## KEYWORDS

Shared-access data, continuous behavioural tracking, trust in computer technologies, healthcare applications

## 1 INTRODUCTION

Pervasive computer technologies are allowing significant advances in the healthcare domain [3]. Among the possibilities, data collected through continuous sensing can be useful for the assessment of affective states, behaviours and mental status [28]. Previous research has shown how personal data sensed through mobile phones, such as calls received, on-screen time and movement across locations can be mapped to possible symptoms of depression [29].

Several tools have been designed to use continuous sensing data to encourage self-management and behavioural change [12]. Besides, the collected data can offer great value to researchers, clinicians and circles of support, especially in the case of chronic illness, in which the monitoring of daily symptoms is crucial to its control [8]. For instance, patients with chronic conditions may voluntarily share self-tracked data to their doctors to get better treatment options [24]. Individuals may also agree to provide their data to open-access research platforms and contribute to scientific investigations [13]. In summary, sharing data can be highly beneficial in a personal and societal level.

However, when it comes to proposing shared-access data platforms, previous research has found that people are reluctant in sharing certain data types, despite it being beneficial for their health [14]. Some of the issues are that the collected data may contain intimate details of the individuals' lives [25] and uncover health disorders that can bring social stigma and discrimination [9]. Furthermore, individuals might be anxious [7] or frustrated [11] about their behaviours, which may also prevent them from sharing their data. Additionally, healthcare experts can also be reluctant to use the behavioural data collected through smartphones and sensors, as they might believe these data sources are not reliable or useful [6, 16]. Such lack of trust in the technology represents a barrier to the adoption of novel digital tools in a clinical setting [31]. An important question is then:

> If individuals are reluctant to share their data and doctors are not confident in using it, how can the potential benefits of data sharing systems be reached?

In order to work towards a better understanding of the enablers and barriers that could be addressed during the design of shared-access systems, we conducted a focus group interview. While previous studies have often focused on patients and clinicians perspectives, there is not much evidence about designers and developers perspectives until now. In the conception of pervasive healthcare systems, they are the ones who have to capture the motivation of each user group and bridge their needs into a solution [23]. Therefore, the findings from the literature review were complemented by the discussions generated in this focus group, to define some critical considerations for the design of future systems.

This paper is structured as the following: first, the background related to the research topic is presented. Then, the methods are described as well as the results. Finally, the findings are discussed taking into consideration the previous research. We hope that this paper serves as the starting point for further research involving the essential aspects to be considered in future designs for data sharing approaches.

## 2 BACKGROUND

Previous research has shown how sharing self-tracked data can bring benefits to healthcare. In a clinical context, patients can come to the consultation and bring data they collected about their daily activities in order to get a more personalised treatment [24, 35]. In a research context, if patients of life-long diseases provide permission to have their data available for open-access medical databases, it can be used to inform policymakers, practitioners and researchers [18]. In a home context, family members can share their health data to create a culture of mutual care [4] or make better sense of each others' behaviours [36]. Similarly, people may share their health data among peers with similar conditions to get motivation, inspiration and support [22, 26].

However, previous research also shows that the process of sharing data does not come without challenges, especially when it comes to behaviour and personal health data. First, while patients might see the value of self-tracking, they might disagree with sharing this data [33], depending on their perception of privacy and security risks [2, 15, 21]. For instance, some individuals are concerned about the possibility of misuse of any personal data by insurance and pharmaceutical companies [27]. Besides, continuous behavioural data also brings the potential for social stigma [9], and the fear of being continuously scrutinised [10, 30]. It has been found that there are aspects of people's lives that they prefer to keep private, such as class attendance [14] or location [10]. The lack of trust in the relationships with those accessing the data might even increase such concerns [19].

Second, there are differences across users' preferences and needs. Whilst some healthcare professionals may see the benefits of having highly detailed data, from multiple sources, to better assess the patients' progress and prepare more customised self-care plans [17, 35], others see self-tracked behavioural data as less reliable [16] and would prefer to see more scientifically validated evidence before using this data [6]. From the perspective of the individuals being tracked, having to collect and share high-quality data from several sources can be a burden. Moreover, some patients may become obsessed and engage in harmful behaviours (e.g. eating disorders) [14] or they might get demotivated with their lack of progress [22].

Third, it is not easy to balance the needs for support and autonomy. The consultation can be the occasion when doctors and patients collaboratively discuss the self-tracked data [12]. During this process, doctors bring to discussion data outliers and trends, while patients have the opportunity to add explanations. Having such discussions in person helps to prevent patients from getting into conclusions without appropriate clinical support and healthcare providers fear that patients will not be able to interpret their data alone[32] correctly. However, it has been suggested that future systems should encourage patients' autonomy to make sense of their data as well so that users are not overly dependent on their healthcare providers and technology can release the demands on the healthcare system [24].

In summary, the possibility of getting customised recommendations and better treatments are some of the advantages for the patients who are willing to share personal and behavioural data. Besides, the creation of systems that allow doctors to have access to data from their patients could also relieve the demands on health services. However, the potential lack of acceptability, the different users' needs and the problematic balance between autonomy and support are challenging. Such challenges could be addressed during the design process of shared-access systems, which leads to the motivation of involving designers and developers in the discussion. Previous research has investigated what requirements designers consider essential in m-government services [? ]. Designers are not only capable of empathising with users, but they can also see flaws of current approaches and the opportunities to create novel features. The focus group conducted with this goal is described next.

## 3 METHODS

A focus group was conducted to investigate further what the enablers and obstacles for the implementation of successful shared-access systems are. In the focus group, there were six participants: two interaction designers and four mobile apps developers with specialised knowledge in implementing and deploying systems for personalised healthcare. As they were part of the same research group, they collaborate across projects which involved depression, cognitive impairment and cardiovascular diseases.

The focus group lasted for 2 hours. The facilitator asked the participants semi-structured questions in order to initiate the process of brainstorming ideas and generate discussions. Participants were asked to share their views about the potential benefits that opening the access to personal health data may bring as well as the aspects that are currently hindering such possibilities. The session was audio-recorded, and the participants' notes were documented. The qualitative data were transcribed and then analysed using Thematic Analysis [5].

## 4 FINDINGS

Discussions in the focus group were organised in three main themes, which ranged from the application data can be used for, the remark that users are still reluctant to share data and the need for further features in current approaches for data sharing. The notes participants took during the discussion are in Figure 1.

### 4.1 Data for science, not for profit

Overall, participants believed that sharing data should have the ultimate goal of being beneficial for individuals and society: *"Good purposes, research purposes, which are going to benefit society in general, going to benefit the health sector"* (P5).

Given their technical knowledge, participants understood that sharing data enables the possibility to create algorithms and models: *"Sharing data can help others in a bigger way or solve a bigger problem. For example, if I share my heart data, how my heart is functioning, that can help to build an artificial intelligence algorithm which can automatically detect diseases or that can help to build some model"* (P3).

They also pointed out that it would be interesting to find ways to use data in the future to get a better diagnosis: *"We might not know what to do with the data right now, but in four years, I might go down with stress. Then we can look at the four years of data leading*

**Figure 1: Participants notes colour coded as: data types willing to share (green) and barriers to sharing (pink)**

up to me having this stress, and we could maybe figure out what is causing it, more accurately" (P4).

However, they recognised that data could be used to create models that might be harmful: *"A company or organisation that has my data can create a profile secretly and use it in the future for data analysis. They may already know about my behaviour before they actually meet me because they have a lot of data about me so that they can predict my actions in the future" (P1).* The idea of allowing personal data for profit-making was perceived negatively: *"It has to be good for all the people, and not for profit making like all the big corporations are doing in some way or another" (P2).*

### 4.2 Users are reluctant to share

During the discussions, it was argued that despite the potential benefit of having access to more data, people might disagree with the idea of sharing: *"It is technically feasible, and we are very much looking forward to getting this kind of data, because if you have more data you can build more robust systems. But, that is the problem: you do not have the data because people are not willing to share it" (P3).*

Furthermore, psychological data was mentioned as one data type that participants saw as potentially problematic: *"I think most people are happier sharing only physiological data, because of the stigma of sharing the mental data" (P6).* The stigma refers to the possibility of social discrimination: *"We take the data from all of these psychiatry patients, but these patients are afraid of other people knowing what is going on with their mental health" (P2).*

One participant pointed out what could be seen as a key requirement for users to feel more comfortable with sharing data, which is a relationship of trust: *"When you talk with your doctor, any data you share with your doctor, it is confidential" (P4).*

### 4.3 Systems could be improved

Participants agreed that the design of current systems are lacking transparency about data usage: *"The most important for me is the journey of the data, so who is going to use it, and at what point, who is going through the data" (P6).* The same applies to the 'terms and conditions' forms, as they are well designed: *"The terms of the data are sometimes not clear: when they want to collect it, like what sort of data they want to collect, it is very general the data agreement" (P1).* Another issue is the lack of further alternatives in the way that terms are proposed: *"Even if you read them you cannot say to the service 'I will not give you consent', then you do not have any option besides not to use it. You have to give away your data. It is like a trade-off" (P1).*

Given that they have the knowledge of how systems are built, participants discussed that it is difficult to convey how security and privacy protection were implemented: *"That is kind of a technical problem, I am not sure that those software developers they covered all the issues, if privacy and security were also considered when developing this platform" (P1).*

## 5 DISCUSSIONS

The technical advances in data collection using smartphones and sensors data allow closer tracking of daily activities and symptoms, thus providing excellent opportunities for healthcare [28]. In the case of patients with chronic health diseases, a better understanding of their condition is undoubtedly beneficial and sharing continuous sensing data is an idea that can aid patients beyond getting peer support [22]. During the focus group, participants discussed that opening the access of data can allow more opportunities for scientific investigations. They mentioned how some of the data tracked now could help doctors to understand patients' health issues in the

future. Participants also understand that data could be used to build algorithms and models that would help people in the long-term.

However, after the review of the literature and the discussions within the focus group, it became evident that there are barriers to the full acceptance and adoption of shared-access systems. The participants of the focus groups discussed that users are still reluctant to share their data. In order to be willing to share, individuals should be able to confirm that the benefits will overlap the possible risks [21]. The first step towards that is the guarantee that data will be primarily used to improve their well-being. Then, changes in the design of future systems could be helpful.

Recent research has pointed to the need for more flexible and fine-grained data control interfaces, which would allow users to actively decide how the different pieces of the data are going to be used [18]. The European General Data Protection Regulation (GDPR) has advanced on the efforts to enhance privacy protection [34]; however, as the participants emphasised, the current style of asking for consent does not suffice. One previous study has proposed a prototype that allows the selection of multiple sources of data, different access levels and combined strategies for privacy preservation [1]. Further features suggested by the participants were that users should have a complete view of the data journey when being asked to provide the consent: who will have access to it, at what point and why. The additional effort that this would imply and the actual engagement of users with such tools would be interesting research questions to investigate.

During the session, there were debates about the willingness to share psychological data. As some previous studies have discussed, data types that do not provide much insight into private information are most likely to be shared [10]. The issue is that the more personal data types might provide excellent value to clinicians and researchers. The participants mentioned that future systems should be more open and transparent about how data is used and protected. One of the main concerns of users is that data can be leaked and for this reason, more efforts towards the communication of risks through the design of the interface could be considered. Showing this extra layer of information could affect the willingness to share, which is another interesting question to investigate.

Furthermore, in order to increase the chances of acceptability and adoption, systems should be designed to get more trust from its users [19, 32]. However, it is necessary to remark that adding such features should not take away the need for data administrators to be trustworthy [20]. More information about data usage, more detailed models of data controls and higher transparency could lead to an increase on user trust, but they come with the responsibility that the data is indeed used as it claims [19, 32].

In summary, when merging the insights from the focus group with some of the evidence found in previous research, we can enumerate three aspects that we consider essential to be considered for future shared-access data platforms for healthcare:

- **User groups involved:** Data can be shared with family, friends, doctors, researchers, and the benefits for individuals and society vary across these. How could the design for shared-access take into account the differences between these user groups?

- **Flexibility and control:** Users could be able to choose which data items will be shared, when and what level of detail will be reported. They could also be able to delete data at any moment as well. How could user interfaces provide more fine-grained data and privacy control mechanisms?

- **Communication and transparency:** It is essential to show the benefits of sharing for both individuals and society and include evidence that those accessing and securing the data can be trusted. How could communication and transparency be improved in the design of future systems?

### 5.1 Limitations and Future Work

This study is very preliminary and small, and have focused on the designers perspective. There is thus a need for a much deeper and broader understanding of the factors that affect the willingness to share, especially from the 'users' point-of-view. An important issue here is that users are a heterogeneous mixture of people with very different health, socio-economic status, generational, and technological characteristics.

Therefore, our future work will focus on investigating these factors and their role in increasing user acceptability of shared-access systems. In order to achieve this goal, focus groups with other users groups, such as doctors and patients will be conducted. Furthermore, studies involving technology probes will be conducted, in order to create situations in which individuals will be asked to share their personal data. The goal is to come up with validated design guidelines that can help the development of future systems that use continuous sensing data to support individuals with a life-long illness.

## 6 CONCLUSION

Data collected from smartphones and wearable sensors are bringing many possibilities within the field of healthcare. The topic of sharing life-log data is particularly relevant to the management of chronic conditions, but challenges and constraints accompany the advances in this area. For this reason, the investigation of these issues is essential to the design of new systems, so that they can be addressed before they are deployed.

Through a review of the literature and a focus group, we found three aspects that could be further considered in future developments. We also reported on some of the perspectives of designers and developers of personalised healthcare systems. We see this workshop on Design Contributions to Pervasive Healthcare as a great venue to disseminate our findings, as we hope to gain valuable inputs from the workshop participants about how our research could go forward. We are also looking forward to discussing with the participants about their approaches to designing pervasive health systems and learn from them.

## 7 ACKNOWLEDGEMENTS

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