

Personal Health Data: Accessibility and Value in a Danish Context

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Abstract

The rapidly-evolving digital life of individuals has led to an increasing amount of personal health data (PHD) that are stored across various databases. This study aims to examine challenges encountered by healthy participants while accessing their PHD and to discuss how this knowledge can be used for the creation of future healthcare services. The participants were tasked to find and access their PHD. Thematic analysis of semi-structured interviews and journaling were the methodologies to examine participants' experience of accessing their PHD, and the perceived value of data. Our findings point out that the participants felt that PHD are accessible through services, nevertheless accessing of PHD were found to be a laborious task. Participants were disappointed by the experience of using various interfaces of the services. The perceived value of PHD was found to be dependent on the usability and personalisation features of the services, rather than on the data itself.

Keywords: personal health data, access, value, user experience

1. Introduction

In modern society, digital traces of everyday life also known as digital footprints, are scattered across world-wide information networks and stored in various databases. According to Sellen et al., it is hard to estimate the quantity of a digital footprint that individuals develop in everyday life due to the exponential growth of data available on network [1]. Nevertheless, digital footprints are informative about social interactions, human mobility patterns, behaviour and relationship patterns [2-4], as well as a population's health [5]. Previous research discussed the potential benefits of utilizing health-related digital footprints using big data techniques to improve a population's health and promote wellbeing [6,7]. Healthcare analytics such as predictive modelling methods have been seen to hold a potential to revolutionize the landscape of services in healthcare based on the information extracted through the classification of large datasets [8].

Along with this growth in big data analytics, there is increasing interest in persuasive technologies. Persuasive technologies utilize interactive computing systems to convince people to change behaviours or attitudes [9]. Well-known examples of such technologies include wearable sensors for health and wellness, solutions to control body weight or mobile applications to stop smoking [10-12]. Persuasive digital solutions can influence people to engage in healthier behaviours by providing informative content on a daily basis [13].

Using personal data have been seen to be beneficial towards understanding of oneself or as a trigger for making life changes through knowledge acquisition processes [14]. Nevertheless, acquiring knowledge from data is a laborious process [15]. Previous research concluded that people are hesitant to collect personal data due to several barriers such as lack of motivation, absence of information contextual to digital tools for data collection, time constraints, and data

scattered across various databases. Therefore, the complexity of the data collection process can hinder knowledge acquisition processes [15].

The accessibility and value of PHD has been the subject of previous research. Previous studies about accessibility were mainly focused on technical challenges of healthcare systems. For example, studies have proposed solutions such as cloud-based prototypes for remote access and sharing of encrypted PHD between patients and caregivers [16]. Or an attribute-based encryption solution for access control of PHD by patients [17]. Besides that, accessibility challenges faced by citizens while collecting their PHD have been the subject of discussion by Gencoglu et al. study [18]. The study pointed out that the collection of PHD in the Finnish context was a demanding task. The value of PHD has been also discussed by Fens and Funk, who suggest that visualization modalities can express human values by presenting data in different modalities and their relations to values [19].

The need for creation of novel health services that facilitate individuals to exploit the available PHD stored in databases across various organizations has been addressed by Harjumaa's et al. pilot study [5]. The purpose of this study was to explore the experiences of highly educated participants by requesting and collecting their health-related digital footprints from various Finnish organizations. Although the participants were highly educated and motivated individuals, the study pointed out that collecting digital data is a demanding task and that the value of the data is strongly related to the format and usability of the data itself. If the health-related footprints were in digital formats and therefore reusable, they were considered to be more valuable than paper prints by the participants.

Although the topics of accessibility and value of PHD has been studied before, less is known about the accessibility and value of PHD from the perspective of healthy individuals. The present study touches upon the work of Harjumaa et al. by sampling from the general healthy population that resides in Denmark [5]. Authors address the following research question: *How do healthy adults living in Denmark perceive their personal health data in terms of accessibility and value?* The research question serves the following purposes: (1) to explore participants' experience of accessing their PHD, and (2) to examine reflections on the perceived value of PHD. Authors aim to explore the availability of PHD to address accessibility challenges contextual to the engagement of a healthy population for PHD, which will contribute towards the creation of future healthcare services. This study aims to explore participants' experiences of accessing their PHD based on their narratives [20].

Nordic countries have high levels of digitalization and have invested a lot resources in digital services. According to the Europe's Digital Progress Report, Denmark has the largest number of active internet users in EU, and the availability of personal data online is over eighty percent [21]. This means that the majority of the Danish internet users have personal data available online. This leads us to assume that the availability of personal health data in Denmark is sufficient. In Denmark, the independent agency Datatilsynet enacts the law for data accessing, processing, and protection, in which it is expressly stated that Danish residents have the right to access their PHD that are stored by organizations [22]. Thus, according to this legislation, the participants of this study were anticipated to have access to their PHD.

The definition used in this paper for perceived value is based on the participants experience and needs when accessing their PHD through a service or application. The service or application has inherent properties which are contextual to the participants' interactions where the perceived value is derived [23]. The role of accessibility in this experience occurs when a participant needs to have a healthcare opportunity fulfilled, such as: viewing, retrieving, or interacting with their personal health, which is provided by a service or application thus affording means and opportunity [24].

The remainder of the paper is organized as follows: The Methodology section outlines the research method and analysis that was used. The Results section reports the findings of the study, while the Discussion section presents the main findings. Finally, the Conclusions section presents the conclusions.

2. Methodology

This section presents a detailed description of the methodology. It provides information about the study participants and study setting, as well as details about the data collection and analytical approaches that were selected by the authors.

2.1. Study participants

The recruitment targeted the healthy population that have lived in Denmark for a minimum of 2 years, as it was important for participants to have digital health records, as well as to be familiar with the public health system and digital communication in Denmark. Interesting to note is from the 39 individuals that were asked to participate in this study through emails or face-to-face contact, only 12 of them initially agreed to participate. In the end, 8 participants, 2 native and 6 non-native speakers, with an age range between 24 to 34 years remained active. Table 1 summarizes the participants' characteristics.

Table 1. Participants' characteristics.

ID	Gender	Age	Educational attainment	Occupation
#1	Male	25-34	Postgraduate	Engineer
#2	Female	25-34	Postgraduate	Engineer
#3	Female	25-34	Postgraduate	Business Intelligence Developer
#4	Female	25-34	Postgraduate	Store Assistant
#5	Male	25-34	Postgraduate	Unemployed
#6	Female	25-34	Postgraduate	Student
#7	Female	25-34	PhD Fellow	Language Technologist
#8	Female	25-34	Postgraduate	Graduate

2.2. Study setting

This study focuses on the experiences of a group of 8 participants in accessing their PHD from organizations of their own choice. To help facilitate participants with this assignment, authors shared a list of potential organizations with them. The list of organizations was created by the authors after running a brainstorming session and taking inspiration from Harjumaa et al. study adapting it to the Danish context [5]. The list comprised of public or private organizations, including: fitness chains, groceries stores, healthcare providers, the national healthcare portal in Denmark, retail chains, a bank, and a public transportation provider. Participants were asked to access any data source that could help them interpret their own health, health habits, and behaviour over the course of time. They were provided with a Word document, in which they were instructed to store the names of the organizations that were accessed. They were also encouraged to write down all the relevant information contextual to their experience. Participants were given a time period of four weeks for data collection.

All participants received and signed an informed consent form prior to the study. It was emphasised that the authors will not access or store any of the PHD that the participants collected at any time. Also, it was stated that they had the right to withdraw their participation from this study at any time. Finally, they were informed about the type of data that authors were aiming to collect and store for the study.

2.3. Data collection: qualitative inquiry

To gain a deeper understanding of participants experience of accessing their PHD, and to capture more openly their opinion, while minimizing bias, a qualitative approach was developed using semi-structured interviews and journals [25,26].

The data was collected through 6 face-to-face and 2 Skype interviews. Interviews were not interrogations or mutual exchange of views between the two parties. Authors followed the approach of Czarniawska, who suggests that interviews are the medium for knowledge

exchange between two parties, who have a common goal to acquire knowledge [20]. As the aim of the study is to gather and investigate the experiences of the participants, a semi-structured interview guide was adopted to provide a flexible setting for sharing experiences. During the interviews, the participants were encouraged to share information that they considered relevant to this study.

The semantic comprehension of the questions was pre-tested with individuals, who did not participate in the study [27]. The interview guide was comprised of two themes: (1) experiences of accessing data, and (2) perceived value of data. Authors were interested in capturing the experiences of participants while accessing their PHD, personal expectations, information accuracy, and their opinion regarding future services that would allow people to track personal health development over years. Finally, authors were interested in the perceived value of PHD, namely how valuable did they consider their PHD to be. The interviews were conducted in May 2017, using the open-ended interview guide designed by author 1, while the analysis of results was a collaborative joint process of three authors. In the end, approximately 80 pages of verbal transcriptions by authors 1 and 2 was produced, while the interviews lasted on average 36 minutes.

2.4. Data analysis

Evaluating the experience of participants is a demanding and challenging task, as the subjective experience of a person is observed indirectly, and thus it is hard to be analysed by another person [28]. Among the main challenges that authors encountered, is the evaluation of reliability of participants subjective experiences, as asking the participants to recall and narrate first-person subjective experiences might have resulted in alterations [29]. Taking this challenge into consideration, authors shared a Word document with participants prior the data collection phase and encouraged them to use it to take notes of their experiences while accessing the organizations of their choice. All of the participants used it to keep notes of their experiences. Previous literature suggests that the combination of taking notes and revising them during narration of past personal events is an effective way to recount experiences [30]. Taking into consideration all the above, we relied not only on narrative first-person descriptions of participants' subjective experience, but also on participants' personal notes. Furthermore, interviews conducted after the end of the four-week data collection period ensured that the time interval was the shortest possible.

Verbal transcriptions of interviews together with the participants' notes (Word documents) were analysed thematically based on the two themes in the interview guide [31]. To analyse the data the following process was adopted: initially two authors read participants' notes and verbal transcriptions to identify relevant quotes that emerged from the interview questions. The identification of quotes was focused on two topics: accessibility and perceived value of PHD. All relevant quotes were then organized in subthemes, and authors had three sessions in which preliminary findings were discussed, and the subthemes were organized within the overarching themes. Subsequently, a third author was included in the data analysis process after an introduction to preliminary findings. Authors had two sessions in which they discussed the outline of the subthemes and themes to arrive at the final framework. Following this collaborative data-driven process, data were clustered into subthemes and findings were analysed. The analysis of findings focused on how participants experienced the interaction they had with organizations for (1) access, and (2) perceived value of data.

3. Results

In this section, the findings of this study will be presented based on participants' experiences. The findings are grouped into the following two themes: (1) Data accessibility, and (2) Content of data. Data accessibility has no subthemes. Content of data is comprised of the following three subthemes: Medical language, Visualizations and Future healthcare services.

3.1. Data accessibility

In a period of four weeks the 8 active participants accessed a total of 31 databases (23 web applications, 8 mobile apps) and wearable sensor data. Based on their content, these sources were sorted into subcategories that can be seen from Table 2.

Table 2. Sources accessed by participants.

Source categories	Source name
Mobile & Web Apps:	8Fit, BedTime, Headspace, Health iPhone, Lifesum, MyFitnessPal, Yoga Studio, Yummly, Amazon, Apple, Google, YouTube
Fitness Chains:	FitnessWorld, FysiskForm
Wearables:	Garmin, Withings
Healthcare Systems:	Borger, Care4U, Sundhed, Plus1 Tandlæger
Social Media:	Facebook, Instagram
Transportation:	Rejseplanen
Employers:	Inspiration
Education:	Københavns Universitet
Finance:	Nordea Bank
Stores:	Coop, Føtex, Louis Nielsen, Synoptik, Matas

The participants of this study apart from accessing traditional healthcare sources, found and accessed their PHD through various other sources. Interestingly, YouTube and Instagram were considered to be sources that hold information about ones' mental health. Participants argued that a song or a picture that posted could evoke vivid memories as well as emotions from their past. Besides that, data of sickness absence from the database of a former employee (Inspiration) and data from a course absence report (Københavns Universitet) was considered to provide information about the participants' personal health. Personal data pertinent to eating habits that were accessed through grocery stores such as Coop and Føtex, and considered relevant to the participants' personal health.

The majority of participants reported that they found it challenging to define where to search for their PHD. When tasked to define where to find their PHD, they either conducted brainstorming sessions or used Google search queries to find where their PHD have been stored:

“Through Google for everything, so first I’ve made a little brainstorm, ok, where can I find [the] doctor... just Google it. I went to Denmark’s doctor website to fit it, and just through Google to find all the websites that I thought would be relevant.” (#5).

Accessibility challenges were also contextual to the design of interfaces of the digital applications that participants interacted with. The interactions that several of the participants had with the interface of the national health data registry, was characterized by a negative experience from navigating through the website where there were broken links, incomplete pages, and a general lack of intuitive content and function:

“One challenge would be in Sundhed, as I’ve mentioned before I had [tried] 3 links to find my appointments and one was working...” (#2).

Data access sequences were conducted in 2 different arrays. The first was the function of verification through an online application such as the national health data registry or the digital platform of a fitness chain. The participants had to verify their identity using their civil registration number and related digital access code, or mobile phone authentication:

“And by using the NemID codes, the citizen can go inside this portal and access medical records from the moment... from the year that he or she has been registered in Denmark as a citizen.” (#1).

The civil registration number in Denmark (CPR) is assigned to each individual resident. The NemID card is an identification verification number card with 4-digit codes that correspond with 6-digit codes which participants used to reply to the source of identity.

The second type of data access was more manual in nature where multiple participants searched for PHD through means such as: search histories on Google or Facebook, purchase histories on Amazon, Rejsekort, and in a bank. Or they were required to physically interact with

medical professionals either through phone, email, or by visiting the doctor's office. Participant 3 was an example of visiting her dentist to ask for her data:

"I had to go to the dentist the same day I've asked them if I can go... but normally I don't go 3 kilometres to ask my dentist about my data, that's not something I do every day." (#3).

Her request was quite surprising to the dental receptionists as it was an unexpected encounter:

"I went to [the] dentist and I [said] 'Can I see these things' and they were like a bit surprised [...] 'Why?' I don't know maybe they thought I [didn't] agree or something [...] whatever it means, it was fun [...] but I think that they got surprised." (#3).

All of the participants reported that the permission process to gain access to their PHD was straightforward, the majority of them noted a standard authentication process with the CPR number and NemID card. In the case of participant 7, she requested her data using an unverified email account, and in order to verify her identity with her dentist to gain access to her personal data, she had to share her CPR number via an SMS-based verification:

"I wrote them from an email that they couldn't know I had, I never used that email with them. And they only asked for my name and CPR number, and I was really disappointed about that. Because a CPR number is often treated as a secret in the public system..." (#7).

The CPR number is considered to be personal information that usually individuals share with public authorities in face-to-face transactions or via the official channels for Government-Resident communication.

3.2. Content of data

Medical language

All of the participants suggested a level of implicit accuracy in the content of PHD, as they could not verify or test the validity of their PHD except if there were blatant errors, such as remaining prescription refills available that was known to be incorrect:

"I think it's hard for me to judge because the list was so long but it looks... like 100% accurate you know [...] like there was no occasion [of] something that I [looked] for and I couldn't find it [...] so I think the accuracy was very good." (#5).

Challenges contextual to the medical terminology was experienced by all of our participants. Several of them noted that medical terminology was used in their PHD which was confusing, meaningless, and had no explanation either through doctor notations or on clarifications that were available on the site. This was a challenge that was expressly considered in the context of the national health registry:

"Because everything is in doctor terminology, so you need to take a little step back and think what it actually means" (#8).

The medical terminology in Danish and the lack of options for selecting a language other than Danish was also a point of contention, as only two of the participants were Danish natives. The other 6 participants who were non-native speakers or who were learning Danish, reported difficulties using the national health registry:

"... although I speak Danish, there are things especially like medical things the way that are written like that you can't really understand." (#6).

Visualisations

Participants also connected the value of their PHD to data visualisations. Some of them suggested that the visualisations of PHD need to be more effective for their contextual use with customisable interactive components such as parameter declarations. Some of these formats were desired, such as graphical forms of bar and pie charts, or image files:

"I am a very visual person, so I would like to see some graphs, so really numbers don't work in my mind so fast, but if I could see for example I have a low iron, or blood or whatever and this goes up and down ..." (#6).

Participants expected visualisations to be a method for managing requirements for technical skills when dealing with heterogeneous formats of PHD:

“...it’s a tough problem having to deal with all these formats. So that would be some way of visualising and predicting future health outcomes...” (#7).

Future healthcare services

Several of the participants expressed that a health change would probably increase their interest to access and keep track of their PHD. When the participants asked if they would use the data that they had accessed during this study, they expressed 2 conditions of which they would use the data, first if a change was taking place, such as moving to another country, or going to a different doctor:

“... not exactly planning, but now that I have the dentist records and I’ve by chance met a cool dentist as a friend. I probably might end up at least considering asking her about something knowing that, it she’s like, I couldn’t tell without [the records] I could say I actually have the data.” (#7)

Second, they wanted to monitor change in health conditions over time:

“I would like for example, to keep track of that information more regularly to see how often do [I] get sick based on [my] medical visits. How much medication [I] take, if [I] have done vaccinations, for instance...” (#1).

When asked of what a future service could offer to utilize their PHD, the majority of the participants envisioned predictive analytics as a service that would centralise data from various available sources. This service would increase future awareness about PHD and would facilitate them to understand how their health would develop over time. Preferably this unified system should be able to detect and report on patterns of mental and physical health, and wellbeing through statistics or customisation options:

“If there was a service to use to predict how your health would develop throughout the years maybe that would be interesting to see like a pattern of behaviour of both physical and mental [health].” (#5).

The majority of participants expressed that this unified collection of their PHD would interface with applications, such as mobile phones or through web browsers that would have enabled them to use their PHD:

“If there was one website that ideally could collect all of the health information related to me than it would be more useful, rather than going into each one of them separately.” (#2).

The participants speculated that if all PHD would be stored centrally by a unified service, it would have to be regulated heavily by legal governing bodies:

“Although I would like to be on Sundhed because that main public health website, so why not have everything there? But if there was a separate one, yes, as long as it is legal to share information there and the government has some kind of control of how this website uses the information” (#2).

Nevertheless, a couple of participants exemplified negative attitudes towards a unified system that would centralise personal data collection and storage:

“I’m not in favour of collecting lots of data in one place anyway. I think it’s positive that I can get it, but I don’t want to have all of it in one place.” (#7).

Concerns of data security around PHD in a unified system was strongly emphasised, along with the hesitation around management of the PHD collection if the unified system required them to manually consent, assemble, and finance their PHD collection. In addition, apprehensions of data handling by other parties whom were not given exclusive permission to use the data by the data owners, was identified as a point of contention for participants:

“I wouldn’t mind as long as this is not taken by [a] third party and used [in] a way that is not correct, whatever that could be.” (#2).

4. Discussion

The present study touches upon Harjumaa's et al. pilot study, using a similar interview guide as a means to explore the experiences of a sample of healthy Danish residents [5]. Our objective was to explore how accessible PHD are, as well as the perceived value of data in order to address challenges encountered by the healthy population, potentially useful for the creation of future healthcare services.

Our findings point out that the participants generally found that PHD were accessible for them. As Denmark is performing well by providing high quality digital services to its residents in addition with the high availability of personal data online, this is perhaps not surprising [32, 21]. In the Boston Consulting Group's e-Intensity index from 2016, which measures to what extent a country embraces the Internet, Denmark ranks number 4 out of 85 countries [33]. These highly ranked numbers are in agreement with the experience reported by the participants of this study. In contrary to these findings, the study of Gencoglu et al. concluded that many Finnish organizations had refused or ignored citizens requests to access their PHD [18]. In the same vein, the Harjumaa et al. in a Finnish context concluded that "it is not very feasible to collect digital footprint data" [5, pp.138], as data was often accessible only in paper format. The Finnish participants experienced difficulties accessing PHD within the databases of both public and private organizations, concluding that the Finnish healthcare organizations and companies were unprepared to provide digital data to individuals. Despite the fact that Finland ranks 3rd out of the 28 EU Member States concerning the provision of digital services [34]. This finding, while preliminary, suggests the quality of provision of digital services is multilevel and depends on factors such as quality of regulations and ICT infrastructures [35].

Although the Danish participants were able to access their PHD, they expressed low motivation to access their data in the future unless there was a contextual change to their health. Similar evidences of this behaviour have been addressed by previous research, suggesting that healthy individuals have low motivation to monitor their own health in order to track possible health changes and potentially to prevent diseases [36]. Interestingly, healthy people have the tendency to avoid reading, discussing, or thinking about their health behaviours, becoming eventually either ignorant or uninformed individuals about possible consequences of their own behaviour [36]. Additionally, raising public awareness to prevent diseases and to engage healthy population to make healthier choices and to monitor their own health has been challenging [37,38]. The study offers some additional insights towards this challenge underling that the medical terminology might be an additional factor that discourages individuals from accessing their PHD, as it might lower their comprehension rates, especially in case of individuals with low levels of education [39]. The Wass et al. study also suggested the lack of medical background or knowledge by individuals or the provision of medical information in a language other than their mother tongue, as challenges which future interventions should address [40].

Another challenge that this study points out is pertinent to accessibility of PHD, which is contextual to medical jargon together with unfriendly user interfaces. The majority of the health services and applications that were accessed by the participants are non-interactive interventions, that are designed mainly to store personal information. Personal informatics systems should fulfil some essential design principles such as simplicity and effectiveness in usage to allow seamless human-computer interaction. This finding further supports the idea that although the number of services pertinent to health and wellness are increasing the design of the services needs further refinement to engage people. To further support this finding, the majority of the applications accessed were uni-faceted systems. Thus, meaning it could provide information only for one facet of one's personal life and not a combination of different facets such as information about health, work life, or interactions with other people [15].

What this study also confirms is a need for creation of future services to enable individuals to collect multiple formats of information contextual to several instances of their life. Providing a holistic view of data could increase individual awareness [15]. Also, a finding of the present study is the demand for personalisation of services without violating ethical standards, which is consistent with the findings of Noar's et al., research [41]. The transtheoretical model

suggests that individuals' attitudes, strategies, and skills differ at each stage of the behaviour change process, so that future interventions would be tailored-made in each stage. Moreover, personalisation of services, means that future interventions should be sensitive to different stages of the process, in order to increase effectiveness and to move individuals closer to the stages of behavioural change [41]. Also, custom visualisation components have been proposed by the present study as components that could contribute towards engaging interventions. Personalisation of visualisations could provide a short-term overview of personal data, but more importantly could enable individuals to specify and identify associations of multiple phases over the course of life [15]. Previous research concluded that visualization modalities can express human values by presenting data in different modalities and their relations to values [19]. Empowering individuals by developing personalised services, means providing the right information on time to enable informed decision-making [42].

One of the major challenges that research confronts is how to create value utilising data. The aim of this study was to explore participants' experience of accessing their PHD stored in various organizations and to comprehend participants' needs. Our findings suggest that future healthcare services should develop solutions to cope with challenges pertinent to technical solutions, such as multi-faceted systems that will enable the integration of data from various sources, or personalisation features to tailor-made services. Besides that, research should be focusing on investigating interventions associated with motivation to change health behaviours, as well as with educational approaches to increase awareness of the healthy population which is pertinent to the adoption of healthy behaviours.

5. Limitations

The present study has several limitations. For instance, participants were recruited through connections of personal contacts, but were not personal contacts themselves, which might have led to a sampling bias. In addition, the limited number of participants and the homogenous age group with high educational attainment, might have also introduced a bias in the findings. Therefore, the generalizability of the study is limited within the Danish context.

6. Conclusions

The scope of this study was to explore how accessible and valuable are PHD for the general healthy population in Denmark. Our study shows that although PHD are accessible through applications and services within the Danish context, the perceived value was found to be dependent on personalisation features and visualizations.

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