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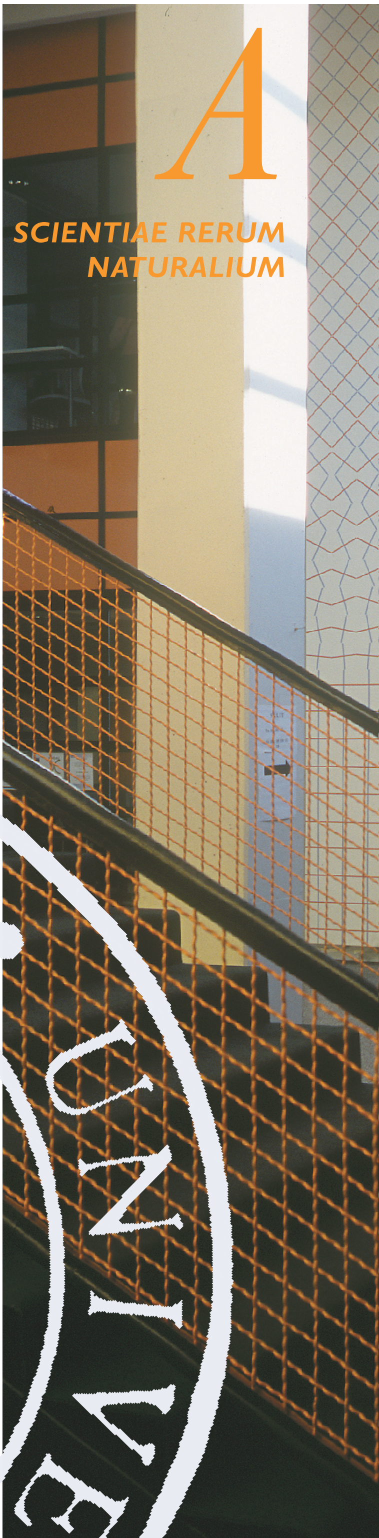

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SCIENTIAE RERUM
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Maria Karampela

RECOMMENDATIONS TO ENABLE AND SUSTAIN PERSONAL HEALTH DATA ACCESS AND SHARING

AN EMPIRICAL APPROACH

UNIVERSITY OF OULU GRADUATE SCHOOL;
UNIVERSITY OF OULU,
FACULTY OF INFORMATION TECHNOLOGY AND ELECTRICAL ENGINEERING

ACTA UNIVERSITATIS OULUENSIS
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MARIA KARAMPELA

RECOMMENDATIONS TO ENABLE AND SUSTAIN PERSONAL HEALTH DATA ACCESS AND SHARING

An empirical approach

Academic dissertation to be presented with the assent of the Doctoral Training Committee of Information Technology and Electrical Engineering of the University of Oulu for public defence in the OP auditorium (L10), Linnanmaa, on 30 June 2021, at 12 noon

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Professor Minna Isomursu

Reviewed by
Professor Ana M. Bernardos
Professor Jonna Häkkilä

Opponent
Associate Professor Elia Gabarron

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University of Oulu, P.O. Box 8000, FI-90014 University of Oulu, Finland

Abstract

The amount of personal health data (PHD) for each individual in Europe has radically increased due to the adoption of various technologies in everyday life, such as mobile phones and wearable sensors. PHD can include different types of health-related data, such as medical records, fitness tracking, transportation data, or behavioral data from social media. Health data are invaluable to support people in acquiring timely knowledge about their health and wellbeing. Access to PHD provides users of information systems (IS) with the opportunity to acquire self-knowledge and participate in decision making, while sharing PHD with other stakeholders can facilitate knowledge sharing. Despite this, recent reports support that, on average, only 18% of the European population have used their PHD through digital services (European Commission, 2019).

Prior research about PHD access in IS has mainly focused on the technical aspects of the topic. This had led to limited empirical knowledge about users' access encounters with PHD. In the frame of this dissertation, access encounters are considered the moments that users interacted with their PHD through IS. As for PHD sharing, the implementation of new General Data Protection Regulation (GDPR) renewed research interest towards the exploration of users' willingness to share their PHD with other stakeholders in a healthcare context. A literature review addressed the lack of case studies in prior work about PHD access and sharing, thus motivating the development of the first empirical studies. The development of the rest of the studies was exploratory, building upon the findings that emerged through the course of empirical work.

This doctoral dissertation uses an embedded case study consisting of four embedded units to answer a single research question (RQ). This dissertation contributes with updated knowledge that lies at the intersection of IS, health informatics, and human-data interaction (HDI), answering the RQ: What recommendations are relevant for IS designers and developers to enable PHD access and sharing? Based on the findings of the case study, five recommendations (R) were found to be relevant for IS designers and developers in connected health (CH) to foster the development of IS. The five recommendations can also sensitize policy makers to consider the timely nature of the two research topics. The recommendations are particularly relevant to this audience due to the timeframe of the study (2018–2020), which coincides with the enforcement of the new GDPR in May 2018. The recommendations highlight the temporal and subjective nature of PHD access and sharing, introducing implications at a theoretical and practical level. This dissertation proposes the consideration of the five recommendations during the design and development phases of IS: R1) consider how users perceive health and PHD; R2) consider what data types and formats foster PHD access; R3) simplify medical terms, provide visualizations, and interfaces to nurture usability and personalization features, thus promoting the perceived value of PHD; R4) consider age, education, occupation, and digitalization to encourage PHD sharing with stakeholders; and R5) consider data privacy under the prism of data types, access control and trust, conditions of sharing, and the purpose of data processing.

Keywords: access, connected health, embedded case study, health informatics, human-data interaction, information systems, information systems designers, information systems developers, personal health data, recommendations, sharing, users

Karampela, Maria, Suosituksia henkilökohtaisen terveystiedon saavutettavuuden ja jakamisen mahdollistamiseen ja ylläpitämiseen. Empiirinen lähestymistapa

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Tiivistelmä

Henkilökohtaisen terveystiedon määrä Euroopassa on kasvanut jokapäiväisen teknologian, kuten matkapuhelimien ja puettavien sensorien, lisäännyttyä. Henkilökohtainen terveystieto voi sisältää erilaista terveyteen liittyvää tietoa, kuten potilasasiakirjoja, kuntoilutietoa tai terveyskäyttäytymiseen liittyvää tietoa. Terveystieto auttaa ihmisiä ymmärtämään terveyttään ja hyvinvointiaan. Pääsy terveystietoon antaa tietojärjestelmien käyttäjille mahdollisuuden parempaan itsetuntemukseen ja päätöksentekoon osallistumiseen, ja terveystiedon jakaminen voi auttaa tietämyksen jaossa. Tästä huolimatta tutkimukset osoittavat, että vain 18 prosenttia eurooppalaisista on käyttänyt henkilökohtaista terveystietoaan (European Commission, 2019).

Aiempi tutkimus henkilökohtaisen terveystiedon saatavuudesta on keskittynyt teknisiin seikkoihin. Tästä johtuen empiiristä tutkimustietoa käyttäjien kokemuksista henkilökohtaisen terveystiedon saatavuudesta on vähemmän. Tässä väitöskirjassa tarkastellaan niitä ajallisia hetkiä, joissa ihmiset käyttivät tietojärjestelmiä henkilökohtaisen terveystietonsa hyödyntämiseen. Eurooppalaisen tietosuojalainsäädännön (General Data Protection Regulation) käyttöönottoa tarkasteltiin tutkimuksessa henkilökohtaisen terveystiedon jakamisen näkökulmasta. Tutkimuksessa raportoitu kirjallisuuskatsaus osoitti, että empiirisestä tutkimuksesta henkilökohtaisen terveystiedon käyttämisestä ja jakamisesta on puute. Tämä johti tutkimuksessa raportoituun tutkimukseen.

Tutkimusmenetelmänä käytettiin sulautettua tapaustutkimusta, joka koostui neljästä tapausyksiköstä, jotka vastasivat yhteen tutkimuskysymykseen. Tämä tutkimuskysymys on: Mitkä suositukset ovat relevantteja tietojärjestelmien suunnittelijoille henkilökohtaisen terveystiedon käytön ja jakamisen suunnitteluun? Tapaustutkimuksen löydösten pohjalta väitöskirjassa esitetään viisi suositusta, jotka ovat relevantteja terveyteen liittyvien tietojärjestelmien suunnittelijoille ja toteuttajille. Nämä viisi suositusta voivat myös auttaa päättäjiä terveystiedon jakamiseen liittyvissä ajankohtaisissa kysymyksissä. Suositukset ovat erityisen relevantteja tälle kohderyhmälle, koska tutkimus on tehty juuri uuden eurooppalaisen tietosuojalainsäädännön (GDPR) soveltamisen aikaan 2018. Suositukset korostavat henkilökohtaisen terveystiedon käytön ja jakamisen ajallista ja subjektiivista luonnetta. Sillä on vaikutuksia sekä teoreettisella että käytännön tasolla. Ehdotetut suositukset ovat: R1) ota huomioon se, kuinka käyttäjät ymmärtävät terveyttä ja terveyteen liittyvää tietoa, R2) ota huomioon eri datatyypit ja formaatit terveystiedon saavutettavuudessa, R3) yksinkertaista lääketieteellisiä termejä, tarjoa visualisaatioita ja rajapintoja käytettävyyden ja personoinnin tueksi ja lisätäksesi henkilökohtaisen terveystiedon koettua arvoa, R4) ota huomioon ikä, koulutustausta, ammattitausta ja digitalisaation aste henkilökohtaisen terveystiedon jakamiseen kannustamisessa, ja R5) ota huomioon yksityisyys eri tietotyyppien, luottamuksen, jakamisen ehtojen ja tiedon prosessoinnin tarkoituksen näkökulmista.

Asiasanat: henkilökohtainen terveystieto, ihmisen ja tiedon vuorovaikutus, jakaminen, käyttäjät, saavutettavuus, sulautettu tapaustutkimus, terveyden tietojärjestelmät, tietojärjestelmäkehittäjät, tietojärjestelmäsuunnittelijat, tietojärjestelmät

To life travelers – enjoy every moment of the journey

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We live only once – unless we reincarnate endlessly – and we should allow ourselves to enjoy the moments we are in to the fullest. The last three and a half years of my life I have been fortunate to indulge myself with the majority of my PhD moments. This PhD journey has been an incredible adventure that took place in different parts of the world and was surrounded by great companions. My journey started approximately six years ago by submitting an application for a Marie Skłodowska-Curie PhD position at the University of Oulu. After being accepted, I actually decided to reject the offer and instead head towards a different direction. Now, six years later, taking a different path, somehow I am back where it all started to complete the circle.

What I have gained throughout this PhD adventure is more than I could possibly imagine, more than I have hoped for. The people I came across, the circumstances I dealt with, along with sounds, tastes, smells and colors have contributed to the making of the person I am today. Pursuing a PhD is much more than a qualification, it's certainly a process of self-discovery. The two topics I discuss in this dissertation – accessibility and sharing – I have now come to realize that I have been dealing with both since my childhood. I always thought that accessibility to information can offer endless possibilities, leading hopefully to a better version of who we are today. I associate sharing with intimacy and companionship, which lay the foundations for meaningful and trustworthy relationships.

Without financial support such endeavors remain usually on the drawing board. Therefore, I would like to express my sincerest gratitude to the *IT-University of Copenhagen*, *the Digital Design Department* for providing me with the funds to conduct research work at an earlier stage. Also, *the University of Oulu*, especially *Professor Markku Oivo* Head of the Department of Information Processing Science, for supporting me in order to finalize the present research work. Thank you to the *ENJECT (COST) action* for a Short Term Scientific Mission (STSM) grant to Imperial College in London and to *NordPlus* for the grant to attend a design course at Reykjavik University.

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To my dear friends, who became my family - one way or another. *Aggeliki*, *Domna*, *Vasiliki*, plus one Doctor (PhD)! Thank you for being such sister-friends, for listening, advising and supporting me to my bittersweet moments. *Gianni*, *Maria* and godson *Filippe* my Greek-Danish family – Aloha! Thank you for your guidance and useful advice – doctoral thesis is now defended, what's next? *Minna* I can't simply find the right words! Thank you for being such a wonderful friend, it has been a mind-blowing journey and I am so delighted I have shared several moments with you. Also, kiitos suomen käännöksen tekemisestä. *Obaida*, my officemate, roommate and 'habibi', I already miss our 'over a coffee' conversations. Thank you for boosting my positive energy – it's a mutual exchange. I am glad I have found you, you have contributed to the way I see the world.

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Last but not least, to my partner-in crime and life, *Andrea*. You are finally done with the proofreading! I am so happy and grateful we have shared moments of this journey together. Thank you for making me smile whatsoever and reminding me again why I should, or not, give a damn about certain things.

I am almost certain that I have omitted people that have somehow contributed to this dissertation. I would like to extend my gratitude for your ‘helping hand’ throughout this journey.

“I have no special talent. I am only passionately curious”, Albert Einstein.

Date Maria Karampela

18/05/2021

Abbreviations

CH	connected health
CHERRIES	checklist for reporting results of internet e-surveys
Covid-19	coronavirus disease 2019
E	element
e.g.	exempli gratia
EC	exclusion criteria
EHRs	electronic health records
EMRs	electronic medical records
Etc.	et cetera
EU	European Union
FI	Finland
FRA	France
GDPR	general data protection regulation
GER	Germany
HCI	human-computer interaction
HDI	human-data interaction
HPV	human papillomavirus
IC	inclusion criteria
IoT	internet of things
ID	identification
IS	information systems
MQ(s)	mapping question(s)
N	number
NL	the Netherlands
P	paper
PHD	personal health data
PHRs	personal health records
R	recommendation
RQ(s)	research question(s)
WHO	World Health Organization

Original publications

This dissertation is based on the following publications, which are referred to in the text as P1–P6. The publications are reproduced at the end of this dissertation with the type of permission from the publisher.

I Karampela, M., Ouhbi, S., & Isomursu, M. (2018). Personal health data: A systematic mapping study. *International Journal of Medical Informatics*, *118*, 86–98. doi.org/10.1016/j.ijmedinf.2018.08.006

II Karampela, M., Grundstrom, C., & Isomursu, M. (2018). Personal health data: access and perceived value in Denmark. In *Proceedings of the 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC)* (pp. 4081–4084). doi: 10.1109/EMBC.2018.8513407.

III Karampela, M., Grundstrom, C., & Isomursu, M. (2018). Personal health data: Accessibility and value in a Danish context. In B. Andersson, B. Johansson, S. Carlsson, C. Barry, M. Lang, H. Linger, & C. Schneider (Eds.), *Designing Digitalization (ISD2018 Proceedings).* Lund, Sweden: Lund University. ISBN: 978-91-7753-876-9. http://aisel.aisnet.org/isd2014/proceedings2018/eHealth/7.

IV Karampela, M., Porat, T., & Mylonopoulou, V. (2019). Needs of head and neck cancer patients and stakeholders during rehabilitation. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth'19) (pp. 415–421). Association for Computing Machinery, New York, NY, USA. DOI: https://doi.org/10.1145/3329189.3329236.

V Karampela M., Ouhbi, S., & Isomursu, M. (2019). Connected health user willingness to share personal health data: Questionnaire study. *Journal of Medical Internet Research*, *21(*11), e14537. doi: 10.2196/14537

VI Karampela, M., Ouhbi, S., & Isomursu, M. (2019). Exploring users' willingness to share their health and personal data under the prism of the new GDPR: Implications in healthcare. In *Proceedings of the 41st Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC)* (pp. 6509–6512).

As the principal author in these studies, I held the responsibility of the overall study conduct and drafting of the manuscripts. Detailed information about the specific contributions in each paper can be found below:

In **study I**, I searched and collected the dataset, and conducted the initial classification and interpretation. Also, participated in the data analysis and classification process. I drafted the first version of the manuscript and coordinated the work of the research team.

In **studies II** and **III**, I designed the study material, recruited the participants, and conducted the one-on-one interviews, participated in data transcription, and the analysis and classification process. I drafted the first version of the manuscript and coordinated the work of the research team.

In **study IV**, I held the overall responsibility of the data analysis and classification process. I drafted the first version of the manuscript and coordinated the work of the research team.

In the **study V**, I was in charge of the data analysis and classification process. I drafted the first version of the manuscript and coordinated the work of the research team.

In the **study VI**, I was in charge of the data analysis and classification process. I drafted the first version of the manuscript and coordinated the work of the research team.

Contents

1 Introduction

The evolution of technologies and their adoption by everyday people has led to a vast amount of data that are descriptive of human nature. Mobile phones and wearable sensors have become extensions of humans’ bodies and are considered animate objects that accompany them (Ventä, Isomursu, Ahtinen, & Ramiah, 2008). In a fashion that has never been possible in the history of humanity, people have the opportunity to monitor multiple aspects of life, including health and wellbeing (Islam, Kwak, Kabir, Hossain, & Kwak, 2015). Technology users, namely everyday people, are now able to quantify various aspects of life, such as emotions, habits, and sleep, as well as activities, such as purchase patterns and social media habits (Sharon & Lucivero, 2019). In consequence, the adoption of technological advancements has increased the volume of personal data (Zargaran et al., 2018).

Personal data are descriptive of various facets of life, including health. Personal health data (PHD) comprises any data related to people’s health and wellbeing, as well as their behavior and lifestyle. Traditionally, health data have been considered to be information administered by healthcare professionals and stored in electronic health records (EHRs) or electronic medical records (EMRs), such as a patient’s medical history, laboratory tests, and medication (Coorevits et al., 2013; Ludwick & Doucette, 2009). Personal health records (PHRs) emerged as a continuation of medical records, allowing patients to hold and control health and wellness data, self-manage their health, and participate in decision making (Archer, Fevrier-Thomas, Lokker, McKibbon, & Straus, 2011; Chang, Hsiao, Hsu, & Chen, 2010; Fuji et al., 2012; Kharrazi, Chisholm, VanNasdale, & Thompson, 2012; Meier, Fitzgerald, & Smith, 2013; Puustjärvi & Puustjärvi, 2016; Tang, Ash, Bates, Overhage, & Sands, 2006; Wells, Rozenblum, Park, Dunn, & Bates, 2014).

In recent decades, the technological evolution and adoption of personal devices has increased human interaction with the network and contributed to the creation of various digital footprints. Digital footprints include digital traces of everyday life that are stored on the network as a product of users’ active or passive interaction with the network (Girardin, Calabrese, Dal Fiore, Ratti, & Blat, 2008) and are informative about peoples’ health, wellbeing, behaviors, and preferences (Harjumaa et al., 2016; Malhotra, Totti, Meira, Kumaraguru, & Almeida, 2012; Raghupathi & Raghupathi, 2014; Zhang, Guo, Li, & Yu, 2010). The generation of PHD outside the ‘strict’ medical environment has resulted in the creation of a personal data ecosystem. Users are at the center of this ecosystem and play a key role as they create, access, and share their PHD, interacting through various interfaces and devices. As the development of a PHD ecosystem is somewhat recent, certain facets remain understudied. The present study focused on two of these facets, PHD access and sharing from the perspective of information system (IS) users, under the prism of knowledge acquisition for participation in decision making.

PHD can facilitate the allocation of decision making outside the strict medical environment, enabling people to participate in health decisions (Kambhampati, Ashvetiya, Stone, Blumenthal, & Martin, 2016; Institute of Medicine (US) et al., 2011). Participation in case decision processes is seen to be beneficial at multiple levels and was linked to improved treatment outcomes for individuals and as a motivation for healthcare professionals; in current public healthcare systems, it is considered a necessity (Vahdat, Hamzehgardeshi, Hessam, & Hamzehgardeshi, 2014). People and healthcare professionals have intertwined expertise; the former in their own health and the latter in clinical matters. Although people are experts in their own health and wellbeing, sometimes it is not enough, as “They [a patient's interests] would not be safe in the hands of the uninformed patient” (Kennedy, 2003, p. 1276). Health data can provide hard evidence, or more tangible evidence, about health changes contributing to the establishment of a relationship of interactive partnership and timely decisions to save lives. To achieve that aim, knowledge about users’ data access and sharing perceptions is imperative as a first step towards the assimilation of human interaction with data to make care decisions.

Currently, access to PHD can be informative about various aspects of life, providing more holistic insights into a combination of triggers that can lead to health or illness. Seeking a definition of health, the World Health Organization (WHO), inter alia, supports that health is “a state of complete physical, mental, and social wellbeing not merely the absence of disease or infirmity.” (WHO, 1946, p. 1). The definition connects health with quality of life, thus defining quality of life as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 1997, p. 1). The definition supports the notion that health is a self-assessed and subjective experience related to wellbeing and not necessarily to the absence of a condition or disease. Health, wellbeing, and lifestyle choices are interrelated. Modern health issues, such as obesity, cancer, type 2 diabetes, and cardiovascular diseases, are rooted in unhealthy lifestyle choices (Anand et al., 2008; Steyn & Damasceno, 2006), which are made on a daily basis and contribute to people's health and wellbeing. Thus, access to data can save lives (Kushniruk, 2019). However, lifestyle, health needs, technologies, and PHD are in a constant state of flux. This flux has created research interest in PHD access in the European context at this time.

Similarly, the implementation of the new General Data Protection Regulation (GDPR) in May 2018 revitalized interest around the topic. PHD sharing has a positive social impact, not only promoting solidarity among patients, but also optimizing resources and contributing to a positive environmental impact, reducing, for example, unnecessary transportation (Ouhbi, Fernández-Alemán, Toval, Pozo, & Idri, 2018). The existence of data sharing barriers at different levels still poses challenges in public health (van Panhuis et al., 2014). However, the emergence of requirements for secure and interoperable data exchange ecosystems is paving the way for transforming healthcare (Fishbein & Ajzen, 1977; Grundstrom, Väyrynen, Iivari, & Isomursu, 2019; Vahidhunnisha, Balasubramaniam, & Ramas 2014). Likewise, the development of legal frameworks provides more transparent regulations to support data disclosure (European Medicines Agency, n.d.; Lo, 2015; Sousa, Ramalho, & Silveira, 2016). Shared decision making encapsulates the current direction of healthcare. If healthcare professionals understand what matters most to patients, they will be better prepared to help them and make health decisions that fit their needs and values. This requires two-way communication between the two parties (Bae, 2017).

A shift toward more data-driven healthcare has been discussed, among others, by connected health (CH) research (Raghupathi & Raghupathi, 2014; Vergados, 2010). In short, CH aims "to offer the correct information to the correct person at the correct time" (Chouvarda, Goulis, Lambrinoudaki, & Maglaveras, 2015, p. 23). Among the benefits of providing data access to patients are engagement with their own health (Bergevi, Lendahls, Crang-Svalenius, & Oscarsson, 2018; Hägglund & Scandurra, 2017), transparency (Adler-Milstein, Sarma, Woskie, & Jha, 2014; Lehnbom, McLachlan, & Brien, 2013), and promotion of user-centered care (Baldwin, Singh, Sittig, & Giardina, 2017; Giardina, Menon, Parrish, Sittig, & Singh, 2014). On this direction, CH envisions the transformation of healthcare systems, bridging patients with caregivers and clinicians and empowering patients to take responsibility for their own health decisions (Caulfield & Donnelly, 2013; Steinhubl, Muse, & Topol, 2013; Swan, 2009; Taylor, 2015). To achieve this, health data plays a key role.

Transitioning to more human-centered care entails that future users of IS in healthcare will need to access or share their PHD to better understand themselves and enable knowledge sharing. Based on rough estimations, healthcare systems collect data from patients approximately three times per year, leaving the rest of the year without health information (Healthcatalyst, n.d.). In contrast, the users themselves have the opportunity to utilize health-related data from personal devices on an almost daily basis. However, for various reasons, such as busy schedules, people give little attention to their own health. As a result, healthy individuals do not consider the problems of accessing and sharing PHD before an illness befalls them.

PHD access and sharing are research topics that, while not new, still attract research interest. The continuous discussions about the term of access underline its complexity, importance, and timely nature (Persson, AAhman, Yngling, & Gulliksen, 2015). As for data sharing, one could argue that the implementation of the new GDPR in 2018 has invigorated interest around this research topic (Formanek & Tahal, 2018; Horák, Stupka, & Husák, 2019; Mazurek & Malagocka 2019; Pratap et al., 2019; Schomakers, Lidynia, & Ziefle, 2020). This dissertation examines both research topics from the perspective of users in this specific time period in Northwest Europe, namely between 2018 and 2020. The European healthcare ecosystem provided fertile ground to study PHD access and sharing. This is not only related to the digitalization of IS in healthcare in this particular region, which enabled me to conduct the present study, but also to the time we live in. Currently, EU healthcare services encounter multiple challenges, such as the upsurge of non-communicable diseases or the increase in the elderly population that exerts considerable pressure on care costs (European Commission, 2018a; WHO, 2018). Furthermore, the lack of coordination in relation to data interoperability standardization and the foreseen shortage of healthcare professionals adds to these challenges (European Commission, Shaping Europe's digital future, 2019; WHO, 2020).

In this digital age, we leave traces as a digital footprint on a daily basis. As healthcare provision is moving towards more connected solutions utilizing technology, PHD access and sharing are fundamental for humanity to acquire health knowledge and to contribute to knowledge sharing. Although the present doctoral research was conducted before the Coronavirus disease 2019 (Covid-19) outbreak, namely between 2018 and 2020, the new coronavirus reality makes this work relevant to a larger audience, as crossing the line from being healthy to sick is a matter of being in the wrong place at the wrong time.

1.1 Development of the research studies

The focus of this dissertation was to contribute updated knowledge about PHD access and sharing as it has been studied over the last three years through empirical work and prior literature. This manuscript consists of an extended introduction and six research papers (P) published in high-impact scientific journals and international conferences. The first publication is a literature review to identify and address research gaps in the literature regarding PHD:

P1: Karampela, M., Ouhbi, S., & Isomursu, M. (2018). Personal health data: A systematic mapping study. *International Journal of Medical Informatics, 118*, 86–98. doi.org/10.1016/j.ijmedinf.2018.08.006.

This study highlighted the increasing interest in PHD since 2014 and also underlined the limited empirical research around PHD access. The evidence supports that PHD access is an understudied area of research, as only 6% of the studies were found to have access as a main topic; however, none of the studies utilized a case study (Karampela, Ouhbi, et al., 2018). Based on this evidence, IS research has limited empirical evidence on this topic from the viewpoint of users. While PHD sharing is a topic that has attracted the interest of researchers, none of the papers included in the literature review study utilized a case study to explore this topic. Based on the aforementioned evidence, there is limited user validation of the proposed solutions in real settings.

Since the literature review highlighted limited empirical evidence about PHD access, the first two empirical studies detailed users' PHD access encounters. To acquire knowledge about this topic, the following two papers were published:

P2: Karampela, M., Grundstrom, C., & Isomursu, M. (2018). *Personal health data: Access and perceived value in Denmark*. In Proceedings of the 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC) (pp. 4081–4084). doi: 10.1109/EMBC.2018.8513407.

P3: Karampela, M., Grundstrom, C., & Isomursu, M. (2018). Personal health data: Accessibility and value in a Danish context. In B. Andersson, B. Johansson, S. Carlsson, C. Barry, M. Lang, H. Linger, & C. Schneider (Eds.), *Designing digitalization (ISD2018 Proceedings)*. Lund, Sweden: Lund University. ISBN: 978-91-7753-876-9. http://aisel.aisnet.org/isd2014/proceedings2018/eHealth/7.

These publications were informative about users' PHD access encounters through various available applications and the perceived value of data. Although PHD access was found to be sufficient in both studies, the findings supported that healthy individuals are not motivated to access their PHD until they are unwell.

People who were healthy were not interested in acquiring knowledge about their health. Therefore, the next study targeted individuals who were motivated to access their PHD to learn about their health because of a health-related incident:

P4: Karampela, M., Porat, T., & Mylonopoulou, V. (2019). *Needs of head and neck cancer patients and stakeholders during rehabilitation*. Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth'19) (pp. 415–421). Association for Computing Machinery, New York, NY, USA. DOI: https://doi.org/10.1145/3329189.3329236.

In this study, PHD access was studied from the perspective of individuals undergoing cancer rehabilitation. This group of users was motivated to access their PHD to acquire health information in relation to rehabilitation. A meta-analysis of qualitative data and a thematic analysis of semi-structured interviews were valuable to understand elements relevant to PHD access for people recovering from a severe illness. One of the findings of this work was related to the notion of shared information needs between stakeholders. Findings supported that patients' and stakeholders' needs, namely healthcare professionals and informal caregivers, are interrelated as they faced common challenges pertinent to the provision and distribution of information. Based on that, the existence of shared information needs between users and stakeholders brought out the topic of PHD sharing. PHD sharing has been discussed in this doctoral dissertation through the lens of users' willingness to share their PHD with other stakeholders. Data sharing entails data that are accessible to stakeholders to facilitate decision making (see chapter Theoretical Positioning; Access in Information Systems; The role of access and data sharing in decision-making). PHD sharing with other stakeholders was therefore the last area of empirical research of this dissertation, resulting in the following publications:

P5: Karampela M., Ouhbi, S., & Isomursu, M. (2019). Connected health user willingness to share personal health data: Questionnaire study. *Journal of Medical Internet Research*, *21*(11), e14537. doi: 10.2196/14537.

P6: Karampela, M., Ouhbi, S., & Isomursu, M., (2019). *Exploring users' willingness to share their health and personal data under the prism of the new GDPR: implications in healthcare*. Proceedings of the 41st Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC) (pp. 6509–6512).

Users' willingness to share their PHD with other stakeholders was studied in relation to different types of personal data, the impact of the new GDPR on users' attitudes, and to a number of conditions, such as for research or financial incentives. Figure 1 visualizes the development of these research studies.

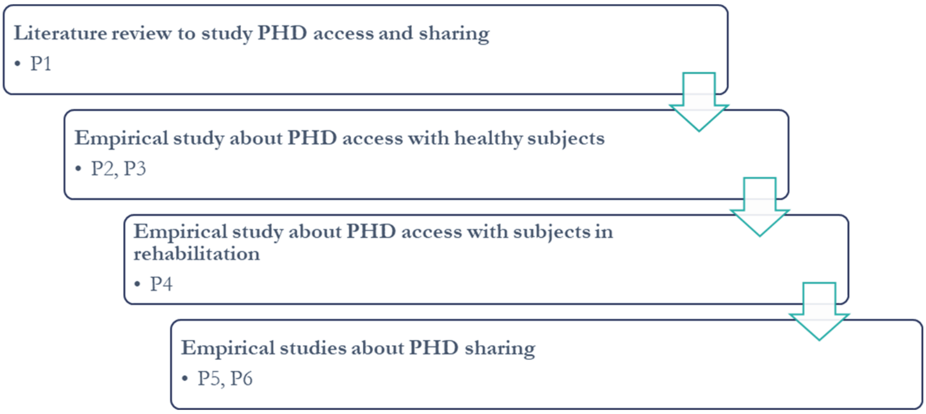

Fig. 1. The development of the empirical studies and the resulting publications.

Following this train of thought, this doctoral dissertation utilized the evidence from a single case study, proposing a number of recommendations to enable PHD access and sharing. The case study explored the research topics at this specific point in time, namely between 2018 and 2020, in Northwest Europe (for more information about the case study, see chapter Methodology; Case Study).

Users can access and share their PHD throughout their lives. The need for PHD access can emerge on various life occasions, for various purposes, and to accommodate health or wellbeing needs. Needs may vary between individuals and age groups. Similarly, the nature of data is also changing with the evolution of new technologies (Datastreams, 2018; Hunter, 2016). Therefore, one could argue about the temporal nature of people needs and data, as both are evolving. PHD sharing with other stakeholders can create new access encounters, which is out of the scope of this work. Considering access from the perspective of users, one can argue that peoples' beliefs about the quality of services are rooted in the intangible characteristics of services that people experience when interacting with services (Stauss & Mang, 1999). The service encounters, either short-term or long-term, are representations of noteworthy 'moments of truth,' while the intangible nature of services is bounded to the moments that people experience these services (Stauss & Mang, 1999). In the context of this work, PHD access encounters are moments that enable users to acquire information about their health and wellbeing. In this context, users' encounters with data can be seen as moments in which they value the quality of PHD access and sharing based on their interactions with data through IS. Therefore, PHD access can enable the acquisition of health knowledge to support participation in decision making, while PHD sharing can facilitate knowledge sharing between stakeholders. Access and sharing encounters signify moments in time that are underpinned by a number of elements. This dissertation studied two PHD encounters in Europe, focusing only on the viewpoint of users, thus excluding those of other stakeholders, to propose recommendations relevant for IS designers and developers in CH.

1.2 Research objective and question

The objective of this dissertation was to ameliorate our understanding of users' perceptions in regard to PHD access and sharing. The extracted empirical knowledge will be used to compose a number of recommendations relevant to IS designers and developers in CH. Therefore, in this context, this dissertation addresses the following research question (RQ):

RQ. What recommendations are relevant for IS designers and developers to enable PHD access and sharing?

The word 'enable' refers to PHD access and sharing recommendations, which are relevant for IS designers and developers. In the context of this dissertation, access to data is seen through the lens of knowledge acquisition to empower users to participate in decision making for their own health, while PHD sharing is seen as an opportunity for information sharing between stakeholders in healthcare. Healthcare stakeholders are groups of people with an interest in PHD, such as different groups of users, healthcare professionals, informal caregivers, or service providers. The RQ was addressed through an embedded case study in Northwest Europe between 2018 and 2020. CH designers and developers in this context are those who capture the motivation of each user group and bridge their needs into a solution (Davis & Yen, 2019; Marcu, Bardram, & Gabrielli, 2011). The embedded case study consists of four units. The methods selected to study the two PHD encounters were a literature review, two empirical studies with semi-structured interviews, and a questionnaire survey. Table 1 presents the research approach followed in each publication and its main objective. The boundaries of the case study are as follows:

- It is an exploratory embedded case study (study design)
- aimed to study PHD access and sharing based on empirical evidence (research topic),
- in Northwest Europe (setting),
- at this point in time (2018–2020).

Table 1. Research approach and main objectives per publication.

P	Research approach	Main objective
P1	Literature review	Map existing research in IS about PHD access and sharing
P2, P3	Semi-structured interviews	Develop an understanding of PHD access and perceived value in healthy subjects
P4	Semi-structured interviews	Develop an understanding of PHD access in rehabilitation and identification of interrelated information needs between stakeholders (subjects in rehabilitation, healthcare professionals, and informal caregivers)
P5	Questionnaire survey	Identify users' willingness to share their PHD compared to other types of personal data and to understand the impact of the new GDPR on users' behavior
P6	Questionnaire survey	Develop an understanding of users' personal characteristics in relation to their willingness to share their PHD and the conditions under which they would be willing to do so

2 Theoretical positioning

This chapter presents previous literature that is relevant to this dissertation. The research areas relevant to this dissertation are IS, human-data interaction (HDI), and health informatics. The role of the subsections 'Data access in the wild' and 'Data sharing' is to present an overview of how access has been contextualized in different genres. Therefore, in the last subsection of the chapter, I a) position the doctoral study within the context of previous work and b) identify the knowledge gap in the existing body of literature that spurred the research motivation for this doctoral dissertation.

2.1 Data access in the wild

The term 'access' has been used in different contexts to serve different purposes. For example, to support the interests of groups, such as persons with disabilities, (US EPA, 2013; Persson et al., 2015) or standardization processes, such as ISO and international web standards (Mabry, 2011; Persson et al., 2015; Stephanidis, 2001; W3C, n.d.; "Web Content Access Guidelines (WCAG) 2.1," n.d.). From a legal viewpoint, the term 'access' has been used to advocate not only equal access to physical spaces but also equal access to information, services, and products, as well as equal rights for all citizens (European Commission, n.d.; United Nations, n.d.).

In human-computer interaction (HCI), access has been seen from the perspective of design and users' ability to access systems, services, or environments, focusing either on the human or technological aspects. For example, assistive technologies aim to assist different groups of users in accessing technologies to ensure digital equality (Vergados, 2010). The development of touch-screens for older adults to access EHRs or cognitive aids to assist people with memory disorders are examples of assistive technologies that provide equal opportunities to access healthcare information (Claypoole, Schroeder, & Mishler, 2016; Migo et al., 2014; Piper & Hollan, 2013). Notably, HCI access approaches have more commonalities than differences (Persson et al., 2015). Design for all, integral accessibility, accessible design, inclusive design, barrier-free design, trans-generational design, and accessibility for all are considered genres that converge into the universal design approach (Persson et al., 2015). Universal design encompasses the notion that technologies and environments should be accessible to the widest range of users, including those who face physical or cognitive disabilities due to a medical condition or ageing (Bergman et al., 1996; Stephanidis, Akoumianakis, Sfyrakis, & Paramythis, 1998). Access can be achieved based on several principles that consider not only personal preferences, such as language skills and sensory abilities, but also embodiment capabilities and space limitations.

In public health policy, access “includes the right to seek, receive and impart information and ideas concerning health issues.” (WHO, accessibility, n.d.). However, access “should not impair the right to have personal health data treated with confidentiality” (WHO, accessibility, n.d.). Health research considers access as the opportunity to identify, look for, reach, and use services to fulfil healthcare needs (Levesque, Harris, & Russell, 2013). It has also been related to users’ access to an institution, a service provider, or a service in relation to the ease of the task and in analogy to health needs (Daniels, 1982; White, Frenk, Ordonez, Paganini, & Starfield, 1992; Whitehead, 1991), as well as to fit between the characteristics of users, services, and service providers (Andersen, McCutcheon, Aday, Chiu, & Bell, 1983; Penchansky & Thomas, 1981). Access has been discussed in relation to financial (Dutton, 1986; Margolis, Carey, Lannon, Earp, & Leininger, 1995; Peters et al., 2008; Salkever, 1976; Shengelia, Murray, & Adams, 2003) and organizational aspects (Dutton, 1986; Salkever, 1976), while the availability and acceptability of services have been linked with users’ experiences of accessing services (Haddad & Mohindra, 2002; Peters et al., 2008; Shengelia et al., 2003). Geographical, physical, cultural, and personal factors in relation to access have also been discussed in previous research (Margolis et al., 1995; Peters et al., 2008; Shengelia et al., 2003). Access to health data has also been connected to the property of data described as “an abstruse and intrinsic property of data that is enacted in various contexts by different stakeholders” (Grundstrom et al., 2019, p. 5040).

In the context of this dissertation, access refers to PHD encounters that users have when utilizing services or applications to have a healthcare opportunity fulfilled. Access encounters are seen in this work as timely moments that occur when users are interacting with their PHD through IS. This dissertation studies PHD access in Europe between 2018 and 2020, focusing only on the viewpoint of users, thus excluding those of other stakeholders in healthcare.

2.2 Data sharing

Health data sharing is an essential part of digital health and is contingent on individuals who are empowered to make informed decisions about their health data. Data sharing has been extensively studied by previous research from various angles, for example, from the viewpoint of users' attitudes (Agarwal & Anderson, 2008; Chang et al., 2010; Fox & Purcell, 2010; Frost & Massagli, 2008; Pickard & Swan, 2014; Weitzman, Kaci, & Mandl, 2010). Willingness to share health data was identified as dependent on various parameters, such as the type of data. For instance, sharing consumption and finance data entails some privacy concerns, while the sharing of health data is a far more intricate issue (Agarwal & Anderson, 2008). In contrast, the purpose of use has an impact on users' attitudes; users would be willing to share data about their diseases and conditions for scientific research (Pickard & Swan, 2014). Another parameter to consider is the health condition of users. Patients with chronic or terminal diseases were found to have a more positive attitude towards data sharing for research purposes (Fox & Purcell, 2010). Personal health data sharing among patients with similar conditions to self-manage diseases also has a positive impact on shared attitudes. Patients facing similar health conditions are willing to share their personal data and knowledge with peers to foster and solidify relationships based on common concerns (Frost & Massagli, 2008). The type of medical information that one is willing to share differentiates the attitudes toward sharing (Pickard & Swan, 2014). Users are also in favor of being in control of their data (Pickard & Swan, 2014; Weitzman et al., 2010). Opt-in models, control options over sharing settings, and patient-centered models were found to have a positive impact on users' willingness (Weitzman et al. 2010). Data sharing has also been studied by previous research from the perspective of dynamic consent (Spencer et al., 2016), attribute based encryption in cloud computing for secure data sharing (Ssembatya & Kayem, 2015; Vahidhunnisha et al., 2014), and interoperability standards (Kouroubali & Katehakis, 2019).

This doctoral dissertation also touched upon sharing of wellness data. The difference between health and wellness can be summarized in the following definition: "Health refers to physical, mental, and social wellbeing; wellness aims to enhance well-being" (Greenberg, 1985; Stoewen, 2015, p. 983). PHD covers many kinds of data sources, including wellness data derived from, inter alia, wearable sensors for preventive care (Pikkarainen, Pekkarinen, Koivumäki, & Huhtala, 2018). Sharing wellness data in publicly visible sharing or in a social context has a great influence on people’s willingness. People want to publicly present a positive image of themselves (Colley, Pfleging, Alt, & Häkkilä, 2020). Similarly, sharing increases motivation for physical exercise behavior change or self-regulation (Munson, 2012).

Although data sharing has been discussed to a great extent by previous researchers, renewed research interest in the topic is connected to the implementation of the new GDPR. Since the enforcement of the new legal framework in May 2018, numerous studies have been published. Data sharing in relation to the implementation of the new GDPR has been approached in relation to cyber security (Horák et al., 2019), marketing or loyalty programs (Formanek & Tahal, 2018; Mazurek & Malagocka, 2019), and privacy (Schomakers et al., 2020; Skatova, McDonald, Ma, & Maple, 2019). Users’ willingness to share social media data has also been discussed by Pratap et al. (2019). A study about German users’ willingness to share health data for secondary use without explicit consent was found to be acceptable by the participants (Richter et al., 2019). However, the study concluded that opt-out mechanisms and transparency about data protection and governance can further contribute to the establishment of a trust relationship between research and patients. Other studies have cemented their focus on legal perspectives in relation to automated data extraction or flaws that require further consideration (Amariles, Troussel, & El Hamdani, 2020; Phillips, 2018; Shabani & Borry, 2018). Data sharing for research purposes to respond to the Covid-19 outbreak has also been discussed in the study of McLennan, Celi, and Buyx (2020), concluding that the new GDPR and ethical obligations can support global collaborative efforts.

Acknowledging that the data sharing topic has been studied extensively, I would like to clarify the stance of the present study. In the context of this doctoral dissertation, PHD sharing focuses only on users’ willingness to share their PHD with other stakeholders after the implementation of the new GDPR (Karampela, Ouhbi, & Isomursu, 2019a, 2019b). Therefore, other data sharing viewpoints, such as those of data providers and healthcare professionals, were excluded, as well as other data sharing aspects, such as interoperability or technical challenges. PHD sharing entangles only users’ attitudes in relation to their willingness to share their PHD. The following subsections will present how the term has been approached in IS, HDI, and health informatics.

2.3 Information Systems: The role of access and data sharing in decision making

IS is “the discipline focused on the acquisition, storage, and use of information in a specific setting or domain” (Hersh, 2009, p. 2). In traditional healthcare, IS manages and facilitates information exchange between stakeholders. With the increase of personal technologies, such as wearable sensors, mobile phones, and Internet of Things (IoT), people are becoming more engaged in the self-management of health and wellness (Chiauzzi, Rodarte, & DasMahapatra, 2015; Dineen-Griffin, Garcia-Cardenas, Williams, & Benrimoj, 2019; Yu et al., 2017). IS in the context of this study are seen as systems that bring together and store data from single or multiple sources to enable users to access and share their PHD, creating opportunities for empowerment and participation in decision making through knowledge acquisition.

Decision making in IS is an area of research that has a long and rich history that unravels with technological evolution (Hosack, Hall, Paradice, & Courtney, 2012), which has an impact on decision making. The ubiquitous nature of technologies introduces decision support systems that enable users to be involved in various ways in decision making, for instance, applications to monitor blood sugar for diabetic patients to share data with doctors, family, or peers (El-Gayar, Timsina, Nawar, & Eid, 2013) or activity trackers for rehabilitation of chronic diseases, such as cardiovascular diseases or chronic obstructive pulmonary disease (Ummels, Beekman, Moser, Braun, & Beurskens, 2020). Subsequently, the ubiquity of decision making creates new research opportunities in emerging areas to understand decision-making processes today (Portela, Santos, & Vilas-Boas, 2013). The surge of PHD from various data sources, such as mobile phones and wearables, has led to the creation of data landscapes, which I will further discuss under the lens of decision making.

The parallelism of data as ‘the new oil’ has been a metaphor that successfully encapsulates not only its value but also its unrefined nature. As petroleum, personal data also require, to various extents, to be accessible to become a valuable entity to users. Data access is among the first enablers for users to acquire knowledge about their health. The quality of users’ decisions is directly related to the quality and accessibility of data (Bose, 2003). Recently, people have the opportunity to keep track of information generated in regard to various human activities. Data understanding and knowledge extraction can play a key role in peoples’ empowerment. However, one of the challenges that exists is related to the complexity of the data ecosystem in relation to data knowledge. Seeking personal data in different technologies and utilizing data to extract health knowledge can be a demanding task for lay people. In addition, the complexity of the task raises questions such as how to make sense of large amounts of personal information.

Data hold information that can be utilized by people to extract knowledge to support decision making. Nevertheless, the terms capture different entities. Data include raw or unprocessed facts, which are not meaningful until they are organized (Zins, 2007). Data “represents a fact or a statement of the event without relation to other things” (Bellinger et al., 2004, p.3). In contrast to data, information “is known as data that have been processed to give meaning by way of relational connection” (Bellinger et al., 2004, p. 1). Utilizing information, people can derive knowledge about their health. Knowledge “is the appropriate collection of information, such that it's intent is to be useful.” (Bellinger et al., 2004, p. 1). However, the relationship between these terms is still unclear.

An early effort to conceptualize the relationship between data, information, and knowledge was made by Aamodt and Nygard (1995) to show how data leads to information and how learning from information leads to the acquisition of knowledge. However, this effort failed to explain how data leads to decision making (Aamodt & Nygaard, 1995). Ingebrigtsen’s (2007) Infogineering model depicted the relational relationship of data, information, and knowledge, showing how they relate to each other to contribute to decision making (Ingebrigtsen, 2007), but the role of understanding during transition was missing . The “Data - Information - Knowledge - Wisdom” model of Bellinger et al. (2004) inserted the notion of understanding in every stage of the transition from data to decision making, explaining its role in each stage (Bellinger et al., 2004). Based on this model, data is a collection of symbols “and has no significance beyond its existence (in and of itself)”, while information “is data that has been given meaning by way of relational connection” (Bellinger et al., 2004, p. 1). Knowledge “is the appropriate collection of information, such that its intent is to be useful. Knowledge is a deterministic process” that leads to an understanding of information (Bellinger et al., 2004, p. 1). Understanding is a cognitive and analytical process in which a person can utilize knowledge and synthesize new knowledge from the previously held body of knowledge. Understanding is present at each of the stages and supports the transition to the next one. People who have understanding can make informed decisions because they are able to synthesize new knowledge or new information based on previous knowledge or information

(Bellinger et al., 2004). Wisdom is a higher cognitive process in which people "discern, or judge, between right and wrong, good and bad" (Bellinger et al., 2004, p. 2). The idea common among these models is that through transitions from data up to knowledge acquisition, people are provided with the opportunity to participate in decision making. Therefore, data access is the first and foremost step for knowledge acquisition. Figure 2 presents a simplified visual of knowledge acquisition through data to decision making.

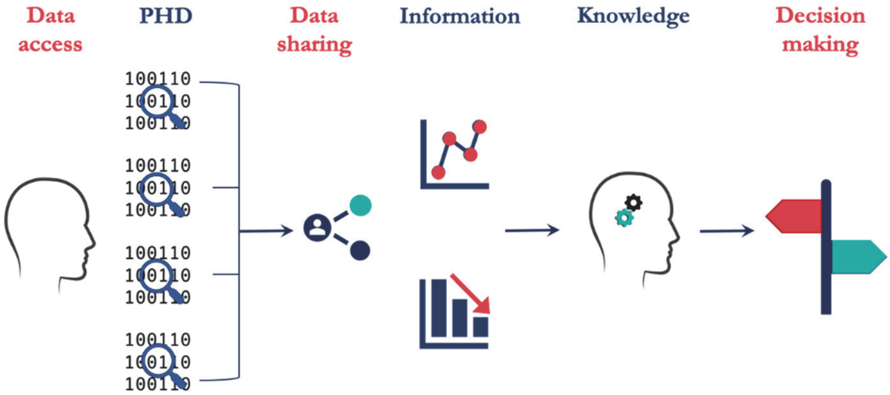

Fig. 2. A simplified visual of the data, information, knowledge model together with the research topics that will be discussed in this doctoral dissertation. The visual focuses only on users' viewpoints. Data includes raw facts; information refers to processed information and knowledge to interlinked information to produce compressive understanding. Access to data is the first step towards knowledge acquisition. Data sharing is placed after access to data.

Users' participation in decision making is not a new paradigm. The term was initially introduced by Plato in his work, "Republic," in the context of politics, arguing for citizens' duty to participate in matters of governance (Pasmore & Fagans, 1992). In the context of IS in healthcare, users' active role in decision making through users' empowerment is based on the premise that people have the ability to make choices and to take responsibility for their actions (Feste & Anderson, 1995; Nutley & Reynolds, 2013). Empowerment is defined as an educational process to facilitate people expanding their knowledge, skills, attitudes, and self-awareness to take responsibility for their health-related decisions (Feste & Anderson, 1995). Participation in decision making has been seen as an opportunity to increase self-awareness, regardless of its challenges (Feste & Anderson, 1995; Fleischmann, 2015). For instance, conflicts stem from internet-informed patients and health care professionals. According to Sjöström, Hörnsten, Hajdarevic, Emmoth, and Isaksson (2019), this is due to inaccurate information and the patients' inability to effectively manage the information. Access to personal data is a key principle of empowerment; if people are to be empowered, data access is a requirement to make informed decisions. Based on that, data access is a key enabler to users' empowerment, enhancing the quality of care (Bose, 2003; Digital Single Market - European Commission, 2018; Topac & Stoicu-Tivadar, 2011).

Shared and informed decision making can be used to encompass the broader concept of people's involvement in decision making about their health and wellbeing. Shared decision making is applicable to various clinical decision situations and is especially important where a preference-sensitive decision is being made (Hersch, Jansen, & McCaffery, 2016). Shared decision making is conceptualized in the context of clinical decisions in which healthcare professionals, patients, and stakeholders have an input. However, health decisions are also made outside of the traditional clinical settings and without any direct input from a healthcare professional. An example is the decision to accept or decline a screening for the detection of cancer offered by a government-funded program. In this context, informed decision-making is taking place outside of clinical settings (Hersch et al., 2016; Karthick, Miraftab, & Ashton, 2010; Pereira, Jácome, Amaral, Jacinto, & Fonseca, 2019).

2.4 Human-data interaction

As this dissertation focuses on humans and their interactions with data, the field of HDI was a relevant research work to consider. HDI is an emerging interdisciplinary research approach specializing in the interaction between individuals and data (Hornung et al. 2015) and lies at the intersection of different research areas, such as IS, HCI, and behavioral science. The interaction with data in the HDI context assumes accountability in the transaction between stakeholders to underline the importance of permission and audit trails. HDI is concerned with the development of ubiquitous and pervasive technologies and focuses on citizens' interaction with data (Cafaro 2012; Elmqvist 2011; Hornung, Pereira, Baranauskas, & Liu, 2015; Mortier, Haddadi, Henderson, McAuley, & Crowcroft, 2013, 2014). This research field is interested in both small and big data, which are open to freely used by anyone. HDI focuses on and studies the human understanding of the data and its processes, including explicit and implicit interactions, to offer transparency regarding data analytics and to give individuals control over their data (Haddadi, Mortier, McAuley, & Crowcroft 2013). HDI proposes to put individuals at the center of the personal data ecosystem, providing people with the instruments to directly interact with the data. HDI differs from HCI in that it deals with passive interactions: “in HDI we consider people interacting with apparently mundane infrastructure, which they generally do not understand and would rather ignore” and in the magnitude of datasets that can be peta- or quintillion-bytes (Haddadi et al., 2013, p. 5).

According to Mortier et al. (2014), three key principles underpin the HDI discipline: agency, legibility, and negotiability (Mortier et al., 2014). Agency concerns consent in relation to data usage and processing by third parties. Legibility focuses on intellectual property rights and ethical considerations related to data utilization, so that it becomes clear to people what rights they have over their personal data. Negotiability is being discussed under the lens of a societal contract pertinent to the use of data. This viewpoint suggests that interactions with data can change over time. Negotiability discusses the notion of dynamic relationships around data, individuals’ knowledge and behaviors, and society. These relationships change over time for various reasons, such as the formation of social norms along with the introduction of different legal and regulatory frameworks, but also due to the subjective interpretation of different data types (Mortier et al., 2014).

2.4.1 Personal data access

The development of new terms in the HDI discipline to describe, study, and discuss procedures that have been taking place in recent years from a new viewpoint may indicate a need for the introduction of new research paradigms or an opportunity to shift the research focus to investigate knowledge from other perspectives. In a healthcare context, HDI distinguishes between the use of three different types of personal data and its related processes, namely production, process, and consumption. Primary data emerge from a wide range of sources and are produced within a healthcare process. Secondary health data originate from the primary data and are relevant to purposes other than care, such as accounting and medical billing. Finally, tertiary data originate from secondary data to satisfy consumers’ needs (Cabitza & Locoro, 2016).

Interactions with tertiary health data are pertinent to data value. Data value is related either to the use of data to achieve goals or to the value that users can extract from data (Cabitza & Locoro, 2016). In terms of whether the value is already in data or created by users' interactions with data, HDI argues that "value is the result of interacting with data and being capable of exploiting them by tertiary users, that is lay people moved by unexpectable motives and toward unanticipated aims" and continues that "data have got value if they are true and have been made accessible and comprehensible; on the other hand, their value lies in the comprehension itself, in the acquisition of true information, in learning notions, techniques, practices, and in the resulting knowledgeable behaviors, in their turn producing some positive effect, on either the single person or her community" (Cabitza & Locoro, 2016, p. 93). Therefore, the value of data is connected to usability and connects further to data comprehension and access—as the former assumes the latter. Access in that sense is a requirement to extract value from data to support knowledge acquisition, resulting in behaviors that are beneficial both at the personal and communal levels. HDI connects access with the use and value of data, arguing that comprehension and acquisition of health information by lay people can have a positive impact on their health and health behaviors.

Apart from that, HDI signifies the emergence of a new need from the viewpoint of users, which is related to the need to find ways to allow users to retrieve and explore complex personal data to gain value in their learning, make decisions based on information, and receive feedback for their actions (Cabitza & Locoro, 2016). Based on that, HDI proposes the term *datafication* of facts to describe the digitalization of facts and *data telling,* which refers to "the creation of accounts and stories that human can tell according to the data they make (a) sense of" (Cabitza & Locoro, 2020, p. 1148).

2.4.2 Personal data sharing

HDI seeks to transform the passive or mundane interaction with data into an active interaction in which individuals will rigorously manage and control their personal data. The focus of HDI research is not on any type of data but on personal data or *my data* and *data about me*. To elaborate, the data that a subject generates in his/her interactions with *other* people include not only information about the subject him/herself but also information for the *other* people (Crabtree & Mortier, 2015). In this sense, control over *my data* in a social context becomes more complex as the boundaries between the owner and the controller of the data blur. Therefore, *my data* co-exists alongside *our data.* An initial attempt to approach this topic was made through the development of the *Dataware* model (Crabtree & Mortier, 2015).

Personal data sharing and the need for the development of social models to enable users' participation in the sharing process has led to the development of the *Dataware* model. This model proposes the construction of a digital infrastructure to enable users to have direct access and control over their data, so that processors' requests to obtain access to data are directed to users (Crabtree & Mortier, 2015). Thus, users should have the opportunity to grant or deny access to their personal data utilizing a personal container that would enable them to manage access to their personal data sources. The need for self-describing data formats is among the key issues the model introduces.

The utopia of this model is related to the social framework in which the latter exists. HDI argues that from a social viewpoint, human and data interactions not only concern the interaction with data itself but also the human relationships that revolve around this interaction (Crabtree & Mortier, 2015). The social aspect of personal data introduces the challenge of how these data can be controlled or who holds their ownership. The articulation of such an ecosystem is not only complex, but also dynamic, as both data and social relationships are constantly evolving. The flow of data and the articulation and coordination of this flow to enable users to manage and coordinate their personal data is an area that has attracted the attention of HDI research (Crabtree & Mortier, 2015).

2.5 Health informatics

2.5.1 PHD data access

The field of health informatics is "concerned with the optimal use of information, often aided by the use of technology, to improve individual health, health care, public health, and biomedical research" (Hersh, 2009, p. 2). In this field, access is related to the surge of health-related data and has been envisioned as an opportunity not only to improve healthcare systems to accommodate the needs of healthcare professionals, but also those of end users, namely patients (Ferguson & Frydman, 2004; Tang et al., 2006; Wells et al., 2014).

To review the existing knowledge and determine gaps in knowledge about PHD access in healthcare informatics, a literature review was conducted (Karampela, Ouhbi, et al., 2018). The findings of this review support that the interest in PHD access started at the end of the last decade. More specifically, the information obtained about the publication trend showed that from 2014, the number of publications rose steadily. The recent interest in PHD access can be attributed to various reasons. For example, the emergence of PHRs occurred in the first decade of the new millennium, while applications to support the adoption of PHRs, such as HealthSpace or Microsoft HealthVault, emerged after 2005 (Karampela, Ouhbi, et al., 2018). In addition, research endeavors to support the systematic utilization of resources in healthcare, such as the CH paradigm, have also developed over the last decade. Similarly, publication channels, which are informative about the process of development of the PHD research area, support the same notion. The majority of publications about access are in scientific journals (Karampela, Ouhbi, et al., 2018), which have been acknowledged as an elaborate process in terms of review criteria, acceptance rate, and manuscript journal fit so that the scientific contributions of publications in high impact journals are not disputable (Knight & Steinbach, 2008; McCartney & Tenenberg, 2008). Additionally, they signify the emergence of a research area, as they usually present more extended pieces of research work and contribute toward the establishment of a knowledge base for a field (Karampela, Isomursu, et al., 2019).

In this review of literature, five of the included publications have been classified as having PHD access as a main topic. In contrast to other research topics, such as data privacy, access was classified as having a less important influence on PHD research, probably due to limited real-life implementation in the healthcare industry. This literature review showed that the majority of the previous studies focused either on the theoretical aspects of access (Gladwin, 2012; Sulthana & Habeeba, 2014) or on the technical aspects of it, such as database architecture (Wu, Cheng, Chiang, Lin, & Lai, 2011) and iCloud solutions (Van Gorp & Comuzzi, 2013). Only the study of Greenberg et al. (2017) empirically evaluated a tool using data from patients with chronic conditions.

2.5.2 PHD sharing

Furthermore, the literature review included previous research work in healthcare informatics about PHD sharing (Karampela, Ouhbi, et al., 2018). Previous literature on this topic has focused on the technical, as well as users aspects concerning the creation of approaches to enable data sharing. Data sharing is mainly connected to security and privacy considerations to propose ways to leverage users' PHD. The majority of studies proposed solutions or conducted evaluation research to propose novel solutions or extensions of existing approaches (Karampela, Ouhbi, et al., 2018).

Pickard and Swan (2014) proposed a framework to increase PHD sharing based on "trust, motivation, community, and informed consent." The results of their survey supported users' strong willingness to share their PHD with researchers. Frost and Massagli (2008) investigated the ways in which patients with amyotrophic lateral sclerosis respond to the shared use of PHD using the online community PatientsLikeMe. They concluded that data sharing can facilitate patient engagement in the management of their own health. They also recommend that future designers "make each patient's health information as clear as possible," paving the way to data-centered patient systems (p. 1). Users' willingness to share PHRs for health research was found to be positive for early adopters of PHRs and highlighted that different social groups and personal characteristics have an impact (Weitzman et al., 2010). Another study with the same topic posed that willingness to share PHD is dependent on several factors, such as the nature of data, the stakeholders to share with (private or public), and unauthorized disclosure to third parties (Weitzman, Kelemen, Kaci, & Mandl, 2012). Opportunities and challenges in the use of PHD for research in healthcare are the topic of the study of Bietz et al. (2016). Based on three stakeholder groups, namely early adopters who monitored their health using data, researchers, and companies, they identified challenges pertinent to legal considerations over users' rights, as well as intellectual property rights to enable collaboration between private companies and researchers. Willingness to share data from lifestyle smartphone applications with researchers was the conclusion of the study of Chen, Bauman, and Allman-Farinelli (2016), highlighting users' privacy concerns. The use of dynamic consent and research feedback to improve patients' data sharing willingness was also found to have a positive impact on users' data sharing attitudes (Spencer et al., 2016).

Other studies have focused on the technical aspects of IS and PHD sharing. Capozzi and Lanzola (2011) proposed a multi-platform synchronization framework for speeding up the implementation of personal health services. Vahidhunnisha et al. (2014) proposed a framework to improve privacy in sharing PHD in cloud computing, utilizing control attribute-based encryption (ABE) techniques to encrypt patients' PHRs and establish patient-centric privacy control over their own PHRs. Ssembatya and Kayem (2015) also based their contribution on encryption focusing on mobile phones and suggested an access control framework with identity-based encryption for secure mPHR systems.

2.6 Summary of research gaps

Based on the above and the literature review, a gap was identified in previous research pertinent to limited empirical knowledge about PHD access (Karampela, Ouhbi, et al., 2018). HDI has discussed access under the umbrella of usability, data value, and social models to enable access control of personal data. Health informatics research has mainly focused on the technical aspects of PHD access, while the proposition of solutions or approaches is mostly based on theoretical evidence.

As for PHD sharing, previous studies have concentrated on both technical and user aspects. In health informatics, the topic is mainly connected to access control and privacy. In HDI research, the Dataware model provides an abstract concept for users to obtain access control over their data. Nevertheless, the contribution lacks empirical evidence. Acknowledging that PHD sharing is a topic that has been extensively studied in previous research, the present dissertation contributes recent empirical evidence and knowledge about the topic in relation to the implementation of the new GPDR.

The timely perspective introduces a temporal aspect of two encounters, connecting them further with the changing nature of the PHD landscape. The motivation for the empirical work of this doctoral dissertation is grounded on the gaps identified in previous literature and on evidence from the literature review of PHD (Karampela, Ouhbi, et al., 2018). The focus was placed on PHD access and sharing Northwest Europe between 2018 and 2020. PHD access is perceived as an opportunity for users to acquire knowledge that would empower them and enable participation in decision making of their own health or wellbeing. In this context, PHD sharing with other stakeholders could facilitate information sharing, contributing further to the development of future IS. The next chapter will present the adopted methodological stance.

3 Methodology

3.1 Research area

This doctoral dissertation connects three academic disciplines under a single embedded case study. The research contribution lies at the intersection of IS, health informatics, and HDI. IS is a highly interdisciplinary area of research that intersects between various disciplines. IS is “focused on the acquisition, storage, and use of information in a specific setting or domain” (Hersh, 2009, p. 2). Although IS and health informatics are distinct disciplines, the sociotechnical changes taking place in research are transforming well-established disciplines and blurring boundaries (Lyytinen & Newman, 2008). Health informatics is a discipline that studies informatics within a healthcare context; it is the field “that is concerned with the optimal use of information, often aided by the use of technology, to improve individual health, health care, public health, and biomedical research” (Hersh, 2009, p. 2). Health data is a specific entity in the health informatics discipline (Agarwal, Gao, DesRoches, & Jha, 2010); therefore, the research work presented in this dissertation lies at the intersection of the two disciplines. The third research area is HDI, which is an emerging interdisciplinary research approach specializing in the interaction between individuals and data (Cafaro, 2012; Elmqvist, 2011; Haddadi et al., 2013; Hornung et al., 2015; Mortier et al., 2013, 2014). The HDI discipline is a new research area and has informed certain aspects of this research work. Figure 3 presents the research areas and contributions of this doctoral dissertation.

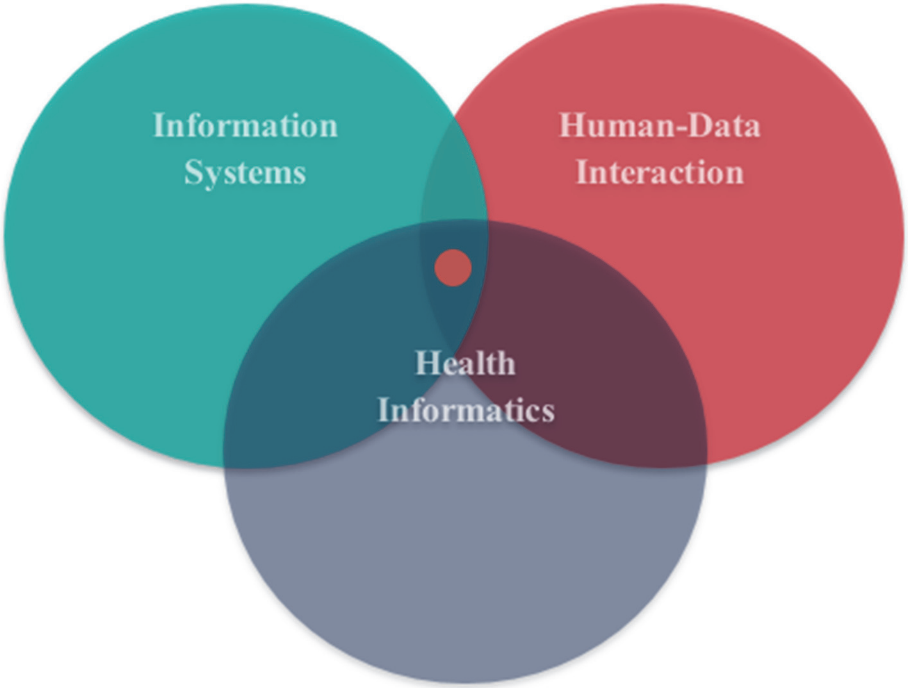

Fig. 3. Venn diagram on related areas of this research work; the smaller orange circle shows the research area where the research contribution lies.

3.2 Study design

Research in IS attempts to make sense of how different users in different settings understand, interact, use, and adopt technology (Chiasson, Reddy, Kaplan, & Davidson, 2007). Users' interaction with technology varies depending on social, psychological, or organizational aspects, among others. To examine such complex real-life phenomena from different epistemological and methodological perspectives, IS researchers utilize a diverse set of qualitative and quantitative methods, for example, quantitative methods from psychology or qualitative methods from sociology (Chiasson et al., 2007).

Case studies examine real-life phenomena within a specific timeframe, thus accepting the condition that both the 'case' and its context are changing over time

(Yin, 1994). Case study method accepts a single or multiple units of analysis, while cases can be either holistic (single unit of analysis) or embedded (multiple units of analysis). Embedded case studies can have multiple units of analysis, and each of the sub-units examines different angles of the case (Yin, 1994). The embedded study design also accepts the compilation of qualitative and qualitative methods into one research study, thus allowing the study of complex real-life phenomena addressing different perspectives of the same phenomenon (Scholz & Tietje, 2002; Yin, 1994).

This dissertation utilizes a single embedded case study consisting of four embedded units to research PHD access and sharing in the last three years (2018–2020). The rationale behind the decision to conduct a single case study was related to the objective of capturing the complex circumstances of an everyday situation (Yin, 1994), namely PHD access and sharing from the perspective of the end users in a real-life context. The studies were conducted in five countries: Denmark, France, Finland, Germany, and the Netherlands. In the frame of this work, an embedded case study was performed to examine different angles of the two research topics that emerged through the course of empirical studies.

The case study followed a phenomenological positionality to examine the research topics. The main objective of phenomenological case studies is to understand the topic within its real-life context. According to Guest, Namey, and Mitchell (2013, p. 13), "in phenomenological research, it is the participants' perceptions, feelings, and lived experiences that are paramount and that are the object of study." Therefore, phenomenology is beyond the experiences of subjects, including their perceptions. Figure 4 visualizes the design of the study, highlighting through the dashed lines that the boundaries between the case and its context are not clear. The publications included in this dissertation consist of qualitative and quantitative data. The qualitative data were extracted from publications and were further analyzed using thematic analysis. The themes captured elements that were related to the RQ and aim. The main reason for the adoption of the thematic analysis approach was to arrive at a rich description of the entire dataset. A rich overall description of the dataset was perceived to be the most suitable method to proceed. According to Braun and Clarke (2006), a rich thematic description can facilitate readers' experience to get a sense of the predominant and prominent themes. Although choosing this analysis approach resulted in some loss of complexity and depth, it provided a rich overall description of the entire dataset. For quantitative data, questionnaire survey data were extracted and utilized from the related embedded unit (embedded unit 4).

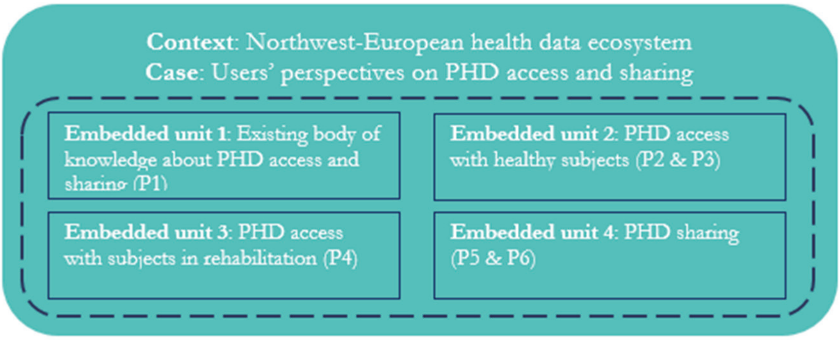

Fig. 4. Embedded case study design consisting of four units to explore PHD access and sharing in Northwest Europe between 2018 and 2020. The dashed lines indicate that the boundaries between the case and its context are not clear.

In the context of this dissertation, the choice of the research perspective expresses personal research interests and predispositions, meaning that focusing on some aspects of the two research topics and eliminating others can be attributed to the bias introduced by the individual perception of the phenomenon under investigation (Bontekoe, 1996; Nagel, 1974; Orlikowski & Baroudi, 1991). According to Morgan (1983, p. 389), who drew on Gödel's theorem, the problem of self-reflection on research perspective is relevant to every researcher, independent of the perspective they adapt to conduct research. Gödel (1962) encapsulated that notion in the following: "in choosing a research strategy the scientist in large measure determines how the phenomenon being studied will be revealed, and indirectly, the consequences of the knowledge thus generated."

Table 2. Overview of the embedded case study approach.

Type:	Embedded case study
Units:	Four
Approach:	Exploratory
Case description:	Empirical approach to study PHD access and sharing
Setting:	Northwest Europe
Study timeframe:	2018–2020
Study boundaries:	IS, HDI, health informatics
	Users' perspectives
Data collection	Qualitative and quantitative
Main limitation:	Generalizability

The epistemological approach reflected upon interpretivism in IS, arguing that both qualitative and quantitative perspectives were useful to be employed in this context to enhance understanding of behavioral IS phenomena (Orlikowski & Baroudi, 1991). Therefore, the research approach chosen in this dissertation aimed to examine PHD access and sharing using a case study to explore the topics more broadly but also to underline the temporal aspect of the phenomenon under investigation (Weick, 1984). PHD access and sharing are timely events, as the surge of PHD concerns a phenomenon that emerged in the last decade and is connected to the growth of data stemming from the adoption of personal devices and ubiquitous technology in everyday life (Karampela, Ouhbi, et al., 2018). Due to this rapid change, researchers and practitioners lack updated empirical knowledge in relation to users' perspectives. Considering the temporal aspect of users and data—as both change over time (users grow older and PHD change)—an embedded case study was considered the most relevant way to examine the topics, focusing on Northwest Europe from 2018 to 2020.

3.3 Case study

This case study focused on PHD access and sharing in Northwest Europe from 2018 to 2020. The geographical definition Northwest Europe, is descriptive of the countries included, which are Denmark, Finland, the Netherlands, Germany, and France (Blondel & Inoguchi, 2006). This study presented a snapshot of how PHD access and sharing is perceived by users; it covered a timespan of approximately three years from 2018 to 2020 and included empirical studies that were mainly performed just before the enforcement of the new GDPR and in the first period after it (European Commission, 2016). In 2017, when data collection of the present case study started, companies and organizations were in the process of responding to the changes that were introduced by the enforcement of the new GDPR. The European Data Protection Directive (Directive 95/46/EC) was adopted in October 1995 to protect the personal data of individuals. In 2016, the EU adopted the GDPR, while its full implementation was enforced in May 2018 (European Data Protection Supervisor, n.d.). The new GDPR aimed to bridge legal inconsistences about personal data privacy and security, introducing components related to data access and control, among others. The focus of this study was on PHD, as defined by the participants of the case study.

The initial interest in focusing my research in this specific region was rooted in that Denmark, the country where I reside, is among the most digitalized countries in the EU (European Commission, 2019a). However, despite the digitalization progress, among the pillars of the National Strategy for Digitalization of the Danish Healthcare Sector (2013) 2013–2017 and 2018–2022 is the provision of more accessible, person-centered healthcare to enable participation in decision making (European Commission, 2019). Similarly, among the pillars of the European Digital Strategy for 2020 is the provision of access to services for citizens and companies, handling of personal data, and development of a data-driven economy (European Commission, 2020). The vision for future healthcare can be summarized in the following quote: "Personalised medicine is an emerging approach that uses data generated by new technologies to better understand the characteristics of an individual and deliver the right care to the right person at the right time." (European Commission, 2018b, p. 7). Therefore, I embarked on my journey to study PHD access and sharing.

The case study included countries across the span of digitalization levels. The various digitalization levels of the different countries provided evidence about the impact of digitalization on PHD access. Recent reports supported that, on average, 18% of the European population used their PHD through digital services (European Commission, 2019b). Almost 50% of the Finnish, 42% of the Danish, nearly 25% of the Netherlands, and less than 15% of the French and German populations accessed and used their PHD (European Commission, 2019b; Rughiniş, Zamfirescu, & Neagoe, 2018). The inclusion of countries with high, medium, and low use of data in this study provides representation of various performing groups based on digitalization in Northwest Europe.

Additionally, the ongoing digital transformation of healthcare services in Europe was another aspect that drove my research. One of the main objectives of the digital transformation in Europe was to develop a healthier society through citizens' empowerment. The notion of empowerment is directly related to self-knowledge and self-awareness and assumes active participation in decision making (Feste & Anderson, 1995). PHD has been envisioned to support self-management and knowledge expansion for people in need of care (European Commission, 2017). Based on that, a priority issue is to provide citizens with access to their PHD and enable sustainable healthcare through data exchange to maximally utilize data-driven capabilities. The promotion of citizens' empowerment for utilizing digital technologies can contribute to stimulating the prevention of and increasing the interaction between stakeholders in healthcare (Digital Single Market - European Commission, 2018). Therefore, the case study presented PHD access and sharing during this transition phase from the more traditional provision of healthcare towards more data-driven and person-centered care.

Europe also provided fertile ground for a microscale observation of global phenomena. Currently, EU healthcare services are facing numerous challenges across multiple levels. In terms of medical conditions, there is an upsurge in non-communicable diseases, such as obesity, high blood pressure, diabetes, and cancer (WHO, 2018). Meanwhile, a global issue that also has implications in Europe is the growing aging population (European Commission, 2018a). The growing number of elderly people is projected to increase care needs and costs. Though the EU is striving to unlock the flow of EHRs across countries within the next few years, data access inequalities still hinder this vision (European Commission, Shaping Europe's digital future, 2019). The lack of a data standardization consensus also hinders interoperability among public sector entities of the EU. These challenges, along with the predicted shortage of healthcare professionals, suggest that the provision of future healthcare services and the role of people in their own health should be reconsidered (WHO, 2020).

The adoption of personal devices in Europe has led to a surge of personal data. According to Cisco's annual report 2018–2023, the number of connected devices and internet connections is predicted to increase from 2.4 billion in 2018 to 4.0 billion in 2023 (Cisco, 2018). A similar trend is expected regarding mobile and internet users. Thus, PHD access can be seen as an opportunity to facilitate people to learn and understand about their health and wellbeing. Among the advantages of new technologies is the provision of real-time data about various facets of peoples' lives, including fitness data, nutrition, and sleeping patterns (Sharon & Lucivero, 2019). The commercialization and affordability of such technologies has also contributed to that phenomenon. Notably, the changing nature of PHD has made it accessible to users in relation to technology innovation. In addition to limited empirical work in this particular area of research (Karampela, Ouhbi, et al., 2018), this also makes this work relevant.

PHD access and sharing topics were focused on the general population of Northwest Europe. The objective was to create baseline knowledge to facilitate researchers in studying these two research topics. In the majority of the studies, the participants were healthy individuals. Healthy refers to the absence of a chronic disease or condition. Only in one study were the participants cancer survivors (embedded unit 3). These users were studied in a transition phase; they were returning to their post-treatment life.

3.4 Data collection per embedded unit

The embedded case study consists of four units of analysis. Each unit utilized different qualitative or quantitative methods, which are described in the following subsections.

3.4.1 Embedded unit 1: Existing body of knowledge about PHD access and sharing

The main objective of the literature review was to identify and address research gaps in the literature about PHD. The study resulted in one journal paper (Karampela, Ouhbi, et al., 2018). In general, mapping studies consist of the following three activities: the search for relevant literature, the definition of a classification scheme, and the mapping of publications (Petersen et al., 2008). The systematic mapping study was conducted to summarize the existing PHD approaches in previous literature and to organize the selected papers according to six classification criteria:

- Publication source,
- Publication year,
- Research types,
- Empirical types,
- Contribution types, and
- Research topic

The included papers were identified by consulting the sources seen in Figure 5. Google Scholar was used to search grey literature. The search string used to perform the automatic research in the selected digital libraries was formulated as follows: “personal” AND “health” AND “data”. The inclusion criteria were limited to ICT studies that addressed personal health data. The exclusion criteria were papers that focused on personal pets, papers whose topic was non-digital health data, papers that focused on systems for data collection, papers that focused on information systems interoperability, papers that focused on systems for data management, and papers whose topic was law.

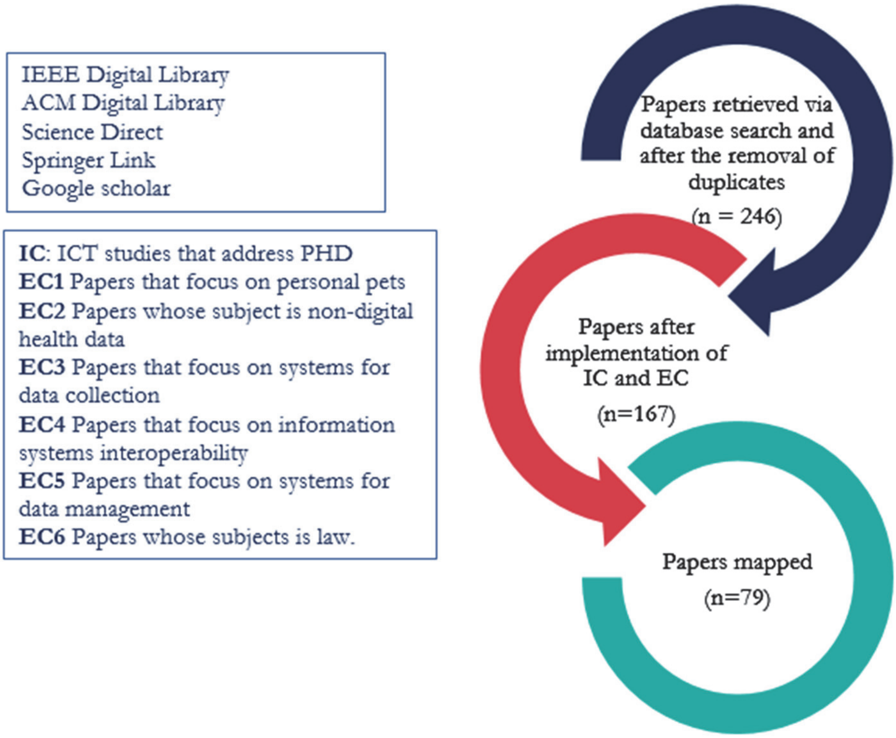

Fig. 5. Selection process of the papers mapped after the removal of duplicates and implementation of the IC and EC.

After applying a set of inclusion and exclusion criteria, in total, 79 papers were included and classified based on well-established guidelines (Kitchenham, Budgen, & Brereton, 2011). Kitchenham et al. (2011) presented the benefits and problems encountered in preceding mapping studies to assess the value of providing examples of best practices. The work in this publication was valuable to map and get a grasp of the existing body of knowledge in the area of PHD access to identify an existing research gap in this particular area of research (Karampela, Ouhbi, et al., 2018).

3.4.2 Embedded unit 2: PHD access

Two studies included in this unit aimed to examine challenges encountered by healthy users while seeking and experiencing PHD access and discussing how this knowledge can be utilized to improve future IS. The qualitative study resulted in two conference papers (Karampela, Grundstrom, & Isomursu 2018a; Karampela, Grundstrom, & Isomursu, 2018b). The recruitment targeted a healthy population that had lived in Denmark for a minimum of two years, as it was important for participants to be familiar with the public health system and digital communications. Data collection was carried out in 2018. Of the 39 people that were asked to participate in this study, only 12 initially agreed to participate. In the end, eight participants, with an age range between 24 and 34 years, completed the requested task.

Table 3. Participants' characteristics.

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

The participants were tasked to find and experience PHD access through various health applications. To keep track of accessed data, participants were provided with a Word document and instructed to store the names of digital sources they accessed and keep notes of their access experiences. To gain a deeper understanding of participants' experiences of accessing their PHD and capture their opinions more openly, while minimizing bias, a qualitative approach was developed using semi-structured interviews and participants' notes (Frankel &

Devers, 2000; Galletta, 2013). The interview guide comprised two themes: experiences of accessing data and the perceived value of data. This study aimed to gather and investigate the participants' experiences; therefore, a semi-structured interview guide was adopted to provide a flexible setting for sharing experiences. During the interviews, all the participants were encouraged to share information relevant to the study based on what they considered to be relevant. Based on Schwarz (1999), self-reports of attitude are influenced by the research instrument in terms of question wording, among others. Therefore, the semantic comprehension of the questions was pre-tested with individuals who did not participate in the study to improve the cognitive comprehension of the questionnaire. The interviews were conducted using the open-ended interview guide designed by author 1, while the analysis of results was a collaborative joint process of all three authors (Karampela, Grundstrom, et al. 2018a; Karampela, Grundstrom, et al., 2018b). Semi-structured interviews have both strengths and weaknesses. An advantage is connected to the flexible nature of the interviews, which enables the researchers to adjust questions to capture the interviewee's thoughts and interests (Alamri, 2019). Conversely, interviews require the allocation of extensive resources, such as time. Additionally, a trustworthy issue of interview methodology is attributed to the possibility of interviewers capturing the participants' opinion about social norms rather than the actual opinion about a topic (Adams, 2015). Approximately 80 pages of verbal transcriptions by authors 1 and 2 were produced. The findings were informative about the participants' experiences in allocating the sources of health-related information based on their perception about health and their experience of accessing their health data. This study was also informative about the perceived value of PHD.

3.4.3 Embedded unit 3: PHD access

The goal of this unit was to understand the utilization of PHD access during the illness to health transition. The qualitative study resulted in one conference paper (Karampela, Porat, et al., 2019c). The decision to focus on such a transition was related to the fact that cancer survivors during the recovering phase would be more prompt to access their PHD more often than healthy individuals. Therefore, their experience was considered valuable in understanding the use of PHD access.

The data collected in this study was based on the exam reports submitted by students in their final year of a Masters' program in IT University of Copenhagen. The exam reports were scrutinized by the healthcare professionals of the center before the final examination. Data collection was carried out in 2017 during the spring semester of the academic year. One of the teachers of the Masters' course is a co-author of the paper (Karampela, Porat, et al., 2019c). The 24 students who participated in the course were divided into five groups. The students carried out semi-structured interviews and fieldwork to obtain information about the needs and expectations of patients recovering from a severe illness. In each of the interview sessions that were organized by the healthcare professionals of the rehabilitation center, one patient was interviewed by the groups of students. Each group selected one of its members to conduct the interviews. Students reported that the semi-structured interviews facilitated an open dialogue in which the respondents could better influence the conversation, embracing the theory that knowledge evolves through dialogue (Kvale, 1996).

Table 4. Participants' characteristics.

#ID	Gender	Age	Rehabilitation time	Education	Cancer type
#1	Male	74	9 months	Bachelor's degree	Not identified
#2	Male	67	12 months	Master's degree	Not identified
#3	Male	34	3 months	Master's degree	Salivary glands
#4	Female	56	10 months	Higher education	HPV1

[1] Human papillomavirus

The interviews were unraveled around information needs in the following six areas: food and nutrition, oral exercises, the role of the relatives, dental hygiene and dentists, intimacy, and physical activities. Inclusion and exclusion decisions about the subjects who participated in the study were made by the healthcare professionals who provided rehabilitation to the participants of the paper (Karampela, Porat, et al., 2019c). A female and three male patients, age ranging between 34 and 74 years old, in their first year of rehabilitation were chosen to be included, as that is a phase in which they have frequent interactions with their PHD. The participants of the study were instructed to express their personal experiences while recovering from a severe illness in relation to access needs that occurred during the transition phase from illness to wellness.

3.4.4 Embedded unit 4: PHD sharing

To understand what access elements are prevalent to sharing PHD with other stakeholders, we conducted a quantitative study in four countries. The quantitative study resulted in two papers, a conference and a journal paper (Karampela, Ouhbi, et al. 2019a; Karampela, Ouhbi, et al. 2019b). In general, quantitative surveys have been used by prior studies to explore and discuss users' perspectives (Courbier, Dimond, & Bros-Facer, 2019; Eurobarometer, n.d.; McCormack et al., 2016). One of the primary weaknesses of questionnaire surveys is that they fail to determine causal relationships (Schnabel, 2021). However, surveys are an invaluable resource to get an understanding of users' attitudes (Fahey, O'Brien, Russell, & Mcginnity, 2019). The questionnaire survey data used in both papers is a subset of a dataset from a large-scale research dataset provided by Sitra. Sitra is a Finnish Innovation Fund that, through its research, aims to influence European policy makers toward more sustainable wellbeing at social, financial, and ecological levels (Sitra, 2018). The questionnaire was designed by Sitra, and the researcher was not involved in the questionnaire design process. The data used in this study are a subset of a dataset from a large-scale research project conducted within the framework of the IHAN project (Sitra, 2018). The scope of the IHAN project is twofold: to develop foundations for a fair and human-driven data economy by creating a method for data exchange and to influence regulatory development towards fair use of data through European Union policy makers.

Table 5. Background information of participants

Demographics Gender	Total percent [a] (n=8.004) [b]
Male	49%
Female	50%
Other	1%
Age	
18–34	32%
34–44	19%
45–65	49%
Region type	
City	40%
Town/urban area	34%
Countryside	22%
Do not know	4%
Education	
Compulsory education	25%
Academic education	14%
[c] Other	58%

Demographics Gender	Total percent [a] (n=8.004) [b]
Do not know	3%
Occupational group or status	
At school or student	6%
Worker	27%
Self-employed or sole trader	6%
Junior white collar	11%
Managerial position/Senior	17%
Pensioner	12%
[d] Other	18%
Do not know	3%

[a] The average of the percentage for all four countries, [b] n=8.004: FI=2.000, NL=2.000, GER=2.004, FR=2.000, [c] Other education: corresponds to vocational education, matriculation, or other types of education, [d] Other occupation: corresponds to other types of jobs or status, such as at-home mother/father

Through a questionnaire survey, we explored users' motivation to share their PHD after the implementation of the new GDPR. The motivation of this study emerged from the findings of embedded unit 3 (for more information, see the Introduction chapter). Data collection was carried out in December 2018 in Finland, the Netherlands, Germany, and France. The inclusion criteria were consent for participation in the questionnaire survey and a self-declaration of being at least 18 years of age. Sampling was random and representative of the age, gender, and locality. The questionnaire was delivered in the official language of each country to give an overview of the current landscape. For the purpose of analysis and reporting, the questions and related responses were translated by professional translators into English. The online survey included a total of 8,004 participants: 2,000 from Finland, 2,004 from Germany, 2,000 from the Netherlands, and 2,000 from France. Among the participants, 49% were male, 50% were female, and 1% did not indicate their gender. The age distribution of the participants was between 18 and 65 years. The survey was anonymous and in compliance with the GDPR legal framework. To comply with the emerging requirements of quality data collection in online surveys, we reported our results based on the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) (Eysenbach, 2004).

Table 6. CHERRIES checklist.

Item category	Checklist item	Survey compliance
Design	Describe survey design	Population 18–65, quotas on age, gender and area
[a] IRB approval and informed consent process	IRB approval	Consent given when joined the online panel
	Informed consent	Yes
	Data protection	Compliant with the new GDPR
Development and pre-testing	Development and testing	Electronic questionnaire, open only for randomly selected participants
Recruitment process and description of the sample having access to the questionnaire	Open survey versus closed survey	Open and Closed
	Contact mode	Recruited to the survey, either by phone or online
	Advertising the survey	No
Survey administration	Web/E-mail	Participants were sent an invitation with a link to the survey
	Context	-
	Mandatory/voluntary	Voluntary
	Incentives	100 points for an online shop for the young, 15 points for the older (one point = 0.01€) b FI 27 cents for complete/ 5 cents for screener only [b] GER , [b] NL, [b] FRA
	Time/Date	December 6 to 18, 2018
	Randomization of items or questionnaires	All the questions were in the same order, but in matrix questions, the statements were rotated
	Adaptive questioning	-
	Number of items	One question/statement per screen
	Number of screens (pages)	27
	Completeness check	Yes
	Review step	No
Response rates	Unique site visitor	After completing the survey, the link can no longer be accessed
	[c] View rate	FI 2,372; GER 3,762; NL 4,101; FRA 3,697
	[d] Participation rate	-
	[e] Completion rate	FI 84%; GER 53%; NL 48%; FRA 54%
Preventing multiple entries from the same individual	Cookies used	No

Item category	Checklist item	Survey compliance
	IP check	Yes
	Log file analysis	-
	Registration	Participants register to the panel platform
Analysis	Handling of incomplete questionnaires	Marked as incomplete and not used
	Questionnaires submitted with an atypical timestamp	-
	Statistical correction	Weighting

[a] IRB: Institutional Review Board, [b] FI: Finland, GER: Germany, NL: the Netherlands, FRA: France, [c] Ratio of unique survey visitors/unique site visitors, [d] Ratio of unique visitors who agreed to participate/unique first survey page visitors, [e] Ratio of users who finished the survey/users who agreed to participate

The questions we chose to include were closed-ended, as the goal was to obtain a quantitative overview of the users' behaviors. The first study explored how motivated the users were to share four different types of personal data: health; perceived values or beliefs; consumption habits and purchases; and wealth. Additionally, the findings were informative about the impact of the new GDPR on users' online behavior. In the second study, the conditions under which the users would be willing to share their PHD with other stakeholders were examined.

Table 7. Summary of research papers, data collection methods, research questions, and contributions

	Participants & resources	Data collection method	Research question (RQ)	Contribution
P1	79 papers: IEEE Digital Library, ACM Digital Library, Science Direct, Springer Link Google scholar	Literature review	Q1. Which publication channels are the main targets for PHD research? Q2. How has the frequency of studies related to PHD changed over time? Q3. What are the research types of PHD	Q1. 62% of the selected papers are published in scientific journals' Q2. Less than 3 papers per year in the period from 1991 to 2013, except the years 2009 and 2012; from 2014 the number of publications rises steadily Q3. Around 41% of the included papers were solution proposal studies, 33% were undertaken to evaluate existing PHD approaches, 11% were opinion papers,

	Participants & resources	Data collection method	Research question (RQ)	Contribution
			studies? Q4. Are PHD studies empirically validated? Q5. What are the approaches that were reported in PHD research? Q6. What are the main topics in PHD literature?	the remaining were classified as reviews; 41% of the solution proposals were empirically validated, the suggested solutions are methods. Q4. 33% were not evaluated empirically, 24% were evaluated with experiments, 24% used surveys, 4% case studies, and 3% history-based evaluations. Q5. 29% are methods, 25% frameworks, the rest were guidelines and tool-based techniques and models Q6. The main research topic is data privacy, followed by data sharing and data security
P2	8 participants	Semi-structured interviews	RQ. In Denmark, what are the accessibility challenges of personal health data, and what is the perceived value of PHD available?	- Search challenge: where to find PHD - Disappointment in ways the data was presented to users through interfaces - Perceived value of data: lowered due to medical jargon, dependent on the usability and personalization features of the services, rather than on the data itself
P3	8 participants	Semi-structured interviews	RQ. How do healthy adults living in Denmark perceive their personal health data in terms of accessibility and value?	- Low motivation to access PHD - The quality of provision of digital services is multilevel and depends on factors such as quality of regulations and ICT infrastructure - The number of services is increasing, but the design of the services needs further refinement to engage people. - Tailor-made services and personalization of visualizations are needed - Perceived value of data: lowered due to

	Participants & resources	Data collection method	Research question (RQ)	Contribution
				provision of medical information in a second language other than their mother tongue, dependent on the usability and personalization features
P4	4 participants	Semi-structured interviews	RQ. What are the needs of the different stakeholders from a rehabilitation service in HNC treatment?	- Data formats: paper formats caused dissatisfaction - Interrelated information needs between stakeholders in healthcare (subject in rehabilitation, informal caregivers, healthcare professionals)
P5	8,004 participants	Questionnaire survey	RQ1. Are users willing to share health data more than other types of data? RQ2. How the new GDPR affected users' online behavior?	RQ1. Respondents were willing to share their PHD more than other types of data. RQ2. For 36% of the respondents, GDPR has had no effect on their online behavior.
P6	8,004 participants	Questionnaire survey	RQ1. Are connected health users willing to share their PHD? RQ2. Under what conditions are they are willing to share their PHD?	RQ1. The majority of respondents were willing to share their PHD under specific conditions. RQ2. For scientific research was ranked higher compared to other conditions[1] (22%) - Age, education, occupation type, and digitalization of country impacted users' willingness - Implications under the prism of the new GDPR

[1] Scientific research, public interest, in exchange for services, or financial benefits

3.5 Analysis per embedded unit

The analysis was performed in the following way. The data were collected from each embedded unit and were synthetized through a meta-analysis process that aimed to answer the research question and present a number of recommendations relevant for IS designers and developers in CH.

3.5.1 Embedded unit 1

This unit included a literature review to identify and address gaps in the literature about PHD and map the existing PHD research. This study addressed six mapping questions (MQs) that were aligned with its rationale. The MQs were classified based on publication source, publication year, research types, empirical types, contribution types, and research topic. Each paper was retrieved and classified by the first author using the guidelines of Kitchenham et al. (2011), while the second author revised the final selection (Karampela, Ouhbi, et al., 2018). The included papers were classified according to six classification criteria: publication source, publication year, research types, empirical types, contribution types, and research topic.

A research type was classified into one of the following categories (Brereton, Kitchenham, Budgen, Turner, & Khalil, 2007):

- Evaluation research: Existing PHD approaches are implemented in practice, and an evaluation of them is conducted.
- Solution proposal: A PHD solution is proposed. This solution may be a new PHD approach or a significant extension of an existing approach. The potential benefits and the applicability of the solution could be shown with an empirical study or good argumentation.
- Opinion paper: These papers express the personal opinion of somebody whether a certain technique is valuable or not, or how things should be done.
- Review: Analysis of existing PHD literature.
- Other (e.g., experience papers, which express the personal experience of author(s), explaining the actions and practical aspects of the topic under discussion).

Empirical type was classified as (Jorgensen & Shepperd, 2006):

- Case study: An empirical inquiry that investigates a PHD approach within its real-life context.
- Survey: A method for collecting quantitative information concerning a PHD approach (e.g., a questionnaire).
- Experiment: An empirical method applied under controlled conditions to evaluate a PHD approach.
- History-based evaluation: Studies evaluating PHD approaches in previously completed software projects.
- Theory: Non-empirical research approaches or theoretical evaluation of a PHD approach.

An approach was classified as (Petersen et al., 2008):

- Process: A series of actions or functions leading to a PHD result and performing operations on data.
- Method: A regular and systematic means of accomplishing PHD.
- Tool-based technique: A technique based on a software tool to accomplish PHD tasks.
- Model: A system representation that allows PHD to be investigated through a hierarchical structure.
- Framework: A real or conceptual structure intended to serve as a support or guide for PHD.
- Other (e.g., guidelines, data mining technique).

To identify the main research topics of the papers, the authors relied on the analysis of the title and keywords. In cases of papers with two main topics, the authors classified the papers maintaining both topics. The synthesis method was based on:

- Counting the number of papers per publication channel and the number of papers found in each bibliographic source per year.
- Counting the primary studies that were classified in each MQ's response.
- Presenting charts for the classification results that were used in the analysis.
- Presenting a narrative summary in the discussion to recount the principal findings.

Descriptive statistics and visualizations were used to analyses and discuss the results in relation to the MQs.

3.5.2 Embedded unit 2

Embedded unit 2 provided evidence in regard to PHD access. Evaluating the experience of people is a challenging task, as the subjective experience of a person is observed indirectly; thus, it is difficult to be analyzed by another person (Nagel, 1974). Among the main challenges encountered was the evaluation of the reliability of participants' subjective experiences (Lutz & Thompson, 2003). Therefore, the authors shared a digital notebook with the participants prior to data collection and encouraged participants to take notes of their experiences while seeking and experiencing PHD access. Previous literature suggested that the combination of taking notes and revising them during narration of past personal events is an effective way to recount experiences (Fisher & Harris, 1973). Thus, the analysis of results relied not only on narrative first-person descriptions of participants' subjective experiences but also on participants' personal notes. Verbal transcriptions of interviews together with the participants' digital notebooks were analyzed thematically based on the themes in the interview guide and the guidelines provided by Braun and Clarke (2006). Initially, the first two authors of the paper identified relevant quotes that emerged from the interview questions. All relevant quotes were then organized into subthemes, and the 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. The 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 the findings were further analyzed.

3.5.3 Embedded unit 3

Embedded unit 3 also focused on users' PHD access experiences, sampling from users that were more motivated to access their PHD as they were undergoing rehabilitation. The approach used to analyze the results in embedded unit 3 was a thematic analysis (Braun & Clarke, 2006). All authors of the study familiarized themselves with the reports by reading and reviewing them. Analytical notes were taken during this process. The authors adopted a collaborative process to analyze the findings, which was performed in two phases. Initially, the first two authors read the reports to identify themes and subthemes. The authors had two face-to-face sessions in which the findings were discussed, and themes and subthemes were further defined. In the second phase, the third and fourth authors were involved in the data analysis process. After a briefing on initial themes and subthemes by the first author, all authors had an additional session, where a discussion on the themes took place and the data were grouped into the final themes. A meta-analysis of qualitative data and thematic analysis of semi-structured interviews were valuable to understand factors relevant to the use of PHD access.

3.5.4 Embedded unit 4

Embedded unit 4 focused on users' overall attitudes about PHD sharing with other stakeholders. The analysis of the survey questionnaire was performed by Kantar TNS Oy, on behalf of Sitra Innovation Fund, using IBM SPSS software. The authors utilized descriptive statistics and visualizations to interpret and discuss the results. In addition, to ensure integrity for reporting the results of the e-survey, the authors relied upon the CHERRIES checklist, which is an established guideline to report results of e-surveys in a systematic and consistent way (Eysenbach, 2004).

3.6 Overall analysis of the units

The analysis of data was twofold; for the qualitative data, thematic analysis was used (P2–P4), and for the quantitative data, descriptive statistics were extracted from publications P5 and P6. Thematic analysis requires a reflexive dialogue between the research objectives and the ongoing research outputs (Braun & Clarke, 2006). After extracting the qualitative and quantitative findings from each embedded unit in an Excel document, a preliminary thematic analysis was performed based on the themes of each embedded unit. To elaborate on this, the following analysis process was followed. The researcher went through the empirical results to read participant quotes and themes as they emerged from the research questions of each study (Braun, Clarke, & Rance, 2014). All relevant quotes from each unit were then organized into emerging themes and subthemes using Dedoose software (Lieber, Weisner, & Taylor, 2011). Dedoose Software is a platform for analyzing qualitative data, among other research. The preliminary thematic analysis of results was revised and further refined. To further safeguard the reliability of the qualitative analysis process, the guidelines of Shenton et al. (2004) were followed. These guidelines support the notion that one of the cornerstones of trustworthiness in qualitative analysis is the provision of a traceable narrative.

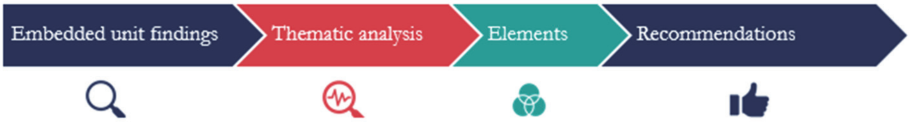

Fig. 6. An overview of this dissertation's analysis process starting from the embedded unit findings to recommendations to IS designers and developers in CH.

This process was data-driven, meaning that a bottom-up approach was followed to arrive at the final themes. The focus of this explorative process was on identifying themes and subthemes that would be informative for the two specific PHD encounters. Figure 6 presents an overview of this dissertation's data analysis process to the composition of the recommendations. This process arrived at the recommendations initiated from the extraction of the embedded units' findings; then, utilizing thematic analysis, the elements, which are high-level abstractions of the themes, were composed. The recommendations are translations of elements to practical suggestions to communicate the best practices relevant for IS designers and developers in CH. Concurrently, the utilization of lay terms was considered appropriate language to communicate the elements to the intended audience. Table 13 in the Appendix presents an overview of the findings per publication. The following chapters introduce the elements and recommendations of this dissertation. General considerations about IS and regulatory or economic aspects were overlooked, as they were outside the scope of this study.

3.7 Ethical considerations

This research followed the ethical guidelines of the University of Oulu Ethics Committee of Human Sciences (Ethics committee of human sciences of University of Oulu., n.d.). All human subjects who participated in this work were informed about the nature and aim of this research project and their rights as subjects before giving their consent to participate. All data gathered from the participants of the papers were anonymized.

4 Findings

This chapter presents the findings of the doctoral dissertation, which included qualitative and quantitative empirical evidence from the publications **P2–P6.** The findings are presented in two subsections titled PHD access and PHD sharing. Before the aforementioned finding subsections, the RQ and overview of embedded units' subsections recap the main RQ and present a summary of the embedded units to facilitate reading.

4.1 Research question

The RQ was answered utilizing an embedded case study. The motivation for composing this dissertation emerged from a gap in empirical knowledge about PHD access, as identified in the literature review in embedded unit 1 (Karampela, Ouhbi, et al., 2018). The research work done in **embedded unit 1** provided new knowledge about the state-of-the-art PHD literature in the health informatics research area. This contribution addresses the lack of empirical evidence, more specifically a case study (research type) on both research topics (Karampela, Ouhbi, et al., 2018), concluding that PHD access is an understudied topic. The gap identified in the area of PHD access informed and motivated the empirical work. The elicitation of empirical studies was built upon the findings that emerged through the course of the empirical work, resulting in the exploration of PHD sharing based on users' perspectives. The renewed interest in PHD sharing is also attributed to the implementation of the new GDPR in May 2018.

The **RQ** aimed to address the knowledge gap identified in **P1** and reflected on evidence that emerged through the empirical work that was conducted throughout **P2–P6**. More specifically, the research work in **P2** and **P3** presented users' perspectives in regard to PHD access and the perceived value of PHD. Building upon evidence from **P2** and **P3**, namely that healthy users were not motivated to search for and experience PHD access, the next empirical study focused on the use of PHD access from the perspective of users recovering from a severe illness. The latter considered using their PHD more often compared to healthy individuals because they were eager to learn about their health. **P4** studied PHD access, which subsequently incentivized the last empirical study. The rationale behind **P4** was related to the value of information sharing among stakeholders and the identification of interrelated information needs. Finally, **P5** and **P6** were developed to study users' willingness to share PHD compared to other types of personal data, the conditions under which they would be willing to do so, the user's personal characteristics that have an impact on this behavior, and the impact of the new GPDP on their willingness.

4.2 Overview of the findings

To ensure traceability of the results, the following subsections provide details on the information extracted from each embedded unit. Combining qualitative and quantitative data from the embedded units, a number of elements were identified for two PHD encounters: PHD access and sharing. For the theme of PHD access, three elements (E) were identified (E1 to E3), while for PHD sharing, there were two elements, E4 and E5. In this context, users' encounters are seen as moments in which PHD access and sharing enabled users to value through interactions with data the quality of PHD (Stauss & Mang, 1999).

4.3 PHD access

This section presents the findings related to PHD access as identified through the empirical work done in embedded units 2 and 3. Three elements (E) were identified: E1) PHD in relation to the perceived definition of health, E2) data types and formats, and E3) perceived value of PHD.

4.3.1 E1: PHD in relation to the perceived definition of health

In general, when people are asked to consider what data sources are available to access their PHD, they should first reflect on what personal health means for them. Then, based on that reflection, identifying the sources that hold such data is the next step. The way that people consider PHD is related to how they perceive personal health. The WHO defines health as "a state of complete physical, mental, and social well-being not merely the absence of disease or infirmity." (WHO, 1946, p. 1). This definition connects health with quality of life, thus defining quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1997, p. 1). Therefore, health is a self-assessed and subjective experience related to wellbeing and not necessarily to the absence of a condition or disease.

When the participants in embedded unit 2 were tasked to search and access their PHD, the perceived definition of personal health impacted the selection of data sources the participants accessed. To form a definition of PHD, they utilized different methods, such as brainstorming sessions and Google search queries. To complete the task, they relied upon the perceived definition of PHD. Table 8 presents the sources accessed by each participant.

Table 8. Sources of PHD accessed per participant. The sources in italics were relevant to mental health, while the rest were for physical health.

# Participant	Sources accessed
# 1	Sundhed.dk[1], Health iPhone, FitnessWorld
# 2	Plus1 Tandlæger[2], Sundhed.dk, *Facebook*, Health iPhone, Google, Føtex, FitnessWorld, Yummly, Rejseplanen[3], Yoga, MyFitnessPal
# 3	Garmin, FysiskForm [4], Louis Nielsen [5], Plus1 Tandlæger, Sundhed.dk, Coop [6], MyFitnessPal
# 4	Care4U [7], FitnessWorld, Google, Matas[8], Inspiration, Apple, Rejseplanen, Synoptik [5], *Facebook*, Københavns Universitet, Nordea Bank, Sundhed.dk
# 5	Amazon, FitnessWorld, Nordea Bank, Care4U, Google, Apple, *Facebook*, *Instagram*, *YouTube*
# 6	Health iPhone, 8fit app, *Headspace*, Lifesum app
# 7	Withings.com, Borger.dk [10], Plus1 Tandlæger
# 8	FitnessWorld, Sundhed.dk, Health iPhone

[1] National health portal in Denmark, [2] Dentist , [3] The Danish public transportation planner, [4] Fitness center chain , [5] Optic store chain, [6] Supermarket chain, [7] Doctors' website, [8] Cosmetics store, [9] The name of a store in Copenhagen, one of the participants accessed the source to retrieve sick leave days, [10] The Danish public citizen's portal

The participants accessed wearable sensors' data (e.g., Withings.com), mobile apps (e.g., Yummly), and web app data (e.g., Borger.dk). The types of PHD that were accessed were related to sources, such as fitness chains, transportation, education, and finance. The types of PHD were informative to participants' perceptions of health. The sources accessed by the participants were different for those who considered only their physical health than those who considered both their physical and mental health. The majority of them accessed data sources that held personal data related to physical health, such as physical activities (e.g., FitnessWorld and Health iPhone). Few participants considered personal health in a more holistic manner, accessing data sources from which they could extract PHD about their mental health. For example, participant #5 argued that YouTube post history enabled him to recall memories and feelings pertinent to his mental health at specific moments in time. Thus, he argued that YouTube is a source that holds data related to personal health. This argument was further supported by comparing the sources accessed by participants #3 and #5; participant #3 considered only physical health, while participant #5 considered physical and mental health (see Table 8).

The subjective nature of health and wellbeing introduces challenges in relation to which data sources hold PHD and which do not. A better understanding of how users consider their health and wellbeing is a way to inform relevant stakeholders in healthcare about the sources that can be valuable for users to extract knowledge about their health and wellbeing.

4.3.2 E2: Data types and formats

Data types and formats were concepts emerging through the data collection process. Data types refers to different kinds of health data accessed by the participants of the case study (e.g., EHRs or wearable sensor data), while data format refers to the proprietary format of the data, which is the file format in which the data is created or stored in, such as .csv or .mp4 (Plastiras & O'Sullivan, 2018). The data types and formats accessed by the participants of the studies in embedded units 2 and 3 were informative on various aspects in relation to human nature and data. The approach followed by the participants of the study in embedded unit 2 to retrieve their data was exploratory in nature and represents a snapshot of their search effectiveness to fulfil their task. In our studies, the participants accessed a large variety of different types of data to learn about their health. They accessed, for example, digital footprints or wearable sensor data, which were suggested to be informative about their health and wellbeing, as well as EHRs to find medical information, such as laboratory test results. The types of data accessed, as Table 9 shows, impacted the knowledge that participants could extract from it. Some of the accessed data were created by them and included their own perceptions about health, but some other types of data, such as EHRs, included data that were descriptive of their health in more objective ways.

Table 9. Sources of data that participants sought to access their PHD in embedded unit 2. The 'by me' category includes sources of data that mainly participants feed with data, and 'about me' are sources that included data that were saved on their behalf by companies, organizations, etc.

Data 'by me'	Data 'about me'
8Fit, BedTime, HeadSpace, Health iPhone, Lifesum, MyFitnessPal, Yoga Studio, Yummly, YouTube, Facebook, Instagram, Garmin, Withings	Amazon, Apple, Google, FitnessWorld, FysiskForm, Borger, Care4U, Sundhed.dk, Plus1 Tandlæger, Rejseplanen, Inspiration, København Universitet, Nordea Bank, Coop, Føtex, Louis Nielsen, Synoptik, Matas

As the participants were healthy individuals, the majority of accessed PHD were either digital footprints or EHRs. Approaching these two types of data from another viewpoint, one could argue that capture access encounters which are informative of the nature of users' contribution to create the data. The data generated 'by me' captured personal data about participants' digital selves—including data about mental health—which required some sort of direct interaction with applications (e.g., setting up a profile, creating a plan, or customizing preferences). Data 'about me' included data created while users interact with applications, and it is mainly captured on their behalf by companies, such as Google. The latter is descriptive of participants' passive interactions with applications, in the sense that in some cases, they did not have explicit control of the personal information that was stored. An example of passive interaction is Google browsing history. Data 'by me' included health information that is limited to wellness and behavioral data that is accessible through wellness applications or social media, e.g., Facebook. These findings portray how healthy participants considered health and PHD. The types of PHD accessed through their digital footprints were informative of their health behaviors and, in some cases, made participants wonder about the amount and types of personal information that were scattered on the network and available for them. They were somewhat surprised about the indirect interactions with applications that resulted in the creation of a digital profile of their personal health.

The sources accessed by the participants can also be discussed from the perspective of data formats. Access and data formats are often research topics discussed in technical studies, such as the database architecture of health data. In embedded unit 2, the participants accessed a variety of different data formats, such as video (YouTube) or photo file formats (Instagram) and .csv format (Sundhed.dk). The participants argued that data formats could play a central role in the ways they use their PHD. According to our findings, the access and usability of data was related to the formats of PHD. Access in this case is closely related to the tasks that participants can or intend to perform using their PHD, and with the knowledge that can be extracted based on what was allowed or supported by the data formats. For example, processing or having an overview of data should correspond to different data formats. Therefore, there is an essential relationship between the format of the data that is accessible to participants and the purpose of data use. Participants preferred data formats that allowed automatic extraction of data for analysis.

Data formats were also discussed in embedded unit 3 in terms of accessing PHD in paper formats:

"The pamphlets were there, but you can't ask questions to a pamphlet!"

For participants accessing their PHD more frequently to obtain information related to rehabilitation, PHD access to pamphlets caused dissatisfaction. The dissatisfaction was rooted in questions in which they felt they could not get answers due to the non-interactive format. Similarly, the provision of a considerable amount of information led to similar feelings:

"I don't want to write back and forth, and I don't want to read 400 pages of paper from this place (rehabilitation center)."

Data access and knowledge extraction from PHD are areas that have emerged in recent decades and somewhat constitute a new experience for companies and service providers, as well as for users. Although the information about data formats is limited due to the design of the studies, our findings support that most data providers or companies accessed by the participants were not prepared to provide data to individuals in a format that would be accessible to them.

4.3.3 E3: Perceived value of PHD

During our lifetime, we have the opportunity to interact with different types of health data. Data can take different forms, such as words or numbers, and include raw or unprocessed facts, which are not meaningful until they are organized (Zins, 2007). Data "represents a fact or a statement of the event without relation to other things" (Bellinger et al., 2004, p. 3). In contrast to data, information "is known as data that have been processed to give meaning by way of relational connection" (Bellinger et al., 2004, p. 1). However, data turn into information when users convert or translate data to information, leveraging knowledge acquisition processes. As has been discussed in the 'Theoretical positioning' chapter, the data, information, and knowledge model introduces the notion that knowledge acquisition is among the final steps of a comprehensive process that entails transitioning from data to information and knowledge to enable participation in decision making (see chapter 'Theoretical positioning'; 'Accessibility in information systems'; 'The role of accessibility in decision making'). In that sense, data transforms into information when users can utilize it to extract value. However, what is valuable to one person is not necessarily valuable to others. Therefore, the value of data is perceived or subjective.

The perceived value of PHD in this dissertation was based on participants' experiences and needs when accessing their PHD through various applications and was found to be dependent on the usability and personalization features of the information systems they accessed. The applications had inherent properties that were contextual to the participants' interactions where the perceived value was derived (Kujala & Väänänen-Vainio-Mattila, 2009). Perceived values capture personal preferences, as well as social and cultural influences (Bilsky & Schwartz, 1994). People have different hierarchical structures and rank values in different positions based on their perceived importance. This hierarchical structure is quite unstable and can change depending on various factors (Verplanken & Holland, 2002).

The perceived value of data influenced how the participants valued the use of data access. The participants connected the value of PHD with personalization features and visual representations of data. Therefore, the value of data is, to some extent, related to the content of data and to whether the participants could extract some health knowledge based on their data. For example, visualizations were suggested as being an effective presentation of information to enable participants to extract personalized knowledge based on the data that they were interested in. The perceived value was also connected to data comprehension. Participants stressed the negative impact of medical terminology on value. Language barriers lowered the perceived value of PHD in relation to medical jargon:

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

Several of the participants noted that the medical terminology used was confusing, meaningless, and had no explanation either through doctor notations or through clarifications available on the site. This was a challenge that was expressly considered in the context of national health registries. The participants had no means to interpret medical notations to infer the meaning of PHD. In addition, second language acquisition, alongside medical terminology, also caused a deterioration in the perceived value of data:

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

The perceived value of PHD was also related to interfaces as a means to access and interact with their PHD. As discussed earlier in this subsection, the perceived value of PHD was found to be related to usability. Usability covers a broad spectrum of aspects, including user interfaces (Simões-Marques & Nunes, 2012). The participants in embedded unit 2 accessed websites, mobile applications, and wearable sensor interfaces to interact with their data. PHD access through traditional medical interfaces, such as national health portals, gave them the impression that interfaces were not designed to accommodate their needs. The poor user experience design included navigation errors and broken links in which users were not able to locate support material, such as a medical dictionary.

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

In contrast to the design of the EHR interfaces, access was perceived as user unfriendly, and the participants claimed to have an intuitive experience through interfaces of various mobile applications and wearable sensors. Interfaces of mobile applications and wearables facilitated participants' access experience with rich and interactive features. However, despite the seamless design of the interfaces, access to PHD was found to be limited. Participants could only access a part of their PHD, while they supported the idea that service providers stored additional personal data that were not accessible to them. Participants mentioned that, in some cases, access to data required them to pay a fee. As data consumers, the access experience they had through the interfaces of the commercial applications was designed so that users were offered a tailored-made and rich user experience.

The perceived value of PHD was also found to be related to visualizations as a means to increase PHD usability. Data visualizations were an effective way to utilize their data to get a better understanding about their health. Therefore, participants proposed visualizations as an effective way to personalize their PHD, thus suggesting a relationship between PHD visualizations and projection of personal requirements or interests. The usefulness and perceived value of PHD was connected to how their information was being visualized. They suggested that tailor-made components, such as parameter declarations, would enable direct interaction with their data. More active ways to manipulate their PHD would enable them to extract value. Therefore, personalization features in visualizations can increase the value of PHD, enabling users to express personal preferences over their data. The following quote extracted from embedded unit 2 supports visualizations as a means for participants to utilize their data:

"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 [sic]" (6#_EMBC).

4.4 PHD sharing

The following sections will present the findings pertinent to users' willingness to share their PHD. In the context of this doctoral dissertation, users' intention to perform actions "are assumed to capture the motivational factors that influence a behaviour; they are indications of how hard people are willing to try, and of how much of an effort they are planning to exert, in order to perform the behaviour." (Ajzen, 1991, p. 181). Based on this definition, willingness to share PHD can be indicative of users' intention to perform an action in a given context. In this study, the conditions under which users would be willing to share their PHD were limited to a set of specific cases, such as for research purposes or financial incentives; therefore, users' willingness to share their PHD will be discussed in this context. Two elements were identified and clustered around two themes: E1) demographics and E2) data privacy.

4.4.1 E4: Demographics

This work explored the impact of demographics on participants' willingness to share their PHD with other stakeholders. PHD sharing is a decision underpinned by personal characteristics. While the results of this study about participants' willingness to share their PHD for research are in line with previous literature (Pickard & Swan, 2014; Shah et al., 2019), as PHD sharing for research was the most preferable option, our study expanded the previous work done by providing deeper insights into a number of attributes that have an impact (Karampela, Ouhbi, et al. 2019b). More specifically, our results support that age, education, occupation, and digitalization level of countries have a share on a user's willingness to share data.

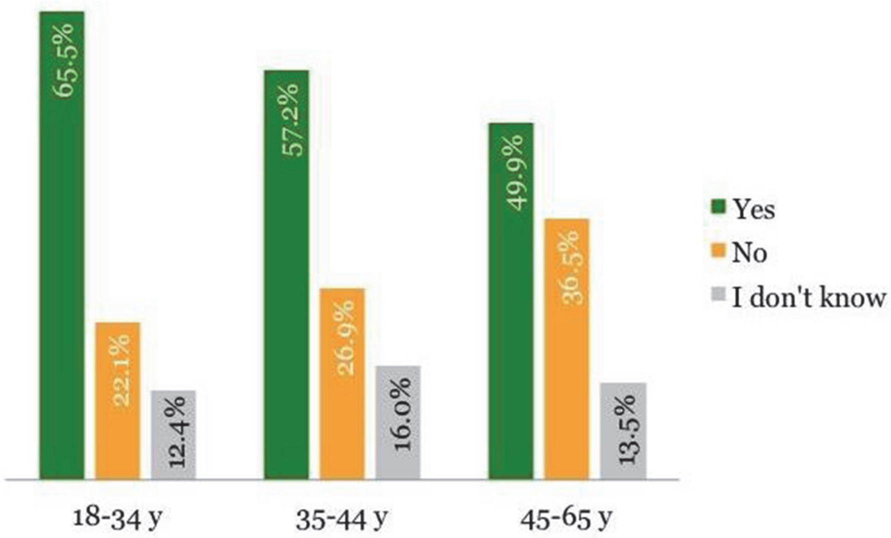

Fig. 7. Willingness to share PHD by age group.

The value of demographics to explore and understand consumers' attitudes has also been utilized in past research (Darker, Donnelly-Swift, & Whiston, 2018; Dutta-Bergman, 2004). As Figure 7 shows, our results supported that the age of the participants had an impact on their willingness to share their PHD; younger people (18–34 years) were more inclined to share their data (65.5%) compared to older participants (45–65 years). Age and willingness to share PHD were found to have a negative relationship; the older people get, the less they are willing to share their data. Considering this trend, together with predictions about the world population change in which the elderly population is increasing (European Commission, 2018a), it should be expected that data sharing reluctance will be a challenge for future healthcare.

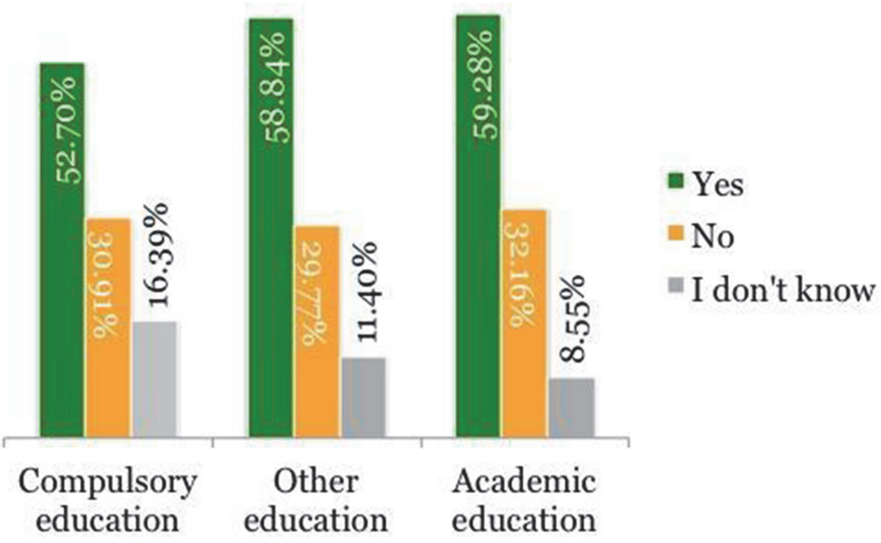

Fig. 8. Willingness to share PHD by education group.

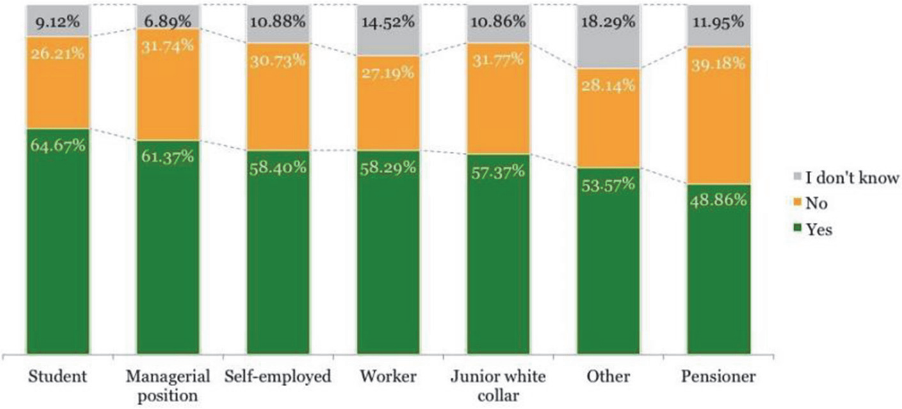

Fig. 9. Willingness to share PHD by occupational group.

The education level and occupation, in addition to the level of digitalization of each country, were also factors that were found to have an association with participants' willingness to share their PHD. Lower levels of educational attainment and occupation were related to hesitancy towards PHD sharing. Of the participants with a compulsory education, 52.70% were willing to share their

PHD, whereas 59.28% of those with academic education were positive towards sharing their PHD (N=8004). Considering the similarity of trends in education and occupation, it is likely that the group of participants with higher educational attainment will hold management positions; subsequently, the profile of these participants is connected to higher data sharing willingness (Figures 8 and 9).

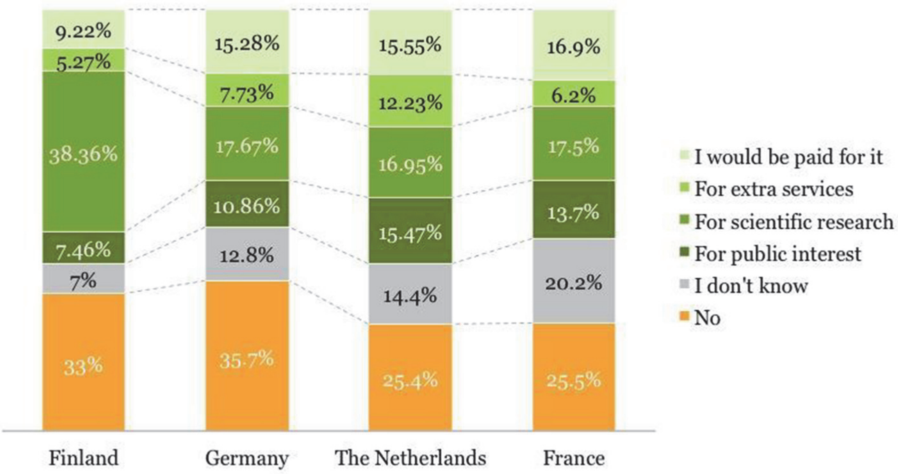

Fig. 10. Results by country (N=8,004: FI=2,000, NL=2,000, GER=2,004, FR=2,000).

Current user trends in the four countries examined (Finland, the Netherlands, Germany, and France) were informative about the impact of digitalization of health care services. The countries of concern belong to different groups in relation to the use of internet services, ranging from more advanced digital economies to medium-performing group and lowest position (DESI, 2018). Finland and the Netherlands have the most advanced digital economies, while Germany and France belong to the medium performing group, with France ranking in the lowest position (DESI, 2018). Therefore, the findings provide a good representation of the digitalization landscape in Northwest Europe. Taking that into consideration, participants from countries with medium level of digitalization were found to be reluctant or unprepared to share their PHD (Figure 10 and Table 15 in the Appendix). The lowest group of digitalization included participants who did not know if they would be willing to share their PHD (20.22%). Based on these evidences, the digitalization level of countries has a stake in peoples' willingness to share their PHD with stakeholders in a healthcare context. However, the digitalization level of countries was not the only factor that had an impact on participants' willingness, as cultural peculiarities can also have an impact on these findings. For example, German participants were apprehensive about experiencing negative consequences as a result of past privacy violations (Voigt et al., 2020; Ziefle, Halbey, & Kowalewski, 2016). Our findings can only provide preliminary evidence in this regard. However, an objective of this work is to pave the way for future efforts to scrutinize these factors using a qualitative approach in addition to historical knowledge.

4.4.2 Data privacy

PHD access triggered participants' considerations over data protection. Data protection concerns the utilization of privacy and security measures to prevent unauthorized access to data. Personal data, regardless of their context, are considered to be sensitive because they include information related to the identification of individuals (European Commission, 2018c). To regulate PHD access and to prevent unauthorized access, privacy and security mechanisms are essential. Privacy considerations are related to policy making and legal considerations, while security refers to more technical means linked to data-prevention breaches and cyber security (Tikkinen-Piri, Rohunen, & Markkula, 2018). In the context of this work, privacy is discussed through the lens of the responders who participated and addressed their considerations and concerns.

Table 10. Participants' responses pertinent to their willingness to share different types of personal data.

Types of personal data		Country				Gender		Age in years		
		FI[1]	GER[2]	NL[3]	FR[4]	M[5]	F[6]	18-34	35-44	45-65
Health or heredity	Yes	60.31%	51.54%	60.19%	54.30%	56.96%	55.95%	65.55%	57.18%	49.92%
	No	32.54%	35.67%	25.37%	25.54%	30.41%	29.68%	22.06%	26.86%	36.55%
	DN[7]	7.15%	12.79%	14.45%	20.16%	12.63%	14.37%	12.40%	15.96%	13.53%
Values or belief	Yes	62.92%	52.70%	61.32%	46.19%	56.92%	54.43%	66.53%	58.57%	46.92%
	No	24.85%	32.00%	21.62%	30.10%	32.69%	36.74%	26.60%	31.42%	41.52%
	DN	12.23%	15.30%	17.06%	23.71%	14.46%	17.89%	15.21%	18.00%	16.38%
Consumption habits	Yes	77.83%	67.88%	67.24%	64.37%	69.98%	68.77%	76.88%	69.92%	63.68%
	No	13.21%	19.45%	17.71%	15.96%	17.13%	16.24%	10.33%	15.33%	21.58%
	DN	8.96%	12.68%	15.06%	19.67%	12.89%	14.99%	12.79%	14.75%	14.74%
Wealth	Yes	48.23%	38.81%	44.85%	47.18%	48.65%	40.57%	58.50%	47.97%	33.60%
	No	41.68%	46.56%	39.12%	30.80%	37.29%	42.37%	26.26%	35.72%	50.66%
	DN	10.09%	14.63%	16.03%	22.02%	14.06%	17.06%	15.25%	16.30%	15.75%

[1] Finland, [2] Germany, [3] The Netherlands, [4] France, [5] Male, [6] Female, [7] Don't know

Privacy concerns have been found to be related to the type of data that one is willing to share with other stakeholders. The notion of subjectivity introduced with the term perceived is associated with the types of personal data in terms of content. As Table 10 shows, among the four types of personal data, namely health or heredity, values or belief, consumption habits, and wealth, participants' willingness to share their PHD was found to be higher compared to wealth data. Approximately two of three participants were willing to share information about their values and beliefs and health and heredity data. Our findings support that data about consumption habits, values or beliefs, and health or heredity were considered less privacy sensitive, as participants' willingness to share these types of personal data was higher than data about wealth.

A personal attribute related to privacy considerations is trust. Trust was a personal attribute that came out in this case study when participants were asked about their willingness to share their PHD with other stakeholders. In embedded unit 2, participants claimed that access control and the purpose of use can have a positive or negative impact on trust. Trust was considered more than a condition that could facilitate or impede granting access to data. PHD sharing was found to be a process underpinned by personal qualities; participants thought that PHD could hold intimate information about their health, behaviors, and preferences. Apprehensions of data handling by third parties who were not given direct access to use the data by the data owners were identified as a point of contention:

Participant #2 "I wouldn't mind as long as this is [PHD] not taken by [a] third party and used [in] a way that is not correct, whatever that could be."

In the same direction, the findings in embedded unit 4 supported the notion that legal frameworks also have a share on trust or mistrust. A factor related to trust was the conditions under which the participants would be willing to share their PHD. Positive attitudes towards personal data sharing for scientific research can be perceived as an indication of trust established between users and academia. In contrast, sharing PHD with public entities was one of the least preferred options (Figure 11). The co-existence of trust and mistrust relationship between users and the public could be a way to round off this discussion; some previous work concluded the existence of a trust, while the rest showed a mistrust relationship (Aitken, Cunningham-Burley, & Pagliari, 2016; Pickard & Swan, 2014; Willison et al., 2007).

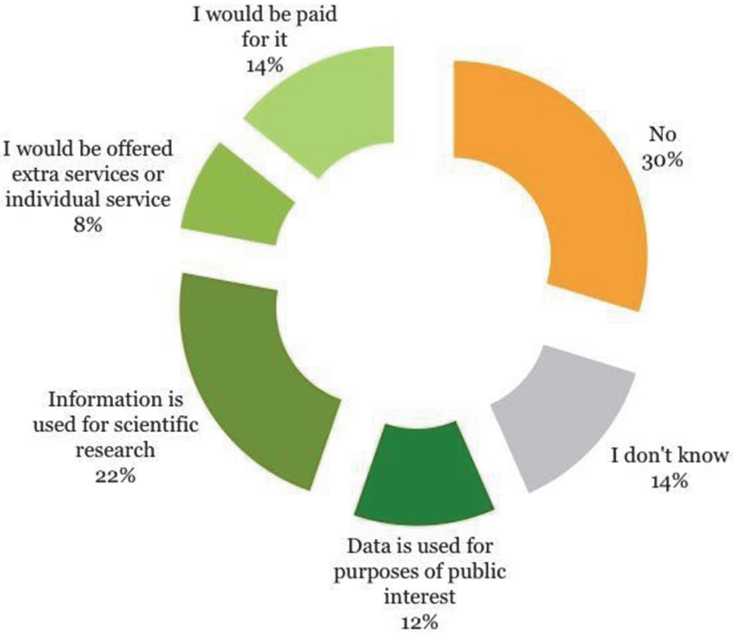

Fig. 11. Participants' willingness to share their PHD (N=8,004).

The timeframe of the study was approximately seven months after the enforcement of the new GDPR on May 25th, 2018, delineating certain aspects related to the impact of the new legislation on users' willingness. When participants were asked if the enforcement of the new GDPR affected their attitudes, they confirmed that the implementation of the new law impacted their trust in sharing their personal data (Table 11). The majority of individuals who participated confirmed that the implementation of the new legal framework influenced their attitudes (nearly 64%), supporting the notion that trust and legal frameworks have an interwoven relationship.

Table 11. Participants’ responses about the impact of the new GDPR on their online behavior.

The impact of GDPR on participants’ behavior	Country				Gender		Age in years		
	FI[1]	GER[2]	NL[3]	FR[4]	M[5]	F[6]	18–34	35–44	45–65
It has not affected my behavior in any way.	36.14%	37.56%	33.31%	36.30%	35.38%	36.80%	30.61%	33.16%	40.69%
Don’t know	9.95%	8.22%	17.66%	10.98%	9.59%	13.16%	10.49%	12.82%	12.09%
It has somehow affected my behavior.	75.82%	77.80%	74.89%	69.80%	82.35%	66.98%	93.52%	77.30%	59.90%

[1] Finland, [2] Germany, [3] The Netherlands, [4] France, [5] Male, [6] Female

4.5 Overview of findings and recommendations

Table 12 presents an overview of the elements and recommendations identified through the embedded case study. The contribution presents two PHD encounters based on empirical evidence focusing on the temporal aspect. The two encounters are PHD access and sharing. For each of the access encounters, a number of elements, five in total, were found using thematic analysis for the qualitative data and extracting descriptive statistics for the quantitative data. The five recommendations emerged through translation of the elements into practical knowledge, which is relevant for IS designers and developers in CH. Table 14 in the Appendix presents an overview of the key findings by publication.

Table 12. PHD access, main findings (elements), description of elements and recommendations to IS designers and developers in CH.

	Elements (E)	Description of elements	Recommendations (R)
PHD access	E1) PHD in relation to perceived definition of health	Subjective nature of health and PHD: Physical health, Mental health	R1) Consider how users perceive health and PHD
	E2) Data types and formats	Data types: EHRs, Digital footprints Wearable sensors, Mobile apps, Web apps Data ’by me’, Data ’about me’ Health status Data formats: Related to purpose of use of PHD Digital formats, Paper formats	R2) Consider what data types and formats foster PHD access
	E3) Perceived value of PHD	Subjective nature of PHD value Related to usability and personalization features: Medical terminology Visualizations Interfaces	R3) Simplify medical terms, provide visualizations and interfaces to nurture usability and personalization features, and so to promote the perceived value of PHD
PHD sharing	E4) Demographics	In relation to: Age Education Occupation Digitalization of the country	R4) Consider age, education, occupation, and digitalization to encourage PHD sharing with stakeholders
	E5) Data privacy	In relation to: Types of personal data Access control and trust Trust relationship and the purpose of PHD utilization GDPR enforcement impact on online behavior Conditions of sharing PHD	R5) Consider data privacy under the prism of data types, access control and trust, conditions of sharing, and the purpose of data processing

R1 encourages designers and developers in CH to consider how users perceive their health. The subjective nature of health and numerous factors influencing the perception of health are a challenge regarding what data are relevant to people's health and what not. R2 suggests that data types and formats can foster PHD access. R3 conveys that the perceived value of data is related to the simplification of medical terms, provision of personalized visualizations, and interfaces to nurture usability. R4 suggests that age, education, occupation, and digitalization are parameters that encourage PHD sharing with stakeholders in healthcare. Finally, R5 recommends considering data privacy through the lens of data types, access control and trust, conditions of sharing, and the purpose of data processing.

5 Discussion

This chapter is multifaceted, presenting the contribution of this doctoral dissertation based on research publications and findings. I discuss the theoretical and practical research contribution introducing implications, outline my response to the research question, and finally position this dissertation contribution in relation to prior work and current affairs. In the last part of the section, I present the case study limitations.

5.1 Contribution

The main contribution of this dissertation consists of five recommendations relevant for IS designers and developers in the CH context and lies at the intersection of IS, health informatics, and HDI. The embedded case study provides updated knowledge about PHD access and sharing, two rapidly changing research topics that attract and nurture scientific interest due to the implementation of the new GDPR. This study considers and explores the research topics through the users' encounters with their PHD, thus offering knowledge about certain elements and proposing five recommendations at this particular point in time (2018–2020) in the Northwest European healthcare ecosystem. This timeframe carries weight due to the surge in personal data and healthcare transformation towards people-centered and CH approaches, among others. The study is unique within its framework because of the empirical work conducted and the methodology adopted, which utilizes qualitative and quantitative evidence.

This dissertation makes a theoretical contribution, addressing the gap in previous literature pertinent to limited empirical evidence about PHD access (R1–R3) (Karampela, Ouhbi, et al., 2018). In the same direction, two of the recommendations (R4, R5) provide updated knowledge relevant to users' willingness to share their PHD with other stakeholders in the first period after the implementation of the new GDPR legal framework. This study addresses the notion of time as an aspect that is related to the dynamic nature of data and people.

As for the practical contribution, these recommendations can effectively aid IS designers and developers in CH, as well as stakeholders in the healthcare industry, in their future endeavors to design IS that will support decision making based on users' perceptions. This research contribution consists of three access recommendations and two recommendations related to PHD sharing, providing knowledge about certain elements and introducing areas of problematization. The five recommendations are concepts that aim to introduce practical knowledge about users' perceptions in relation to two specific data encounters with IS. The implications introduced that particular elements, such as the R1, should be considered during the design and development process of IS. In line with this proposition, previous studies support to consider different aspects—for example, privacy—during the design and development phases. The findings also emphasized the importance of the privacy by design principle to support privacy considerations throughout the whole development process (Cavoukian, 2009; Ceross & Simpson, 2018). The principle *by design* can perhaps encapsulate the practical contribution of this study, underlining the importance of incorporating the recommendations into the design and development process of IS and not as an afterthought. The elements should be embedded in these processes in creative ways so that the interests of various stakeholders are represented with equal diligence. These findings also have implications for practitioners working in CH who would like to acquire knowledge about the specific users' encounters with their PHD. The value of human-centered design, especially in CH, cannot be neglected. Certain parts of this research can also be relevant for IS experts who work outside the healthcare field as a framework in relation to design considerations about users' data-related needs. Policy makers can also acquire knowledge to inform future policies. Privacy by design and by default principles are concepts incorporated in the new GDPR (ICT Legal Consulting, 2018). This research work introduced the timely nature of PHD access and sharing, underlining that policies need to keep pace with these changes.

5.2 Research question

The research contribution presented answers to the RQ. The fit of this work in relation to prior research has been discussed in detail for each of the elements that were proposed in the chapter 'Findings.' The overall fit of this dissertation in relation to prior work will be discussed in the following subsection.

The research work conducted in **P1** was threefold. First, it provided a clearer picture of the current landscape of PHD access and sharing, then revealed a gap in existing knowledge, and finally spurred motivation for the development of the first empirical study. The systematic review was among the first studies to provide an overall analysis of the prior work in the area of PHD, contributing with updated knowledge about the publication trend, publication channels, research and empirical types, approaches, and main research topics (Karampela, Ouhbi, et al., 2018). The value of including users when proposing or evaluating approaches has been recognized by previous research work (Aidemark, Askenäs, Nyg\aardh, & Strömberg, 2015; Ouhbi, Karampela, & Isomursu, 2019; Piller, Schubert, Koch, & Moesleim, 2004). To address the identified gap in prior work, the following RQ was extended:

What recommendations are relevant for IS designers and developers to enable PHD access and sharing?

The RQ was answered through the empirical work conducted in **P2–P6** and substantiated further with previous related literature. The **RQ** was answered based on the elements identified through the embedded case study, leading to the composition of the corresponding recommendations. To position and complement the present research work, previous research was presented together with the recommendations. **P2–P4** were mainly informative about users' PHD access encounters, while introducing the notion of shared information needs between stakeholders. Based on that, the focus of **P5** and **P6** was on elements connected to PHD sharing with other stakeholders. The proposition of recommendations was based on the elements that emerged through the empirical work. The recommendations offer contemporary guidance to IS designers and developers in CH that is pertinent to users' needs in this particular time in the Northwest European Healthcare Ecosystem.

5.3 Discussion of the five recommendations

A literature review, semi-structured interviews, participants' journaling, and a questionnaire survey were artefacts collected from the users who participated in our studies and provided a rich collection of qualitative and quantitative data, based on which I developed the proposed recommendations to support decision making through data access and data provisions to relevant stakeholders. Although the following recommendations do not generalize to all user populations, the scientific methods followed to synthesize the evidence follow good research practices to best support the specific user group at this time in Northwest Europe. The proposed recommendations contribute with updated knowledge about two PHD encounters; R1–R3 concern PHD access, and R4 and R5 PHD sharing.

R1) Consider how users perceive health and PHD

When developing IS in a CH context, designers and developers should consider how users perceive their health. The subjective nature of health and numerous factors influencing the perception of health rise a challenge pertinent to what data are relevant to one's health and what are not. A better understanding of how the identified users consider their health and wellbeing is a way to inform CH designers and developers of which sources are valuable for the users to self-manage their health and wellbeing. Additionally, since health is subjective in nature, different types of PHD could affect users' willingness to access it.

The subjective perception of health requires the incorporation of personal characteristics into the design and development of IS. The way that people define, experience, and consider their health is interrelated with what data they perceive as health related. Therefore, future IS in healthcare should aim to support the integration of various types of data, as different users can retrieve fractures of their health from distinct data sources. The users participating in this study suggested that they primarily perceive health in relation to physical health; few of them approached health considering both physical and mental health. However, mental and physical health should not be thought of as separate. Therefore, it is recommended for future IS to provide access opportunities to data that will support users to consider their health in more holistic ways. The acceleration of mental health problems in modern society (Scott, Valley, & Simecka, 2017) requires that IS support users in decision making, considering health in a holistic manner.

R2) Consider what data types and formats foster PHD access

Based on the types of data accessed in the studies of embedded unit 2, it is possible to get an understanding of the search strategies users followed to find their PHD. Users' journals showed that the majority of them relied upon general purpose search engines to seek their PHD. General search engines, such as Google, rely mostly on the identification of unstructured data, which are text-heavy information and metadata, that are often imprecise on the way they describe datasets (Koesten, Kacprzak, Tennison, & Simperl, 2017). The search results from general search engines extract and represent sufficient web-based information but not always information published in datasets (Gregory, Groth, Cousijn, Scharnhorst, & Wyatt, 2017). Therefore, the types of data accessed might not well represent the data that are accessible to users. The approach followed by the users of this study to retrieve their data was exploratory in nature and represented a snapshot of their search effectiveness to fulfil the requested task. A factor to consider is what type of digital data was accessible for users and how this data could facilitate or not users' health-related needs and wellbeing.

Apart from that, searching the web for different types of PHD, as has been suggested by the users of this research work, is a laborious task because different types of data are often stored in various online locations. People's hesitation to collect personal data is due to several barriers, such as lack of motivation, ignorance about digital tools for data collection, time constraints, or siloed data. The complexity of the data collection process itself also hinders knowledge acquisition processes (Li, Dey, & Forlizzi, 2010). The stage model proposed by Li et al. (2010) to facilitate people to collect and reflect upon their personal information concluded that personal IS should support a combination of automatic extraction of information and manual collection to allow users' control over data, but also to facilitate their experience. Investing time and effort to search and access PHD would mean that users would have to neglect other tasks. On this topic what HDI research suggests is that even the introduction of various existing data aggregation, analytics, and summarization choices to users is a challenging task (Haddadi et al., 2013). Based on that, the access of different types of PHD and the utilization of these sources by users to manage health and wellbeing is a laborious task due to various barriers.

Although knowledge about data formats extracted from this case study was preliminary, the findings support the idea that data providers were not fully prepared to provide data to individuals in a format that would be accessible to them. Despite the limited information, this case study showed that the users were engaged with the concerns of format when reflecting on how the PHD they accessed could be utilized in the future. Regarding the degree of data providers' readiness to grant users access to personal data, previous research reached similar conclusions. Studies found that companies and organizations were unprepared to provide access, as the paper format or analysis-unfriendly data restricted users' data access (Gencoglu, Similä, Honko, & Isomursu, 2015). This is also in line with the Harjumaa et al. (2016), where format was a point of contention when being supplied in a practical way from organizations (Harjumaa et al., 2016).

Conversely, although evidence about the benefits of self-management to health has been proven (Lorig et al., 1999; Mitchell & Begoray, 2010; Yu et al., 2017), the landscape of self-management of personal health is in its infancy

(Chiauzzi et al., 2015; Dineen-Griffin et al., 2019). The area of personal health and self-management of wellbeing is a relatively newly established experience for data providers, as well as for users. From the perspective of comprehension, different formats are relevant for different audiences. For example, turning data into knowledge, especially for older audiences, is a sophisticated task that assumes, among others, that data formats facilitate comprehensibility (Koops van ‘t Jagt, Hoeks, Jansen, de Winter, & Reijneveld, 2016).

Similarly, the EU guidelines for open data broach the relationship between access and formats as a factor that facilitates data access: “The most usable format for data is likely to be one in which the dataset was first created.” The right format of data can facilitate management and access (European Data Portal, 2020). Different file formats accommodate different users’ needs, so that the file format has an impact on the type of tasks that users can perform with their data. Access and user-friendly formats to support self-knowledge is a need that future healthcare should find ways to accommodate. Evidence-based decision making requires accessible formats so that users can make more informed decisions about their health (Goldberg et al., 2011). The empowerment of individuals to participate in decision making for their own health, or a step further, the fulfilment of the vision that encapsulates the idea of self-management of health and wellbeing, should correspond to the provision of data formats that support users to analyze and extract knowledge from their PHD.

This work also touched on the users’ motivation to access PHD, suggesting that it depends on their health status. Similar evidence of this behavior has been seen in previous literature, demonstrating that health status plays a key role in the motivation of users to access their PHD (Prochaska, Johnson, & Lee, 1998). Healthy individuals avoid reading, thinking, or discussing their health behaviors, so that they end up being ignorant or unaware of the possible consequences of their own behavior (Prochaska et al., 1998). Raising self-awareness and engaging healthy people in their own health is a challenging task (Jordan & Osborne, 2007; Lockyer, Spiro, & Stanner, 2016). The motivation to access PHD and an awareness of personal health are challenges that future healthcare interventions should address.

The second recommendation highlights the need to consider what data types and formats can foster PHD access. This study suggests that the data types influence the knowledge and perception of health that users can extract from the data. Certain data types include users’ own perceptions about health; in contrast, other types of data, such as EHRs, include more objective descriptions of health.

Accessible data types and the health status of the users are also interrelated; being healthy was not a motivation to access PHD. System development is essential to motivate users to access their PHD. Data formats and the usability of data have a positive relationship. The provision of multifaceted IS should provide opportunities for manual and automatic extraction of data in ways that users have access control over their PHD.

R3) To foster the perceived value of PHD, IS should simplify medical terms, provide personalized visualizations and interfaces to nurture usability.

The perceived value of data is a topic discussed in embedded unit 2. Language barriers decreased the perceived value of PHD in relation to medical terminology. Previous literature argued that medical terminology can trigger comprehension problems, especially in the case of individuals with low levels of education, potentially resulting in a lack of motivation to access data (Castro, Wilson, Wang, & Schillinger, 2007; Wass, Vimarlund, & Ros, 2019). The provision of health information in medical terminology in a second language of users has been seen as an additional challenge (Wass et al., 2019). Living in an era of globalization and international migration, the challenge of PHD access comes down to speaking a common language. Therefore, considering access is an opportunity to think of users' language skills and to find ways to support them.

In contrast to medical terminology, personalized visualization elements contribute to the creation of more engaging interventions. Personalization features not only facilitate the display of a short-term data overview but, more importantly, enable people to uncover associations in multiple phases of their life (Choe, Lee, Lee, Pratt, & Kientz, 2014; Colley, Halttu, Harjumaa, & Oinas-Kukkonen, 2016; Häkkilä et al., 2016; Li et al., 2010). Previous work concluded that visualizations can display data in different modalities in relation to human values (Fens & Funk, 2014). However, consuming visualizations versus creating visualizations to make sense of one's health entails different stages. When users are consuming a visualization, they undergo three stages that can be summarized as perception, interpretation, and comprehension (Kirk, 2016). The first stage corresponds to readability (perception), the second to understanding (comprehension), and the third to reflection (perception + comprehension). Creating personalized visualizations requires some sort of visual designer's skills and an understanding of the context of the data. Therefore, personalizing visualizations can increase the value of PHD, allowing users to express their values and preferences through their data, given that they have the skillset to successfully perform the task.

Additionally, interfaces also contribute to the perceived value of PHD. In the present research work, the users accessed various interfaces, such as EHRs, and interfaces of corporate applications, such as mobile apps. A comparison between these two types of interfaces in relation to data access adds knowledge about the relationship between interface design and data access. The design of the EHR interface was perceived as user unfriendly. In contrast, the users claimed that PHD access through interfaces of mobile applications and wearables was more intuitive. Despite the seamless UX design of the accessed corporate interfaces, PHD access was found to be limited. Users could only access a subset of their PHD, while they supported the idea that data providers stored additional personal data that were accessible to users after paying a subscription or service fee. As data consumers, the access experience users had through the interfaces of these corporate applications was designed so that they were offered tailored and rich UX. Limited PHD access was probably a kind of delusion from the users' perspective. They were likely not aware that using services offered by corporate applications entailed giving an explicit or implicit consent to service providers to extract various personal data in return for using a service (Zang, Dummit, Graves, Lisker, & Sweeney, 2015). The free services delusion is likely connected to users' ignorance of privacy policy notices. As technologies are becoming more and more invasive, there is a need for users to understand what types of information they consent to give to data providers in exchange for a great UX design and provision of personalized services (Zang et al., 2015). Educating users about their rights and data-management risks is part of the solution. Legal frameworks are also part of the equation, but apart from these ethical considerations are essential to safeguard users' rights.

The design and development of IS in healthcare should enhance the perceived value of data considering elements that increase usability, simplification, and personalization of systems. In that direction, value co-creation approaches, such as the utilization of the Service-Dominant (SD) logic framework to co-design CH services, can contribute to the development of user-centered IS (Ouhbi et al., 2019).

R4) Consider age, education, occupation, and digitalization to encourage PHD sharing with stakeholders

Based on estimations, the world population is ageing (European Commission, 2018a), meaning that in the near future, IS in healthcare will have to accommodate the care needs of a growing population. In this equation, data have a central role in providing timely knowledge to different stakeholders involved in the care process. In embedded unit 4, age and willingness to share PHD were found to have a negative relationship. From prior work, it was found that older individuals have growing concerns over security breaches and misuse of data. These concerns, in addition to a lack of knowledge over factual risks, can partially explain users' hesitancy (Kowalewski, Ziefle, Ziegeldorf, & Wehrle, 2015; Papoutsi et al., 2015). Another factor that explains this trend is in relation to digital literacy and competency in using technologies (Choi & Dinitto, 2013; Ziefle et al., 2016). Digital competency is age-dependent, so users of different generations grow up accustomed to different technologies (Akhter, 2014). Based on that, users develop different mental models regarding technology and the way it functions (Fogel & Nehmad, 2009; Freestone & Mitchell, 2004). To follow digitalization advancements, users need to develop or improve their existing competences (Wilson, Scalise, & Gochyyev, 2015). This finding agrees with R3, which also proposes users' education as an antidote for ignorance of their data rights. However, as users grow older, they tend to lose interest in learning to use technologies, while the same trend applies to digital literacy to exchange and use health information (Choi & Dinitto, 2013). Taking into consideration all the above, together with the predictions about the world population change, it should be expected that data-sharing reluctance will be a burning issue for future healthcare. On that direction, previous work supports that patients with chronic or terminal diseases have more positive attitudes toward data sharing for scientific research (Fox & Purcell, 2010; Pickard & Swan, 2014; Weng, Friedman, Rommel, & Hurdle, 2019).

In contrast to age, occupation and education were a set of factors that have a positive impact on users' willingness to share their PHD. Lower levels of educational attainment and occupation were related to hesitancy towards PHD sharing. Lower education has been suggested to have a positive relationship to higher exposure to media and misuse of information, which results in an unwillingness to share health data (Anderson & Agarwal, 2011). Considering the similarity of trends in education and occupation, it is very likely that the group of users with higher educational attainment will land to a management positions; thus, the profile of these users is connected to a higher data-sharing motivation.

Users' attitudes to share their data was also studied from the perspective of the digitalization of countries. Reports about the digitalization levels in healthcare suggest that 1 of 5 EU citizens has utilized digital healthcare services (DESI, 2018). Current user trends in Northwest European countries were informative about the impact of digitalization of health care services. The four countries belong to different groups in relation to the use of internet services. Finland and the Netherlands have the most advanced digital economies, while Germany and France belong to the medium performing group, with France ranking in the lowest position (DESI, 2018). Taking that into consideration, users from countries with a medium level of digitalization were reluctant or unprepared to share their PHD. France belonged to the lowest group of digitalization and was found to have users who did not know if they would be willing to share data. German users were found to be the most hesitant. Finnish users had the highest percentage of willingness to share PHD for research, although they were the most unwilling to share their PHD with other stakeholders. Dutch users were the most willing to share data.

Based on this evidence, the digitalization level of countries has a stake in users' attitudes. However, this topic has many more aspects to consider. For example, one could argue that cultural peculiarities have an impact on these findings. For example, German users are apprehensive about experiencing negative consequences as a result of past privacy violations (Ziefle et al., 2016). The evidence presented in this doctoral dissertation can only provide preliminary evidence. However, this work paves the way for future endeavors to explore these aspects using a qualitative approach to identify causal relationships.

In summary, the evidence of this research work suggests a number of personal characteristics that have a positive impact on users' willingness to share their PHD with other stakeholders. The age, education, occupation, and digitalization of countries have an impact on users' attitudes towards sharing their PHD. Thus, the design and development of IS should adhere to the intended users' qualities, while taking into consideration that increased digitalization of systems has a positive impact on users' attitudes. As the world's population is ageing (European Commission, 2018a), future IS will have to confront the challenge of sustaining accessible PHD.

R5) Consider data privacy under the prism of data types, access control and trust, conditions of sharing, and the purpose of data processing

In embedded unit 4, users' data sharing willingness was explored in relation to different types of personal data, including health data. Regarding data types, PHD sharing was found to be among the types of data that users were keen to share. Previous literature suggested that users' willingness to share their PHD was dependent on several factors, such as expectations for care improvements, exchange of health information, provision of personalized services, or in support of research efforts (Medford-Davis, Chang, & Rhodes, 2017; Pickard & Swan, 2014; Weitzman et al., 2012). In agreement with previous literature, this study also concluded that approximately two out of three users were positive about sharing their PHD with other stakeholders (Malhotra, Kim, & Agarwal, 2004; Phelps, Nowak, & Ferrell, 2000). The idea of data altruism could possibly explain users' motivation to share their PHD, as users often believe that sharing their health data could contribute to health improvements for the general population or contribute to better public health (Agarwal & Anderson, 2008; Medford-Davis et al., 2017). Health innovation and the development of new medication can also have an impact (Asthmapolis, n.d.; Fuzzy Logix, n.d.; Stanford Medice, n.d.). In the same vein, PHD is already treated as a currency; the existence of blockchain in healthcare and trade of PHD in exchange for personalized recommendations and analytics can also have an impact (Dataswift, n.d.; Miinome, n.d.).

The topic of trust and access control over the use of PHD is an important part of the equation. Trust and how to elicit and keep users informed about consent preferences over their data has been discussed in previous work, resulting in various solutions (Kalkman et al., 2019). Providing personalized consent preferences to users has been related to more control over their data (Kass et al., 2003; Robling et al., 2004; Willison et al., 2007). Suggestions for personalized access control policies have also been proposed as a solution that could address individual preferences (Whiddett, Hunter, Engelbrecht, & Handy, 2006). However, the most powerful control determinant is trust in humans. Trust to medical researchers that control the purpose of PHD processing was a prevalent determinant, which also resulted in a less strict process for obtaining users' consent (Anderson & Dedrick, 1990; Damschroder et al., 2007). Nevertheless, the relationship between trust and consent to share data is weak. Providing consent cannot be equated to putting trust in service providers (Papoutsi et al., 2015).

The legal perspective of trust was one of the research topics discussed in embedded unit 4. The findings of the embedded unit can contribute to the existing literature, with new knowledge about the relationship between trust and the implementation of the new GDPR. The majority of users who participated in this study (nearly 64%) confirmed that the implementation of the new legal framework had an influence on their attitudes, further supporting the idea that trust and legal frameworks are related. Therefore, awareness campaigns and notifications were successful in informing them about changes over their individual rights. Conversely, the change in users' behavior does not necessarily mean that organizations or data providers are more trusted or that users have the knowledge to fully understand changes in their privacy rights. Privacy policies often fail to communicate data leakage threats and processing rights; a recent example is the Facebook privacy breach scandal (Lapaire, 2018). Knowledge over data sharing threads and privacy rights should not be taken for granted (Nowak & Phelps, 1992; Wachter, 2018). Implementation of the new GDPR somehow enforced a trust relationship between users, research, and public entities in healthcare, as PHD processing is exempted from requiring explicit users' consent, as long as the processing does "not result in personal data being processed for other purposes by third parties…" (Price, Kaminski, Minssen, & Spector-Bagdady, 2019, p. 5). However, establishing a trusting relationship based on the ambiguous definitions of scientific research, public health, and public interest is tenuous. The exemption given in accordance with Article 89 of the EU-GDPR also leaves room for national legislation to provide derogations regarding the protection measurements (Richter et al., 2019). Transparency and access to legal information, as well as the effectiveness of government competence, are factors that have a positive impact on establishing a trustworthy relationship between users and data controllers (OECD, 2017; Richter et al., 2019).

Research evidence supports that access control in relation to data sensitivity has a positive impact on users' data privacy considerations (Weitzman et al., 2012; Weng et al., 2019). The implementation of the new GDPR was found to have a positive impact on users' willingness to share their PHD. However, future efforts need to be directed toward simplification of privacy statements and reconsideration of IS design to enable users to make informed and timely decisions over their data. Regarding systems' design, the provision of simplified privacy controls to support faster and seamless screening of privacy options could be another practical implication for technology designers and developers in CH. Increasing users' awareness through education so that they understand the scale of threads related to data access provision is another action to take into consideration.

From the viewpoint of policymakers, the present study can inform policies toward more user-centered approaches to understand and support users more effectively. Educating users to manage and exert data rights, along with reconsiderations of IT professionals and designers' curricula towards more user-oriented and humanistic education, is another recommendation. In the same direction, raising awareness of service providers through professional training and public dialogue should also be considered a remedy to humanize PHD privacy policies. Ethical responsibility is extended to service providers towards the importance of public policy implementation to support the responsibility of users-mediators. Considerations about ways to increase users' willingness to share their data with stakeholders show that certain motives are more trustworthy than others. The purpose of data utilization is among the aspects that the users value to be important. Developing transparent IS that would allow not only access control over the data but also transparency in relation to stakeholders who can have access to data, such as data utilization from third parties, is not only among the fundamental rights of users but also has a positive impact on their attitudes towards sharing their data. A transparent flow of communication is a foundation for the establishment of accountable relationships between stakeholders. Table 13 provides a summary of the discussion of the recommendations.

Table 13. Summary of recommendations and discussion points.

Recommendations (R)	Discussion points
R1) Consider how users perceive health and PHD	Inclusion of users in the design and development phases will provide IS experts with valuable knowledge about users' perceptions of health and PHD
R2) Consider what data types and formats foster PHD access	The purpose of PHD use should inform which types and formats of PHD to select
R3) Simplify medical terms, provide visualizations and interfaces to nurture usability and personalization features, and so to promote the perceived value of PHD	The perceived value of data is dependent on PHD usability and personalization features, to foster it include visualizations, interfaces that have accessible elements, simplify medical terminology
R4) Consider age, education, occupation, and digitalization to encourage PHD sharing with stakeholders	To encourage PHD sharing, design and develop IS considering the age, education, occupation of the intended users, and digitalization level of the country
R5) Consider data privacy under the prism of data types, access control and trust, conditions of sharing, and the purpose of data processing	Focus on access control and trust, offer incentives to users, increase transparency of IS pertinent to data processing rights

The work presented in this doctoral dissertation is relevant to IS designers and developers in CH. The recommendations can be perceived as a set of good practices useful for experts who strive toward increased accessible IS. The provision of IS recommendations pertinent to the current landscape of PHD access and sharing in Northwest Europe is a topic of renewed interest for various reasons. The recommendations were developed based on an intended target audience and their needs at this juncture. The timeframe of the study—right before and after the enforcement of the new GDPR—coincided with the preparations of companies and organizations for the new data protection regime (Freitas & da Silva, 2018; Deloitte.Legal, 2019). The new legal framework transferred the responsibility of compliance from governments to companies and organizations, introducing technological changes, among others (Freitas & da Silva, 2018). In this new reality, designers and developers of IS in CH were requested to incorporate certain GDPR requirements into the design and development of IS to comply with the new legal framework (Jakobi et al., 2020). The foreseen complexity of the request in a CH context (Mountford & Starič, 2016), along with the emergence of fair data in research (FORCE11, 2016:11) and the EU commission (European Commission Expert Group on FAIR Data, 2018), highlighted a need to inform the aforementioned target audience with recommendations about PHD access and sharing in CH. Along with that, the selection of the Northwest European Healthcare Ecosystem provided a fertile ground to achieve it. Nordics, as well as countries positioned in Northern Europe, are frontrunners of technology adoption and innovation diffusion (DESI, 2020; McKinsey & Company, 2017). Considering the aforementioned framework and limitations, this dissertation contribution is relevant for IS designers and developers in CH to enable and sustain PHD access and sharing in this specific timeframe.

The audience of this work can also include practitioners in healthcare, as fractures of this work can be relevant for data management planning or review of data policies and procedures. Therefore, the language of the proposed recommendations is plain English, as I wanted to be as clear as possible to ensure effective communication with different stakeholders.

5.4 Comparison with prior work and current affairs

Although data access is not a newly established topic of discussion, the interest around the concept remains vivid (European Commission, 2020; European Commission, Shaping Europe’s digital future, 2019). This can be attributed to the fact that users are given the opportunity to discover different facets of their lives by exploiting data that are available on network or pervasive technologies, such as mobile devices, to acquire knowledge about their health and wellbeing (Archer et al., 2011; Chiauzzi et al., 2015; Dineen-Griffin et al., 2019; Kharrazi et al., 2012; Meier et al., 2013; Noy, 2020; Puustjärvi & Puustjärvi, 2016; Yu et al., 2017). Access encounters are perceived as interactions with data underpinned by personal and data characteristics, such as trust, motivation, or data formats. Therefore, this research proposes to consider access in a holistic manner and acknowledging its contemporary nature.

While the benefits of people’s participation in decision making are indisputable (Bose, 2003; Kiesler & Auerbach, 2006; Topac & Stoicu-Tivadar, 2011), as discussed in the ‘Theoretical positioning’ chapter, decision making entails knowledge acquisition, which is rooted in data and transitioning through information to knowledge extraction (Aamodt & Nygaard, 1995; Bellinger et al., 2004; Ingebrigtsen, 2007). Therefore, access to PHD is a prerequisite for knowledge extraction to participate in decision making. The present study acknowledged that seeking access to PHD entails user interaction with PHD, while experiencing and utilizing PHD access presumes user interactions with information to transition to the final stage, which is knowledge acquisition. PHD sharing with other stakeholders can be considered an access encounter that signifies a transition to data with or without knowledge extraction. The findings highlight the importance of access as an enabler to decision making and people's empowerment.

Prior research in health informatics concluded that PHD access is among the research topics that are still unaddressed, as there is limited empirical work (Karampela, Ouhbi, et al., 2018). To address the knowledge gap, I studied PHD access based on empirical evidence extracted from an embedded case study. Research endeavors in this discipline have mainly given attention to the IS in an effort to propose technical solutions for the development of a future centralized IS, such as data security, privacy, sharing, and protection, as well as to the healthcare professionals' needs (Archer et al., 2011; Blumenthal & McGraw, 2015; Brown, 2007; Castillo, Martínez-García, & Pulido, 2010; Day, 2001; Detmer & Steen, 1996; Ishikawa et al., 1995; Karampela, Ouhbi, et al., 2018; Pullman et al., 2009; Roehrs, da Costa, da Rosa Righi, & de Oliveira, 2017; Staccini & Lau, 2018; Street, 1991). As for PHD sharing, the topic is connected to privacy and security considerations or users' attitudes before the implementation of the new GDPR (Capozzi & Lanzola, 2011; Chen et al., 2016; Frost & Massagli, 2008; Karampela, Ouhbi, et al., 2018; Pickard & Swan, 2014; Ssembatya & Kayem, 2015; Vahidhunnisha et al., 2014; Weitzman et al., 2010). This study contributed updated knowledge regarding users' willingness to share their PHD after the implementation of the new GDPR legal framework. The presented research places a strong focus on understanding PHD access and sharing through the lens of users' encounters with their PHD, so that future works can, for example, utilize these findings as a baseline to elaborate further on data access encounters of other user groups, such as patients with specific health needs, to add specialized knowledge.

HDI is a relatively newly established discipline with areas of interest that intersect with those discussed in this doctoral study. Both HDI and the present research work have a strong focus on people and interactions with personal data, discussing how data can be used in a transparent way (legibility), as well as in a way that will engage people with management of their data (agency) (Mortier et al., 2014). Interaction with data in the HDI context assumes accountability in the transaction between stakeholders to underline the importance of access permission and audit trails. In line with this, this doctoral dissertation discussed access control through the lens of users' trust and transparency in data processing rights. In the context of healthcare, HDI focuses on access through the lens of usability (Cabitza & Locoro, 2016, 2017). Therefore, in terms of this aspect, the present research study adds recent empirical knowledge to the field connecting usability with the perceived value of PHD and proposing specific elements relevant for the design and development of IS.

The notion of dynamic relationships between data, people, and legislations has also been discussed in HDI, underlining the impact of change on data-sharing behaviors (Mortier et al., 2014). While HDI discusses these topics from a legal and ethical viewpoint, the findings of the doctoral study contribute to acquiring updated knowledge about PHD sharing in relation to the implementation of the new GDPR, focusing on peoples' attitudes (Mortier et al., 2014). HDI research and communities, such as *MyData,* are paving the way towards reconsideration of the asymmetrical power of data markets and analytics (Poikola, Kuikkaniemi, & Honko, 2015). Personal data management has been suggested as a way to alleviate such disparities. In this direction, the present findings contribute updated empirical knowledge about specific personal qualities, which can play a key role in understanding users' willingness to share PHD with other stakeholders in healthcare.

Recent reports show that, on average, only 18% of the European population have used their PHD through digital services (European Commission, 2019b; Lin, Lyles, Sarkar, & Adler-Milstein, 2019). Despite the contribution of individuals in creating health data and consuming health-related services, "... they do not yet have the power to act as drivers for accessing and exchanging their own health information" (Kouroubali & Katehakis, 2019, p. 2). Quantified-self or self-knowledge through evidence is an opportunity to better evaluate and formulate judgments about health and wellbeing (Lee, 2014). Scrutinizing access encounters is perhaps a better way to understand how humans interact with and perceive their personal data. In the framework of the current Covid-19 pandemic, initiatives, such as the Quantified Flu, already show the increasing public interest and importance of data access (Open Humans Foundation, n.d.). However, there is a long way to go. PHD remains a black box for users, as people are still unaware of how their personal data is collected, stored, traded, and used by data providers and processors (Driscoll & Walker, 2014). The power of data and its value for humans should lead future initiatives to balance the benefits between commercial and personal utilization or even better towards the common good (Tang, Plasek, & Bates, 2018).

At the beginning of 2020, Europe landed in a new reality with the arrival of the Covid-19 outbreak. Like other pandemic spreads that occurred in the beginning of the 21st century, the present one introduced rippling effects underlining the importance of health data to prevent and investigate outbreaks (Ienca & Vayena, 2020; Kraemer et al., 2020; Wu & McGoogan, 2020; Zhou et al., 2020). Looking at the bright side of the Covid-19 outbreak, humankind has been given a remarkable opportunity to seize the moment and prepare for future incidents. Zoonotic diseases—diseases caused by a virus that jumped from animals to humans or vice-versa—threaten to wipe out humanity (Bonilla-Aldana, Dhama, & Rodriguez-Morales, 2020). The Covid-19 death toll revealed how inadequate healthcare systems are in terms of preparedness, capacity, and governance (Armocida, Formenti, Ussai, Palestra, & Missoni, 2020; Legido-Quigley et al., 2020; Poole, Escudero, Gostin, Leblang, & Talbot, 2020). The present research study is one small step towards examining how PHD could be a useful asset in tackling global pandemics. Data sharing in relation to Covid-19 is a research topic that has attracted increasing research interest (Cosgriff, Ebner, & Celi, 2020; Ienca & Vayena, 2020; McLennan et al., 2020). Reflecting upon this work and considering the Covid-19 outbreak, accessible PHD can be proposed as a remedy for acquiring the health knowledge necessary for individual pandemic preparedness. In the same direction, PHD sharing on a global scale can create opportunities for knowledge sharing and informed decision making not only among care providers but also among user communities (Georgiou, Mittas, Angelis, & Chatzigeorgiou, 2020; Nathavitharana et al., 2020). To enable citizens to take accountability for their own health and wellbeing requires, apart from other initiatives, accessible health data. However, as has been discussed, accessible data entails far more than the provision of information in accessible formats.

5.5 Limitations

The work presented in this doctoral dissertation should be interpreted considering its limitations, which are discussed below.

There are a number of limitations introduced by the embedded case study methodology. Previous research has demonstrated that case studies have certain limitations in relation to their usage, such as sampling bias, lack of rigor in data collection, data analysis, and collection biases (Hamel, Dufour, & Fortin, 1993). As discussed in the 'Methodology' chapter, the subjectivity of the researcher who conducts the research is a bias related to the individual perception of the phenomenon under investigation (Bontekoe, 1996; Nagel, 1974; Orlikowski &

Baroudi, 1991). However, the aforementioned arguments against certain aspects of qualitative research are only one aspect. Qualitative research acknowledges its weaknesses and proposes guidelines to alleviate these issues by recognizing the concept of human nature (Hamel et al., 1993; Yin, 1994). In addition, the provision of an audit trail disregarded threads related to this matter and increased transparency of the analysis process.

The proposed work was an outcome of a research exploration where certain directions were considered in relation to the development of empirical studies, which yielded questions about the generalizability and scientific rigor. This type of weakness in case studies has been criticized by researchers (Crowe et al., 2011; Hollweck, 2015; Yin, 2013), suggesting alleviating the risk in the design phase of the case study. Nevertheless, one could argue that generalizability is somewhat contradictory to the nature of case studies, which, by definition, limit the investigation of a phenomenon around narrow study boundaries, timeframes, and real-life settings (Crowe et al., 2011). To mitigate these concerns, I established transparency throughout the research process—defining the case, providing information about data collection and analysis—and I utilized previous studies to complement and interpret the conclusions (Crowe et al., 2011).

The reasoning behind the particular decision to investigate this case study was also related to the different cases that I had the opportunity to work on due to the research project, which influenced the actions that took place within the scope of the project. In line with the above, Northwest Europe was selected as the sole geographical focus of this case study, excluding, for example, culture-dependent aspects. From an IS design and development perspective, the proposed recommendations were based on experiences that stemmed from a single case study. Evaluation of the five recommendations involving the indented users will allow further refinement of the findings. Conversely, one should consider that the research niche focused on certain access encounters without interfering with the 'how to' type of knowledge. The work presented in this dissertation was systematically constructed based on the provision of multiple sources of evidence, namely empirical studies and previous related literature, to increase the validity of the findings (Yin, 1994). Therefore, the five recommendations were developed by the generalization of subthemes within its context and provide a baseline for future studies.

This research work is based on the access encounters of healthy individuals with their PHD, as identified from empirical work. It is possible that people living with chronic conditions or diseases or people with multimorbidities will encounter additional or different access moments. Notwithstanding, the empirical work done in the framework of the present dissertation aimed to provide a baseline for the general population and to pave the way for future research endeavors towards the exploration of access from a data perspective, underlining its richness.

6 Conclusions and future work

Although research about PHD access is still in its infancy, the data surge along with the emergence of CH solutions and adoption of technologies by lay people has increased not only scientific interest but also practitioners' attention. In this doctoral dissertation, PHD access was discussed as an opportunity to enable peoples' participation in decision making of their own health and wellbeing outside the traditional medical settings. This can result not only in better utilization of the available data resources but potentially in empowerment through knowledge acquisition to participate in care decisions. Furthermore, the implementation of the new GDPR increased interest in PHD sharing with other stakeholders, enabling knowledge sharing opportunities.

Based on the above, this dissertation proposed five recommendations relevant for IS designers and developers in CH. This dissertation suggested consideration of the five recommendations during the design and development phases of IS: R1) consider how users perceive health and PHD, R2) consider what data types and formats foster PHD access, R3) simplify medical terms, provide visualizations and interfaces to nurture usability, and personalization features and so to promote the perceived value of PHD, R4) consider age, education, occupation, and digitalization to encourage PHD sharing with stakeholders, and R5) consider data privacy under the prism of data types, access control and trust, conditions of sharing, and the purpose of data processing.

The five recommendations introduced implications on a theoretical and practical level. On a theoretical level, they address the gap in previous health informatics and HDI literature in relation to empirical evidence to study PHD access. Additionally, this dissertation contributes updated knowledge about users' willingness to share their PHD with other stakeholders after the enforcement of the new GDPR. As for the practical contribution, it introduced knowledge and implications useful for the development of future IS in CH. This research work highlighted the temporal and subjective nature of human interaction with PHD and proposed recommendations for IS designers and developers to consider during the design and development phases. Additionally, it supports the notion that the timely aspect of access encounters requires research to be a frontrunner. In addition, the recommendations aimed at sensitizing policy makers to consider the timely nature of access. Ethical considerations about PHD access and sharing are also considered to be valuable to safeguard the sensitive nature of data and to promote peoples' rights over their personal data.

The present work provided a baseline for future research to validate the recommendations to develop CH solutions. The exploration of the research topics in specific interest groups or other stakeholders might also shed light on access encounters and willingness to share PHD from the viewpoint of specific users and health needs. The findings of the present research do not propose any components of perceived value. Additional work is needed to clarify the components of perceived value. The recommendations consist of a number of abstractions relevant for designers and developers of IS in CH. Future work should entail translation of the recommendations to design guidelines to allow users and multidisciplinary experts to become involved and evaluate the recommendations in CH interventions. Living in the era of globalization entails that populations from different cultures, religions, and ethnicities live under the same roof. Therefore, it would be relevant to consider how these aspects can affect PHD access and sharing.

Taking this information into consideration, we live in an era of data. Scientific and technological advances have contributed to the creation of a data landscape that remains partly undiscovered. Access to data can save a life (Kushniruk, 2019). The way that humankind will proceed to utilize data is something that no one can currently predict. As technologies progress and the availability of PHD increases, healthcare will not remain the same. As the Indian philosopher and writer Jiddu Krishnamurti phrased, there is hope in people, not in society, not in systems but in you and me (Krishnamurti & Rajagopal, 1970).

List of references

Aamodt, A., & Nygaard, M. (1995). Different roles and mutual dependencies of data, information, and knowledge—An AI perspective on their integration. *Data & Knowledge Engineering, 16*(3), 191–222.

Adams, W. C. (2015). Conducting semi-structured interviews. In K. E. Newcomer, H. P. Hatry, & J. S. Wholey (Eds.), *Handbook of practical program evaluation* (pp. 492–505). Hoboken, NJ: John Wiley & Sons.

Adler-Milstein, J., Sarma, N., Woskie, L. R., & Jha, A. K. (2014). A comparison of how four countries use health IT to support care for people with chronic conditions. *Health Affairs, 33*(9), 1559–1566.

Agarwal R., & Anderson C. (2008). The complexity of consumer willingness to disclose personal information: Unraveling health information privacy concerns. eHealth Initiative’s 5th Annual Conference; Washington, DC. 2008.

Agarwal, R., Gao, G., DesRoches, C., & Jha, A. K. (2010). Research commentary—The digital transformation of healthcare: Current status and the road ahead. *Information Systems Research, 21*(4), 796–809.

Aidemark, J., Askenäs, L., Nygårdh, A., & Strömberg, A. (2015). User involvement in the co-design of self-care support systems for heart failure patients. *Procedia Computer Science, 64*, 118–124.

Aitken, M., Cunningham-Burley, S., & Pagliari, C. (2016). Moving from trust to trustworthiness: Experiences of public engagement in the Scottish health informatics programme. *Science and Public Policy, 43*(5), 713–723.

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes, 50*(2), 179–211.

Akhter, S. H. (2014). Privacy concern and online transactions: The impact of internet self-efficacy and internet involvement. *Journal of Consumer Marketing*. Vol. 31 No. 2, pp. 118-125. https://doi.org/10.1108/JCM-06-2013-0606.

Alamri, W. A. (2019). Effectiveness of qualitative research methods: Interviews and diaries. *International Journal of English and Cultural Studies, 2*(1), 65. doi: 10.11114/ijecs.v2i1.4302.

Amariles, D. R., Troussel, A. C., & El Hamdani, R. (2020). Compliance generation for privacy documents under GDPR: A roadmap for implementing automation and machine learning. arXiv e-prints, arXiv-2012.

Anand, P., Kunnumakara, A. B., Sundaram, C., Harikumar, K. B., Tharakan, S. T., Lai, O. S., … Aggarwal, B. B. (2008). Cancer is a preventable disease that requires major lifestyle changes. *Pharmaceutical Research, 25*(9), 2097–2116. doi: 10.1007/s11095-008-9661-9.

Andersen, R. M., McCutcheon, A., Aday, L. A., Chiu, G. Y., & Bell, R. (1983). Exploring dimensions of access to medical Care. *Health Services Research, 18*(1), 49-74.

Anderson, C. L., & Agarwal, R. (2011). The digitization of healthcare: Boundary risks, emotion, and consumer willingness to disclose personal health information. *Information Systems Research, 22*(3), 469–490.

Anderson, L. A., & Dedrick, R. F. (1990). Development of the trust in physician scale: A measure to assess interpersonal trust in patient-physician relationships. *Psychological Reports, 67*(S3), 1091–1100..

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K.A., & Straus, S. E. (2011). Personal health records: A scoping review. *Journal of the American Medical Informatics Association*, 18(4), 515–522.

Armocida, B., Formenti, B., Ussai, S., Palestra, F., & Missoni, E. (2020). The Italian health system and the COVID-19 challenge. *The Lancet Public Health, 5*(5), e253. doi: 10.1016/S2468-2667(20)30074-8.

Asthmapolis. (n.d.). Asthmapolis, now propeller, moves beyond asthma. Retrieved from https://www.mobihealthnews.com/25255/asthmapolis-now-propeller-moves-beyond-asthma.

Bae, J.-M. (2017). Shared decision making: Relevant concepts and facilitating strategies. *Epidemiology and Health 39, e2017048*. doi: 10.4178/epih.e2017048.

Baldwin, J. L., Singh, H., Sittig, D. F., & Giardina, T. D. (2017). Patient portals and health apps: Pitfalls, promises, and what one might learn from the other. In *Healthcare*. Vol. 5. pp. 81–85. Elsevier.

Bellinger, G., Castro, D., & Mills, A. (2004). Data, information, knowledge and wisdom. Received from https://www.systems-thinking.org/dikw/dikw.htm

Bergevi, C., Lendahls, L., Crang-Svalenius, E., & Oscarsson, M. G. (2018). From passive passenger to participating co-pilot – Pregnant women's expectations of being able to access their online journal from antenatal care. *Sexual & Reproductive Healthcare, 15*, 35–39. doi: 10.1016/j.srhc.2017.11.009.

Bergman, E., Edwards, A., Kaplan, D., Lowney, G., Raman, T. V., & Johnson, E. (1996). Universal design: Everyone has special needs. In *Conference companion on human factors in computing system*s. pp. 153–154.

Bietz, M. J., Bloss, C. S., Calvert, S., Godino, J. G., Gregory, J., Claffey, M. P.,Patrick, K. (2016). Opportunities and challenges in the use of personal health data for health research. *Journal of the American Medical Informatics Association, 23*(e1), e42–48. doi: 10.1093/jamia/ocv118.

Bilsky, W., & Schwartz, S. H. (1994). Values and personality. *European Journal of Personality, 8*(3), 163–181.

Blondel, J., & Inoguchi, T. (2006). Political cultures in Asia and Europe: Citizens, states and societal values. Routledge. https://doi.org/10.4324/9780203966907.

Blumenthal, D., & McGraw, D. (2015). Keeping personal health information safe: The importance of good data hygiene. *JAMA, 313*(14), 1424–1424.

Bonilla-Aldana, D. K., Dhama, K., & Rodriguez-Morales, A. J. (2020). Revisiting the one health approach in the context of COVID-19: A look into the ecology of this emerging disease. *Advances in Animal and Veterinary Sciences, 8*(3), 234–237.

Bontekoe, R. (1996). *Dimensions of the hermeneutic circle*. Atlantic Highlands, N.J.: Humanities Press International.

Bose, R. (2003). Knowledge management-enabled health care management systems: Capabilities, infrastructure, and decision-support. *Expert Systems with Applications, 24*(1), 59–71. doi: 10.1016/S0957-4174(02)00083-0.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101.

Braun, V., Clarke, V., & Rance, N. (2014). How to use thematic analysis with interview data (process research). In Moller, N. P. & Vossler A. (Eds.), *The Counselling & Psychotherapy Research* Handbook Sage.

Brereton, P., Kitchenham, B. A., Budgen, D., Turner, M., & Khalil, M. (2007). Lessons from applying the systematic literature review process within the software engineering domain. *Journal of Systems and Software, 80*(4), 571–83. doi: 10.1016/j.jss.2006.07.009.

Brown, B. (2007). The number of online personal health records is growing, but is the data in these records adequately protected? *Journal of Health Care Compliance, 9*(3), 35-36.

Cabitza, F., & Locoro, A. (2016). *Human-data interaction in healthcare: Acknowledging use-related chasms to design for a better health information*. Proceedings from the 8th IADIS International Conference on e-Health, 1-3 July, Funchal, Madeira, Portugal. 91–98.

Cabitza, F., & Locoro, A. (2020). Human-data interaction in healthcare. In Data analytics in medicine: concepts, methodologies, tools, and applications. IGI global. 1148-1167.

Cabitza, F., & Locoro, A. (2017). Human-data interaction in healthcare. In *Smart Technology Applications in Business Environments* (pp. 184–203). IGI global. DOI: 10.4018/978-1-5225-2492-2.ch009.

Cafaro, F. (2012). *Using embodied allegories to design gesture suites for human-data interaction.* In Proceedings of the 2012 ACM Conference on Ubiquitous Computing, pp. 560–563. doi: https://doi.org/10.1145/2370216.2370309.

Capozzi, D., & Lanzola, G. (2011). A data synchronization framework for personal health systems. In *International Conference on Wireless Mobile Communication and Healthcare* (pp. 300–304). Springer.

Castillo, V. H., Martínez-García, A. I., & Pulido, J. R. G. (2010). A knowledge-based taxonomy of critical factors for adopting electronic health record systems by physicians: A systematic literature review. *BMC Medical Informatics and Decision Making, 10*(1), pp. 1-17.

Castro, C. M., Wilson, C., Wang, F., & Schillinger, D. (2007). Babel babble: Physicians' use of unclarified medical jargon with patients. *American Journal of Health Behavior, 31*(1), S85–95.

Caulfield, B. M., & Donnelly, S. C. (2013). What Is connected health and why will it change your practice? *QJM: An International Journal of Medicine, 106*(8), 703–707. doi: 10.1093/qjmed/hct114.

Cavoukian, A. (2009). Privacy by design: The 7 foundational principles. Information and Privacy Commissioner of Ontario, Canada 5. 12. Retrieved from https://www.ipc.on.ca/wp-content/uploads/2013/09/pbd-primer.pdf.

Ceross, A., & Simpson, A. (2018). *Rethinking the proposition of privacy engineering*. Proceedings of the New Security Paradigms Workshop. pp. 89–102. Association for Computing Machinery, New York, NY, USA, 89–102. https://doi.org/10.1145/3285002.3285006.

Chang, I.-C., Hsiao, S.-J., Hsu, H.-M., & Chen, T.-H. (2010). Building MPHR to assist diabetics in self-healthcare management. In *2010 7th International Conference on Service Systems and Service Management, 2010, pp. 1-5,* doi: 10.1109/ICSSSM.2010.5530092.

Chen, J., Bauman, A., & Allman-Farinelli, M. (2016). A study to determine the most popular lifestyle smartphone applications and willingness of the public to share their personal data for health research. *Telemedicine and E-Health, 22*(8), 655–665.

Chiasson, M., Reddy, M., Kaplan, B., & Davidson, E. (2007). Expanding multi-disciplinary approaches to healthcare information technologies: What does information systems offer medical informatics? *International Journal of Medical Informatics, 76*, S89–97. doi: 10.1016/j.ijmedinf.2006.05.010.

Chiauzzi, E., Rodarte, C., & DasMahapatra, P. (2015). Patient-centered activity monitoring in the self-management of chronic health conditions. *BMC Medicine, 13*(1), 77. doi: 10.1186/s12916-015-0319-2.

Choe, E. K., Lee, N. B., Lee, B., Pratt, W., & Kientz, J. A. (2014). *Understanding quantified-selfers' practices in collecting and exploring personal data*. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, pp. 1143–1152. doi: https://doi.org/10.1145/2556288.2557372.

Choi, N. G., & DiNitto, D. M. (2013). The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. *Journal of medical Internet research (JMIR)*, 15(5), e93.

Chouvarda, I. G., Goulis, D. G., Lambrinoudaki, I., & Maglaveras, N. (2015). Connected health and integrated care: Toward new models for chronic disease management. *Maturitas, 82*(1), 22–27. doi: 10.1016/j.maturitas.2015.03.015.

Cisco. (2018). Cisco annual internet report (2018–2023). Cisco Annual Internet Report White Paper. Retrieved from https://www.cisco.com/c/en/us/solutions/collateral/executive-perspectives/annual-internet-report/white-paper-c11-741490.html

Claypoole, V. L., Schroeder, B. L., & Mishler, A. D. (2016). Keeping in touch: Tactile interface design for older users. *Ergonomics in Design, 24*(1), 18–24. doi: 10.1177/1064804615611271.

Colley, A., Halttu, K., Harjumaa, M., & Oinas-Kukkonen, H. (2016). Insights from the design and evaluation of a personal health dashboard. In *2016 49th Hawaii International Conference on System Sciences (HICSS),* pp. 3483–3492. IEEE. doi: 10.1109/HICSS.2016.435.

Colley, A., Pfleging, B., Alt, F., & Häkkilä, J. (2020). Exploring public wearable display of wellness tracker data. *International Journal of Human-Computer Studies, 138*, 102408. doi: 10.1016/j.ijhcs.2020.102408.

Coorevits, P., Sundgren, M., Klein, G. O., Bahr, A., Claerhout, B., Daniel, C.,…Singleton, P. (2013). Electronic health records: New opportunities for clinical research. *Journal of Internal Medicine, 274*(6), 547–560.

Cosgriff, C. V., Ebner, D. K., & Celi, L. A. (2020). Data sharing in the era of COVID-19. *The Lancet Digital Health, 2*(5), e224. https://doi.org/10.1016/S2589-7500(20)30082-0.

Courbier, S., Dimond, R., & Bros-Facer, V. (2019). Share and protect our health data: An evidence based approach to rare disease patients' perspectives on data sharing and data protection - Quantitative survey and recommendations. *Orphanet Journal of Rare Diseases, 14*(1), 1-15. doi: 10.1186/s13023-019-1123-4.

Crabtree, A., & Mortier, R. (2015). Human data interaction: Historical lessons from social studies and CSCW. In *ECSCW 2015: Proceedings of the 14th European Conference on Computer Supported Cooperative Work,* pp. 3–21. Oslo, Norway: Springer.

Crowe, S., Cresswell, K., Robertson, A., Huby, G., Avery, A., & Sheikh, A. (2011). The case study approach. *BMC Medical Research Methodology, 11*(1), 100. doi: 10.1186/1471-2288-11-100.

Damschroder, L. J., Pritts, J. L., Neblo, M. A., Kalarickal, R. J., Creswell, J. W., & Hayward, R. A. (2007). Patients, privacy and trust: patients' willingness to allow researchers to access their medical records. Social science & medicine (1982), 64(1), 223–235. https://doi.org/10.1016/j.socscimed.2006.08.045.

Daniels, N. (1982). Equity of access to health care: Some conceptual and ethical issues. *The Milbank Memorial Fund Quarterly. Health and Society*, 60(1), 51–81.

Darker, C. D., Donnelly-Swift, E., & Whiston, L. (2018). Demographic factors and attitudes that influence the support of the general public for the introduction of universal healthcare in Ireland: A national survey. *Health Policy, 122*(2), 147–156. doi: 10.1016/j.healthpol.2017.11.009.

Datastreams. (2018). *The world of data is changing and evolving*. Datastreams. Retrieved from https://www.datastreams.io/data-world-change-envolving/.

Dataswift. (n.d.). The hub of all things. Retrieved from https://www.hubofallthings.com/.

Davis, W. S., & Yen, D. C. (2019). *The information system consultant's handbook: Systems analysis and design.* CRC press. https://doi.org/10.1201/9781420049107.

Day, J. (2001). Privacy and personal health data in cyberspace. *The Journal of Contemporary Dental Practice, 2*(1), 45-56.

Digital Economy and Society Index (DESI). (2018). Digital economy and society index report. Digital Public Services. Retrieved from http://ec.europa.eu/newsroom/dae/document.cfm?doc_id=52244.

Digital economy and society index (DESI). (2020|) Shaping Europe's digital future. Integration of Digital Technology 2020. Retrieved from https://digital-strategy.ec.europa.eu/en/library/digital-economy-and-society-index-desi-2020.

Detmer, D. E., & Steen, E. B. (1996). Shoring up protection of personal health data. *Issues in Science and Technology, 12*(4), 73–78.

Digital Single Market - European Commission. (2018). Communication on enabling the digital transformation of health and care in the digital single market; Empowering citizens and building a healthier society. Retrieved from https://digital-strategy.ec.europa.eu/en/library/communication-enabling-digital-transformation-health-and-care-digital-single-market-empowering.

Dineen-Griffin, S., Garcia-Cardenas, V., Williams, K., & Benrimoj, S. I. (2019). Helping patients help themselves: A systematic review of self-management support strategies in primary health care practice. *PLOS ONE, 14*(8), e0220116. doi: 10.1371/journal.pone.0220116.

Driscoll, K., & Walker, S. (2014). Big data, big questions| Working within a black box: Transparency in the collection and production of big Twitter data. *International Journal of Communication 8*, 1745–1764.

Dutta-Bergman, M. J. (2004). Health attitudes, health cognitions, and health behaviors among internet health information seekers: Population-based survey. *Journal of Medical Internet Research, 6*(2). doi: 10.2196/jmir.6.2.e15.

Dutton, D. (1986). Financial, organizational and professional factors affecting health care utilization. *Social Science & Medicine, 23*(7), 721–735.

El-Gayar, O., Timsina, P., Nawar, N., & Eid, W. (2013). Mobile applications for diabetes self-management: Status and potential. *Journal of Diabetes Science and Technology*, *7*(1), 247–262. doi: 10.1177/193229681300700130.

Elmqvist, N. (2011). Workshop on embodied interaction: theory and practice in HCI. In CHI '11 Extended Abstracts on Human Factors in Computing Systems (CHI EA '11). Association for Computing Machinery, New York, NY, USA, 5–8. doi: https://doi.org/10.1145/1979742.1979592.

Ethics committee of human sciences of University of Oulu. (n.d.). Retrieved from https://www.oulu.fi/eudaimonia/node/196276.

Eurobarometer, E. U. (n.d.). *Special Eurobarometer 359: Attitudes on data protection and electronic identity in the European Union.* Retrieved from https://data.europa.eu/data/datasets/s864_74_3_ebs359?locale=en.

European Commission. (2016). *General data protection regulation (GDPR)*. Retrieved from https://gdpr.eu/tag/gdpr/.

European Commission. (2017). *Council conclusions on health in the digital society — Making progress in data-driven innovation in the field of health*. Retrieved from https://op.europa.eu/en/publication-detail/-/publication/9d2c8cd4-e61a-11e7-9749-01aa75ed71a1/language-en.

European Commission. (2018a). *Ageing report: Policy challenges for ageing societies.*. Retrieved from https://ec.europa.eu/info/news/economy-finance/policy-implications-ageing-examined-new-report-2018-may-25_en.

European Commission. (2018b). *Enabling the digital transformation of health and care in the digital single market; Empowering citizens and building a healthier society.* Retrieved from https://eur-lex.europa.eu/legal-content/EN/TXT/HTML/?uri=CELEX:52018DC0233&from=EN.

European Commission. (2018c). *What is personal data? European Commission*. Retrieved from https://ec.europa.eu/info/law/law-topic/data-protection/reform/what-personal-data_en

European Commission. (2019a). T*he digital economy and society index (DESI)*. Retrieved from https://ec.europa.eu/digital-single-market/en/digital-economy-and-society-index-desi.

European Commission. (2019b). *The digital economy and society index (DESI). Digital Public Services*. Retrieved from https://ec.europa.eu/digital-single-market/en/digital-public-services.

European Commission. (2020). EU digital single market. Retrieved from https://eufordigital.eu/discover-eu/eu-digital-single-market/.

European Commission. (n.d.). *European disability strategy 2010-2020 - Employment, social affairs & inclusion*. Retrieved from https://ec.europa.eu/social/main.jsp?catId=1484&langId=en.

European Commission Expert Group on FAIR Data. (2018). *Turning FAIR into reality*. Retrieved from https://ec.europa.eu/info/sites/default/files/turning_fair_into_reality_1.pdf.

European Commission, Shaping Europe's digital future. (2019). *Exchange of electronic health records across the EU.* Retrieved from https://ec.europa.eu/digital-single-market/en/exchange-electronic-health-records-across-eu.

European Data Portal. (2020). *Choosing the right format for open data*. Retrieved from https://www.europeandataportal.eu/elearning/en/module9/#/id/co-01

European Data Protection Supervisor. (n.d.). The history of the general data protection regulation | European data protection supervisor. Retrieved from https://edps.europa.eu/data-protection/data-protection/legislation/history-general-data-protection-regulation_en

European Medicines Agency. (n.d.). *Clinical data publication*. Retrieved from https://www.ema.europa.eu/en/human-regulatory/marketing-authorisation/clinical-data-publication.

Eysenbach, G. (2004). Improving the quality of web surveys: The checklist for reporting results of internet e-surveys (CHERRIES). *Journal of Medical Internet Research, 6*(3), e34. doi: 10.2196/jmir.6.3.e34.

Fahey, É., O'Brien, D., Russell, H., & Mcginnity, F. (2019). European survey data on attitudes to equality and human rights, Technical paper. *Research Series.* doi: 10.26504/sustat83.pdf.

Fens, P., & Funk, M. (2014). Personal health data: Visualization modalities and their perceived values. In: Proceedings of the 22nd international conference on centre European computer graphics visualization and computer visualization, (WSCG 2014), Plzen, Czech Republic, 2-5 June 2014. pp. 339–344.

Ferguson, T., & Frydman, G. (2004). The first generation of e-patients. *British Medical Journal Publishing Group*. BMJ (Clinical research ed.), 328(7449), 1148–1149. https://doi.org/10.1136/bmj.328.7449.1148.

Feste, C., & Anderson, R. M. (1995). Empowerment: From philosophy to practice. *Patient Education and Counseling, 26*(1), 139–144. doi: 10.1016/0738-3991(95)00730-N.

Fishbein, M., & Ajzen, I. (1977). Belief, attitude, intention, and behavior: An introduction to theory and research. *Contemporary Sociology*, 6(2), 244-245. doi:10.2307/2065853.

Fisher, J. L., & Harris, M. B. (1973). Effect of note taking and review on recall. *Journal of Educational Psychology, 65*(3), 321.

Fleischmann, K. (2015). The democratisation of design and design learning–how do we educate the next–generation designer. *International Journal of Arts & Sciences, 8*, 101–108.

Fogel, J., & Nehmad, E. (2009). Internet social network communities: risk taking, trust, and privacy concerns. *Computers in Human Behavior, 25*(1), 153–160.

FORCE11. (2016). The FAIR data principles. Retrieved from https://www.force11.org/group/fairgroup/fairprinciples.

Formanek, T., & Tahal, R. (2018). Analysis of personal data-sharing consent factors, with focus on loyalty programs in the Czech Republic. *Verslas: Teorija Ir Praktika*, *19*(1), 70–79.

Fox, S., & Purcell, K. (2010). *Chronic disease and the internet*. Washington, DC: Pew Internet & American Life Project.

Frankel, R., & Devers, K. (2000). Study design in qualitative research—1: Developing questions and assessing resource needs. *Education for Health, Mumbai, 13*(2), 251–261.

Freestone, O., & Mitchell, V. (2004). Generation Y attitudes towards e-ethics and internet-related misbehaviours. *Journal of Business Ethics, 54*(2), 121–128.

Freitas, M. d. C., & da Silva, M. M. (2018). GDPR Compliance in SMEs: There is much to be done. *Journal of Information Systems Engineering & Management, 3*(4). doi: 10.20897/jisem/3941.

Frost, J., & Massagli, M. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Medical Internet Research, 10*(3), e15. doi: 10.2196/jmir.1053.

Fuji, K. T., Abbott, A. A., Galt, K. A., Drincic, A., Kraft, M., & Kasha, T. (2012). Standalone personal health records in the United States. *Health and Technology*. 2012. 2: 197-205.

Fuzzy Logix. (n.d.). Opioid abuse prediction-Fuzzy Logix. Retrieved from http://www.fuzzylogix.com/use-cases-2/opioid-abuse-prediction/.

Galletta, A. (2013). *Mastering the semi-structured interview and beyond: From research design to analysis and publication*. Vol. 18. New York; London: NYU Press..

Gencoglu, O., Similä, H., Honko, H., & Isomursu, M. (2015). *Collecting a citizen's digital footprint for health data mining.* 2015 37th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC). Milan, Italy, 25-29 Aug. 2015. pp. 7626–7629. doi: 10.1109/EMBC.2015.7320158.

Georgiou, K., Mittas, N., Angelis, L., & Chatzigeorgiou, A. (2020, August). A preliminary Study of Knowledge Sharing related to Covid-19 Pandemic in Stack Overflow. In 2020 46th Euromicro Conference on Software Engineering and Advanced Applications (SEAA), Portoroz, Slovenia 26-28 Aug. 2020. pp. 517-520. doi: 10.1109/SEAA51224.2020.00086.

Giardina, T., Menon, S., Parrish, D. E., Sittig, D. F., & Singh, H. (2014). Patient access to medical records and healthcare outcomes: A systematic review. *Journal of the American Medical Informatics Association, 21*(4), 737–741.

Girardin, F., Calabrese, F., Dal Fiore, F., Ratti, C., & Blat, J. (2008). Digital footprinting: Uncovering tourists with user-generated content. *IEEE Pervasive Computing, 7*(4), 36–43.

Gladwin, J. (2012). Patients welcome access to online health records. *Primary Health Care (through 2013), 22*(5), 10-10.

Gödel, K. (1962). *On formally undecidable propositions*. N.Y.: Basic Book.

Goldberg, L., Lide, B., Lowry, S., Massett, H. A., O’Connell, T., Preece, J.,Shneiderman, B. (2011). Usability and accessibility in consumer health informatics: Current trends and future challenges. *American Journal of Preventive Medicine, 40*(5:S2), S187–197. doi: 10.1016/j.amepre.2011.01.009.

Greenberg, J. S. (1985). Health and wellness: A conceptual differentiation. *Journal of School Health, 55*(10), 403–406. doi: https://doi.org/10.1111/j.1746-1561.1985.tb01164.x.

Greenberg, A. J., Falisi, A. L., Rutten, L. J. F., Chou, W. Y. S., Patel, V., Moser, R. P., & Hesse, B. W. (2017). Access to electronic personal health records among patients with multiple chronic conditions: a secondary data analysis. *Journal of medical Internet research,* 19(6), e188.

Gregory, K., Groth, P., Cousijn, H., Scharnhorst, A., & Wyatt, S. (2017). Searching data: A review of observational data retrieval practices. *Journal of the Association for Information Science and Technology*, 70(5), 419-432. CoRR Abs/1707.06937.

Grundstrom, C., Väyrynen, K., Iivari, N., & Isomursu, M. (2019). *Making sense of the general data protection regulation—Four categories of personal data access challenges*. Proceedings of the 52nd Hawaii international conference on system sciences.5039-5048. https://oadoi.org/10.24251/HICSS.2019.605.

Guest, G., Namey, E. E., & Mitchell, M. L. (2013). Collecting qualitative data: A field manual for applied research. Sage. ISBN: 9781506374680.

Haddad, S., & Mohindra, K. (2002). Access, opportunities and communities: Ingredients for health equity in the south. Public Health and International Justice Workshop. New York: Carnegie Council on Ethics and International Affairs; 2002.

Haddadi, M., & McAuley D., Crowcroft J. (2013). Human-data interaction. Technical Report Number 837. University of Cambridge Computer Laboratory. ISSN 1476-2986. Retrieved from https://www.cl.cam.ac.uk/techreports/UCAM-CL-TR-837.pdf

Hägglund, M., & Scandurra, I. (2017). A socio-technical analysis of patient accessible electronic health records. *Studies in Health Technology and Informatics*, *244*, 3–7.

Häkkilä, J., Alhonsuo, M., Virtanen, L., Rantakari, J., Colley, A., & Koivumäki, T. (2016). Mydata approach for personal health–A service design case for young athletes. In *2016 49th Hawaii International Conference on System Sciences (HICSS),* pp. 3493–3502.

Hamel, J., Dufour, S., & Fortin, D. (1993). *Case study methods*. Vol. 32. Sage Publications. ISBN: 9781412983587.

Harjumaa, M., Saraniemi, S., Pekkarinen, S., Lappi, M., Similä, H., & Isomursu, M. (2016). Feasibility of digital footprint data for health analytics and services: An explorative pilot study. *BMC Medical Informatics and Decision Making, 16*(1), 1-9.

Healthcatalyst. (n.d.). The digitization of healthcare: 5 keys to progress. Retrieved from https://www.healthcatalyst.com/insights/digitization-healthcare-5-keys-progress.

Hersh, W. (2009). A stimulus to define informatics and health information technology. *BMC Medical Informatics and Decision Making, 9*(1), 24. doi: 10.1186/1472-6947-9-24.

Hersch, J., Jansen, J., & McCaffery, K. (2016). Chapter 16 - Informed and shared decision making in breast screening. In N. Houssami & D. Miglioretti (Eds.), *Breast Cancer Screening* (pp. 403–420). Boston, MA: Academic Press.

Hollweck, T. (2015). Robert K. Yin.(2014). Case study research design and methods. Thousand Oaks, CA: Sage. 282 Pages. *Canadian Journal of Program Evaluation* 30(1).

Horák, M., Stupka, V., & Husák, M. (2019). *GDPR compliance in cybersecurity software: A case study of DPIA in information sharing platform*. In Proceedings of the 14th International Conference on Availability, Reliability and Security (ARES '19). Association for Computing Machinery, New York, NY, USA, Article 36, 1–8. doi: https://doi.org/10.1145/3339252.3340516.

Hornung, H., Pereira, R., Baranauskas, M. C. C., & Liu, K. (2015). Challenges for human-data interaction – A semiotic perspective. In M. Kurosu (Ed.), *Human-computer interaction: Design and evaluation, lecture notes in computer science* (pp. 37–48). Cham: Springer International Publishing. doi: https://doi.org/10.1007/978-3-319-20901-2_4.

Hosack, B., Hall, D., Paradice, D., & Courtney, J. F. (2012). A look toward the future: decision support systems research is alive and well. *Journal of the Association for Information Systems, 13*(5), 315-340.

Hunter, P. (2016). The big health data sale. *EMBO Reports, 17*(8), 1103–1105. doi: 10.15252/embr.201642917.

ICT Legal Consulting. (2018). Preliminary opinion on privacy by design. European Data Protection Supervisor. Retrieved from https://edps.europa.eu/sites/edp/files/publication/18-05-31_preliminary_opinion_on_privacy_by_design_en_0.pdf.

Ienca, M., & Vayena, E. (2020). On the responsible use of digital data to tackle the COVID-19 pandemic. *Nature Medicine, 26*(4), 463–464. doi: 10.1038/s41591-020-0832-5.

Ingebrigtsen, N.. (2007). *The differences between data, information and knowledge*. Retrieved from http://www.infogineering.net/data-information-knowledge.htm

Institute of Medicine (US), LeighAnne O., Robert S. S., & J. McGinnis, M. 2011. Patients, Clinical Decisions, and Health Information Management in the Information Age. National Academies Press (US). Retrieved from https://www.ncbi.nlm.nih.gov/books/NBK92062/.

Ishikawa, K., Miyaji, M., Nakamura, Y., Nishi, S., Sasaki, T., Tsuji, K. Watanabe, R. (1995). Troubles about privacy protection as security issues of the personal health data management in Japan and some solution proposals. *Studies in Health Technology and Informatics*, 151–154.

Islam, S. M. R., Kwak, D., Kabir, Md. H., Hossain, M., & Kwak, K.-S. (2015). The internet of things for health care: A comprehensive survey. *IEEE Access, 3*, 678–708. doi: 10.1109/ACCESS.2015.2437951.Jakobi, T., von Grafenstein, M., Legner, C., Labadie, C., Mertens, P., Öksüz, A., & Stevens, G. (2020). The role of IS in the conflicting interests regarding GDPR. *Business & Information Systems Engineering, 62*(3), 261–272. doi: 10.1007/s12599-020-00633-4.

Jordan, J. E., & Osborne, R. H. (2007). Chronic disease self-management education programs: Challenges ahead. *Medical Journal of Australia, 186*(2), 84–87.

Jorgensen, M., & Shepperd, M. (2006). A systematic review of software development cost estimation studies. *IEEE Transactions on Software Engineering, 33*(1), 33–53.

Kalkman, S., van Delden, J., Banerjee, A., Tyl, B., Mostert, M., & van Thiel, G. (2019). Patients’ and public views and attitudes towards the sharing of health data for research: A narrative review of the empirical evidence. *Journal of Medical Ethics*, 1-11. doi: 10.1136/medethics-2019-105651.

Kambhampati, S., Ashvetiya, T., Stone, N. J., Blumenthal, R. S., & Martin, S. S. (2016). Shared decision-making and patient empowerment in preventive cardiology. *Current Cardiology Reports, 18*(5), 49. doi: https://doi.org/10.1007/s11886-016-0729-6.

Karampela, M., Grundstrom, C., & Isomursu, M. (2018a). *Personal health data: Access and perceived value in Denmark*. Annual International Conference of the IEEE Engineering in Medicine and Biology Society. IEEE Engineering in Medicine and Biology Society Annual Conference Vol. 2018 (pp. 4081–4084). doi: 10.1109/EMBC.2018.8513407.

Karampela, M., Grundstrom, C., & Isomursu, M. (2018b). Personal health data: Accessibility and value in a Danish context. In B. Andersson, B. Johansson, S. Carlsson, C. Barry, M. Lang, H. Linger, & C. Schneider (Eds.), *Designing digitalization* (ISD2018 Proceedings). Lund, Sweden: Lund University. ISBN: 978-91-7753-876-9. http://aisel.aisnet.org/isd2014/proceedings2018/eHealth/7.

Karampela, M., Isomursu, M., Porat, T., Maramis, C., Mountford, N., Giunti, G.,… Lehocki, F. (2019). The extent and coverage of current knowledge of connected health: Systematic mapping study. Journal of Medical Internet Research 21(9):e14394.

Karampela, M., Ouhbi, S., & Isomursu, M. (2018). Personal health data: A systematic mapping study. *International Journal of Medical Informatics, 118*, 86–98. doi.org/10.1016/j.ijmedinf.2018.08.006

Karampela, M., Ouhbi, S., & Isomursu, M. (2019a). Exploring users' willingness to share their health and personal data under the prism of the new GDPR: Implications in healthcare. In *2019 41st Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC)* (pp. 6509–6512). IEEE.

Karampela, M., Ouhbi, S., & Isomursu, M. (2019b). Connected health user willingness to share personal health data: Questionnaire study. *Journal of Medical Internet Research*, *21*(11), e14537.

Karampela, M., Porat, T., & Mylonopoulou, V. (2019c). Needs of head and neck cancer patients and stakeholders during rehabilitation. Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth'19) (pp. 415–421). Association for Computing Machinery, New York, NY, USA. DOI: https://doi.org/10.1145/3329189.3329236.

Karthick, K. G., Miraftab, M., & Ashton, J. (2010). Development of a decision support system for determination of suitable dressings for wounds. *In Woodhead Publishing Series in Textiles, Medical and Healthcare Textiles*, 215-225, ISBN 9781845692247, https://doi.org/10.1533/9780857090348.215.

Kass, N. E., Natowicz, M. R., Hull, S. C., Faden, R. R., Plantinga, L., Gostin, L. O., & Slutsman, J. (2003). The use of medical records in research: What do patients want? *The Journal of Law, Medicine & Ethics, 31*(3), 429–433.

Kennedy, I. (2003). Patients are experts in their own field. *British Medical Journal, 326*(7402), 1276–1277.

Kharrazi, H., Chisholm, R., VanNasdale, D., & Thompson, B. (2012). Mobile personal health records: An evaluation of features and functionality. *International Journal of Medical Informatics, 81*(9), 579–593.

Kiesler, D. J., & Auerbach, S. M. (2006). Optimal matches of patient preferences for information, decision-making and interpersonal behavior: Evidence, models and interventions. *Patient Education and Counseling, 61*(3), 319–341.

Kirk, A. 2016. *Data visualisation: A handbook for data driven design*. Sage Publications. ISBN: 1473912148.

Kitchenham, B. A., Budgen, D., & Brereton, O. P. (2011). Using mapping studies as the basis for further research–A participant-observer case study. *Information and Software Technology, 53*(6), 638–651.

Knight, L. V., & Steinbach, T. A. (2008). Selecting an appropriate publication outlet: A comprehensive model of journal selection criteria for researchers in a broad range of academic disciplines. *International Journal of Doctoral Studies, 3, 59-79*.

Koesten, L. M., Kacprzak, E., Tennison, J. F. A., & Simperl, E. (2017). *The trials and tribulations of working with structured data: A study on information seeking behaviour*. In Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI '17). Association for Computing Machinery, N.Y., 1277–1289. doi :https://doi.org/10.1145/3025453.3025838.

Koops van ‘t Jagt, R., Hoeks, J. C. J., Jansen, C. J. M., de Winter, A. F., & Reijneveld, S. A. (2016). Comprehensibility of health-related documents for older adults with different levels of health literacy: A systematic review. *Journal of Health Communication, 21*(2), 159–177.

Kouroubali, A., & Katehakis, D. G. (2019). The new European interoperability framework as a facilitator of digital transformation for citizen empowerment. *Journal of Biomedical Informatics, 94*, 103166. doi: https://doi.org/10.1016/j.jbi.2019.103166.

Kowalewski, S., Ziefle, M., Ziegeldorf, H., & Wehrle, K. (2015). Like us on Facebook!– Analyzing user preferences regarding privacy settings in Germany. *Procedia Manufacturing, 3*, 815–822.

Kraemer, M. U. G., Yang, C.-H., Gutierrez, B., Wu, C.-H., Klein, B., Pigott, D. M., Scarpino, S. V. (2020). The effect of human mobility and control measures on the COVID-19 epidemic in China. *Science, 368*(6490), 493–497. doi: 10.1126/science.abb4218.

Krishnamurti, J., & Rajagopal, D. (1970). *Think on these things*. New York: Harper & Row.

Kujala, S., & Väänänen-Vainio-Mattila, K. (2009). Value of information systems and products: Understanding the users’ perspective and values. *Journal of Information Technology Theory and Application, 9*(4), 23-39.

Kushniruk, A. (2019). The importance of health information on the internet: How it saved my life and how it can save yours. *Journal of Medical Internet Research, 21*(10), e16690. doi: 10.2196/16690.

Kvale, S. (1996). The interview as a conversation. In *Interviews: An introduction to qualitative research interviewing* (pp. 19–37). Sage Publications.

Lapaire, J.-R. (2018). Why content matters. Zuckerberg, Vox Media and the Cambridge Analytica data leak. *ANTARES: Letras e Humanidades, 10*(20), 88–110.

Lee, V. R. (2014). *What’s happening in the quantified self movement?* Instructional Technology and Learning Sciences Faculty Publications. Paper 491, 1032-1036. https://digitalcommons.usu.edu/itls_facpub/491.

Deloitte.Legal. 2019. The GDPR: Six months after implementation. Retrieved from https://www2.deloitte.com/content/dam/Deloitte/ce/Documents/legal/ce-deloitte-the-gdpr-six-months-after-implementation-report-1.pdf?nc=1.

Legido-Quigley, H., Mateos-García, J. T., Campos, V. R., Gea-Sánchez, M., Muntaner, C., and McKee, M. (2020). The resilience of the Spanish health system against the COVID-19 pandemic. T*he Lancet Public Health, 5*(5), e251–252. doi: 10.1016/S2468-2667(20)30060-8.

Lehnbom, E. C., McLachlan, A. J., & Brien, J. E. (2013). A Qualitative study of Swedes' opinions about shared electronic health records. In C. U. Lehmann, E. Ammenwerth, & C. Nøhr (Eds.), MEDINFO 2013: proceedings of the 14th World Congress on Medical and Health Informatics. pp. 3-7. (Studies in health technology and informatics; Vol. 192). IOS Press. https://doi.org/10.3233/978-1-61499-289-9-3.

Levesque, J.-F., Harris, M. F., & Russell, G. (2013). Patient-centred access to health care: Conceptualising access at the interface of health systems and populations. *International Journal for Equity in Health, 12*(1), 18. doi: 10.1186/1475-9276-12-18.

Li, I., Dey, A., & Forlizzi, J. (2010). *A stage-based model of personal informatics systems*. Proceedings of the SIGCHI conference on human factors in computing systems (pp. 557–566). doi: https://doi.org/10.1145/1753326.1753409.

Liebe,E., Weisner, T., S., & Taylor, J. (2011). *Dedoose software*. California: Sociocultural Research Consultants. Retrieved from https://www.dedoose.com/.

Lin, S. C., Lyles, C. R., Sarkar, U., & Adler-Milstein, J. (2019). Are patients electronically accessing their medical records? Evidence from national hospital data. Health Affairs (Millwood). 2019 Nov;38(11):1850-1857. doi: 10.1377/hlthaff.2018.05437. PMID: 31682494.

Lo, B. (2015). Sharing clinical trial data: Maximizing benefits, minimizing risk. *JAMA, 313*(8), 793–794.

Lockyer, S., Spiro, A., & Stanner, S. (2016). Dietary fibre and the prevention of chronic disease–Should health professionals be doing more to raise awareness? *Nutrition Bulletin, 41*(3), 214–231.

Lorig, K. R., Sobel, D. S., Stewart, A. L., Brown, B. W., Jr., Bandura, A., Ritter, P., Holman, H. R. (1999). Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: A randomized trial. *Medical care, 37(1), 5–14.* https://doi.org/10.1097/00005650-199901000-00003.

Ludwick, D. A., & Doucette, J. (2009). Adopting electronic medical records in primary care: Lessons learned from health information systems implementation experience in seven countries. *International Journal of Medical Informatics, 78*(1), 22–31. doi: 10.1016/j.ijmedinf.2008.06.005.

Lutz, A., & Thompson, E. (2003). Neurophenomenology integrating subjective experience and brain dynamics in the neuroscience of consciousness. *Journal of Consciousness Studies, 10*(9–10), 31–52.

Lyytinen, K., & Newman, M. (2008). Explaining information systems change: A punctuated socio-technical change model. *European Journal of Information Systems, 17*(6), 589–613.

Mabry, P. L. (2011). Making sense of the data explosion. *American Journal of Preventive Medicine, 40*(5:S2), S159–161. doi: 10.1016/j.amepre.2011.02.001.

Malhotra, A., Totti, L., Meira, W., Jr., Kumaraguru, P., & Almeida, V. (2012). Studying user footprints in different online social networks. In *2012 IEEE/ACM International Conference on Advances in Social Networks Analysis and Mining,* pp. 1065-1070, doi: 10.1109/ASONAM.2012.184.

Malhotra, N. K., Kim, S. S., & Agarwal, J. (2004). Internet users' information privacy concerns (IUIPC): The construct, the scale, and a causal model. *Information Systems Research, 15*(4), 336–355.

Marcu, G., Bardram, J. E., & Gabrielli, S. (2011). A framework for overcoming challenges in designing persuasive monitoring and feedback systems for mental illness. In *2011 5th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth) and Workshops* (pp. 1–8). doi: 10.4108/ICST.PERVASIVEHEALTH.2011.246097.

Margolis, P. A., Carey, T., Lannon, C. M., Earp, J. L., & Leininger, L. (1995). The rest of the access-to-care puzzle: Addressing structural and personal barriers to health care for socially disadvantaged children. *Archives of Pediatrics & Adolescent Medicine* 149(5):541–45.

Mazurek, G., & Malagocka, K. (2019). What if you ask and they say yes? Consumers' willingness to disclose personal data is stronger than you think. *Business Horizons*, *62*(6), 751–759.

McCartney, R., & Tenenberg, J. (2008). From conference to journal. *Journal on Educational Resources in Computing, 8*(1), 1–4.

McCormack, P., Kole, A., Gainotti, S., Mascalzoni, D., Molster, C., Lochmüller, H., & Woods, S. (2016). *You Should at Least Ask*. The expectations, hopes and fears of rare disease patients on large-scale data and biomaterial sharing for genomics research. *European Journal of Human Genetics*, 24(10), 1403-1408..

McKinsey & Company. (2017). Digitally-enabled automation and artificial intelligence: Shaping the future of work in Europe's digital front-runners. Retrieved from https://www.mckinsey.com/~/media/mckinsey/featured%20insights/europe/shaping%20the%20future%20of%20work%20in%20europes%20nine%20digital%20front%20runner%20countries/shaping-the-future-of-work-in-europes-digital-front-runners.ashx.

McLennan, S., Celi, L. A., & Buyx, A. (2020). COVID-19: Putting the general data protection regulation to the test. *JMIR Public Health and Surveillance, 6*(2), e19279. doi: 10.2196/19279.

Medford-Davis, L. N., Chang, L., & Rhodes, K. V. (2017). Health information exchange: What do patients want? *Health Informatics Journal, 23*(4), 268–278.

Meier, C. A., Fitzgerald, M. C., & Smith, J. M. (2013). EHealth: Extending, enhancing, and evolving health care. *Annual Review of Biomedical Engineering, 15*(1), 359–382. doi: 10.1146/annurev-bioeng-071812-152350.

Migo, E. M., Haynes, B. I., Harris, L., Friedner, K., Humphreys, K., & Kopelman, M. D. (2014). MHealth and memory aids: Levels of smartphone ownership in patients. *Journal of Mental Health (Abingdon, England), 24(5), 266–270.* https://doi.org/10.3109/09638237.2014.951479.

Miinome. (n.d.). Miinome - It's in your DNA. Retrieved from http://miinome.com/.

Mitchell, B., & Begoray, D. (2010). Electronic personal health records that promote self-management in chronic illness. *The Online Journal of Issues in Nursing, 15*(3), 1B-10B. doi: 10.3912/OJIN.Vol15No03PPT01.

Morgan, G. (1983). *Beyond method: Strategies for social research.* Sage Publications.

Mortier, R., Haddadi, H., Henderson, T., McAuley, D., & Crowcroft, J. (2013). *Challenges & opportunities in human-data interaction.* In Proceedings of DE2013: Open Digital - The Fourth Annual Digital Economy All Hands Meeting.

Mortier, R., Haddadi, H., Henderson, T., McAuley, D., & Crowcroft, J. (2014). Human-data interaction: The human face of the data-driven society. doi: http://dx.doi.org/10.2139/ssrn.2508051.

Mountford, N., & Starič, K. D. (2016). *Connected health in Europe: Where are we today?* Dublin: University College. Retrieved from https://www.um.edu.mt/library/oar/handle/123456789/18050.

Munson, S. A. (2012). Exploring goal-setting, rewards, selfmonitoring, and sharing to motivate physical activity. In *2012 6th International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth)* (pp. 25–32). doi: 10.4108/icst.pervasivehealth.2012.248691.

Nagel, T. (1974). What is it like to be a bat? *The Philosophical Review*, *83*(4), 435–450.

Nathavitharana, R. R., Patel, P. K., Tierney, D. B., Mehrotra, P., Lederer, P. A., Davis, S., & Nardell, E. (2020). Innovation and knowledge sharing can transform COVID-19 infection prevention response. *Journal of hospital medicine, 15(5), 299–301*. https://doi.org/10.12788/jhm.3439.

National Strategy for Digitalization of the Danish Healthcare Sector. (2013). Making EHealth work. Retrieved from https://www.healthcaredenmark.dk/information/reports/.

Nowak, G. J., & Phelps, J. E. (1992). Understanding privacy concerns: An assessment of consumers' information-related knowledge and beliefs. *Journal of Direct Marketing, 6*(4), 28–39.

Noy, N. (2020). Discovering millions of datasets on the web. Google. Retrieved from https://blog.google/products/search/discovering-millions-datasets-web/

Nutley, T., & Reynolds, H. W. (2013). Improving the use of health data for health system strengthening. *Global Health Action, 6*(1), 20001. doi: 10.3402/gha.v6i0.20001.

Organisation for Economic Co-operation and Development (OECD). (2017). *Trust and public policy - How better governance can help rebuild public trust - En*. Retrieved from https://www.oecd.org/gov/trust-and-public-policy-9789264268920-en.htm

Open Humans Foundation. (n.d.). Quantified flu. Retrieved from https://quantifiedflu.org/

Orlikowski, W. J., & Baroudi, J. J. (1991). Studying information technology in organizations: Research approaches and assumptions. *Information Systems Research, 2*(1), 1–28.

Ouhbi, S., Fernández-Alemán, J. L., Toval, A., Pozo, J. R., & Idri, A. (2018). Sustainability requirements for connected health applications. *Journal of Software: Evolution and Process, 30*(7), e1922. doi: https://doi.org/10.1002/smr.1922.

Ouhbi, S., Karampela, M., & Isomursu, M. (2019). Integrating users logic into requirements engineering for connected healthcare co-design. In *Proceedings of the 14th International Conference on Evaluation of Novel Approaches To Software Engineering (enase 2019)* (pp. 480–485). SCITEPRESS Digital Library.

Papoutsi, C., Reed, J. E., Marston, C., Lewis, R., Majeed, A., & Bell, D. (2015). Patient and public views about the security and privacy of electronic health records (EHRs) in the UK: Results from a mixed methods study. *BMC medical informatics and decision making*, 15, 86. https://doi.org/10.1186/s12911-015-0202-2..

Pasmore, W. A., & Fagans, M. R. (1992). Participation, individual development, and organizational change: A review and synthesis. *Journal of Management, 18*(2), 375–397.

Penchansky, R., & Thomas, J. W. (1981). The concept of access: Definition and relationship to consumer satisfaction. *Medical Care, 19*(2), 127–140. doi: 10.1097/00005650-198102000-00001.

Pereira, A. M., Jácome, C., Amaral, R., Jacinto, T., & Fonseca, J. A. (2019). Real-time clinical decision support at the point of care. In *I*mplementing Precision Medicine in Best Practices of Chronic Airway Diseases, Academic Press, pp. 125-133. doi: https://doi.org/10.1016/B978-0-12-813471-9.00022-0.

Persson, H., Åhman, H., Yngling, A. A., & Gulliksen, J. (2015). Universal design, inclusive design, accessible design, design for all: Different concepts—One goal? On the concept of accessibility—Historical, methodological and philosophical aspects. *Universal Access in the Information Society, 14*(4), 505–526.

Peters, D. H., Garg, A., Bloom, G., Walker, D. G., Brieger, W. R., & Rahman, M. H. (2008). Poverty and access to health care in developing countries. *Annals of the New York Academy of Sciences, 1136*(1), 161–171.

Petersen, K., Feldt, R., Mujtaba, S., & Mattsson, M. (2008). *Systematic mapping studies in software engineering*. 12th International Conference on Evaluation and Assessment in Software Engineering (EASE) (pp. 1–10). doi: 10.14236/EWIC/EASE2008.8.

Phelps, J., Nowak, G., & Ferrell, E. (2000). Privacy concerns and consumer willingness to provide personal information. *Journal of Public Policy & Marketing, 19*(1), 27–41.

Phillips, M. (2018). International data-sharing norms: From the OECD to the general data protection regulation (GDPR). *Human Genetics, 137*(8), 575–582. doi: 10.1007/s00439-018-1919-7.

Pickard, K. T., & Swan, M. (2014). Big desire to share big health data: A shift in consumer attitudes toward personal health information. AAAI Spring Symposium Series.

Pikkarainen, M., Pekkarinen, S., Koivumäki, T., & Huhtala, T. (2018). Data as a driver for shaping the practices of a preventive healthcare service delivery network. *Journal of Innovation Management, 6*(1), 55–79.

Piller, F., Schubert, P., Koch, M., & Moesleim, K. (2004). From mass customization to collaborative customer codesign. ECIS 2004 Proceedings. 118. https://aisel.aisnet.org/ecis2004/118.

Piper, A. M., & Hollan, J. D. (2013). Supporting medical communication for older patients with a shared touch-screen computer. *International Journal of Medical Informatics, 82*(11), e242–50. doi: 10.1016/j.ijmedinf.2011.03.005.

Plastiras, P., & O'Sullivan, D. (2018). Exchanging personal health data with electronic health records: A standardized information model for patient generated health data and observations of daily living. *International Journal of Medical Informatics, 120*, 116–25. doi: 10.1016/j.ijmedinf.2018.10.006.

Poikola, A., Kuikkaniemi, K., & Honko, H. (2015). Mydata a Nordic model for human-centered personal data management and processing. http://urn.fi/URN:ISBN:978-952-243-455-5.

Poole, D. N., Escudero, D. J., Gostin, L. O., Leblang, D., & Talbot, E. A. (2020). Responding to the COVID-19 pandemic in complex humanitarian crises. *International Journal for Equity in Health, 19*(1), 41. doi: 10.1186/s12939-020-01162-y.

Portela, F., Santos, M. F., & Vilas-Boas, M. (2013). A pervasive approach to a real-time intelligent decision support system in intensive medicine. In A. Fred, J. L. G. Dietz, K. Liu, & J. Filipe (Eds.), *Knowledge discovery, knowledge engineering and knowledge management, communications in computer and information science* (pp. 368–381). Berlin, Heidelberg: Springer.

Pratap, A., Allred, R., Duffy, J., Rivera, D., Lee, H. S., Renn, B. N., & Areán, P. A. (2019). Contemporary views of research participant willingness to participate and share digital data in biomedical research. *JAMA Network Open, 2*(11), e1915717. doi:10.1001/jamanetworkopen.2019.15717.

Price, W. N., Kaminski, M. E., Minssen, T., & Spector-Bagdady, K. (2019). Shadow health records meet new data privacy laws. *Science, 363*(6426), 448–450. doi: 10.1126/science.aav5133.

Prochaska, J. O., Johnson, S., & Lee, P. (1998). The transtheoretical model of behavior change. The handbook of health behavior change. Springer Publishing Company. 59-84.

Pullman, D., Buehler, S. K., Felt, L., Gallagher, K., House, J., Keough, T. M., Ryan, A. (2009). Sorry, you can't have that information: Data holder confusion regarding privacy requirements for personal health information and the potential chilling effect on health research. *Healthcare Policy, 4*(4), 61-76.

Puustjärvi, J., & Puustjärvi, L. (2016). Managing fragmented personal data: Going beyond the limits of personal health records. In Proceedings of the International Joint Conference on Biomedical Engineering Systems and Technologies (BIOSTEC 2016). SCITEPRESS - Science and Technology Publications, Lda, Setubal, PRT, 145–150. doi: https://doi.org/10.5220/0005626101450150.

Raghupathi, W., & Raghupathi, V. (2014). Big data analytics in healthcare: Promise and potential. *Health Information Science and Systems* 2(1):3.

Richter, G., Borzikowsky, C., Lieb, W., Schreiber, S., Krawczak, M., & Buyx, A. (2019). Patient views on research use of clinical data without consent: Legal, but also acceptable? *European Journal of Human Genetics, 27*(6), 841–847. doi: 10.1038/s41431-019-0340-6.

Robling, M. R., Hood, K., Houston, H., Pill, R., Fay, J., & Evans, H. M. (2004). Public attitudes towards the use of primary care patient record data in medical research without consent: A qualitative study. *Journal of Medical Ethics, 30*(1), 104–109.

Roehrs, A., da Costa, C. A., da Rosa Righi, R., & de Oliveira, K. S. F. (2017). Personal health records: A systematic literature review. *Journal of Medical Internet Research, 19*(1), e13. doi: 10.2196/jmir.5876.

Rughiniş, C., Zamfirescu, R., & Neagoe, A. (2018). Visions of robots, networks and artificial intelligence: Europeans' attitudes towards digitisation and automation in daily life. *ELearning & Software for Education, 2, pp. 114-119.*

Salkever, D. S. (1976). Accessibility and the demand for preventive care. *Social Science & Medicine (1967), 10*(9–10), 469–475.

Schnabel, L. (2021). Survey experiments in the study of religions. https://doi.org/10.31235/osf.io/grche.

Scholz, R. W., & Tietje, O. 2002. *Embedded case study methods: Integrating quantitative and qualitative knowledge*. Sage Publications. ISBN: 9781452216218.

Schomakers, E.-M., Lidynia, C., & Ziefle, M. (2020). All of me? Users' preferences for privacy-preserving data markets and the importance of anonymity. Electron Markets 30, 649–665 (2020). https://doi.org/10.1007/s12525-020-00404-9.

Schwarz, N. (1999). Self-reports: How the questions shape the answers. *American Psychologist* 54(2):93.

Scott, D. A., Valley, B., & Simecka, B. A. (2017). Mental health concerns in the digital age. *International Journal of Mental Health and Addiction, 15*(3), 604–613.

Shabani, M., & Borry, P. (2018). Rules for processing genetic data for research purposes in view of the new EU general data protection regulation. *European journal of human genetics : EJHG, 26(2), 149–156. https://doi.org/10.1038/s41431-017-0045-7.*

Shah, N., Coathup, V., Teare, H., Forgie, I., Giordano, G. N., Hansen, T. H.,…Ruetten, H. (2019). Sharing data for future research—Engaging participants' views about data governance beyond the original project: A DIRECT study. *Genetics in Medicine, 21*(5), 1131–1138.

Sharon, T., & Lucivero, F. (2019). Introduction to the special theme: The expansion of the health data ecosystem – Rethinking data ethics and governance. *Big Data & Society*, *6*(2), 2053951719852969. doi: 10.1177/2053951719852969.

Shengelia, B., Murray, C. J. L., & Adams, O. B. (2003). Beyond access and utilization: Defining and measuring health system coverage. In *Health systems performance assessment: Debates, methods and empiricism* (pp. 221–234). Geneva: World Health Organization.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*(2), 63–75.

Simões-Marques, M., & Nunes, I. L. (2012). Usability of interfaces. *Ergonomics-A Systems Approach*, 155–170. doi: 10.5772/37299.

Sitra. (2018). *IHAN – Proof of concept pilots*. Sitra. Retrieved from https://www.sitra.fi/en/projects/ihan-proof-concept-pilots/

Sjöström, A. E., Hörnsten, Å., Hajdarevic, S., Emmoth, A., & Isaksson, U. (2019). Primary health care nurses' experiences of consultations with internet-informed patients: Qualitative study. *JMIR Nursing, 2*(1), e14194. doi: 10.2196/14194.

Skatova, A., McDonald, R. L., Ma, S., & Maple, C. (2019). Unpacking privacy: Willingness to pay to protect personal data. https://doi.org/10.31234/osf.io/ahwe4.

Sousa, V. D., Ramalho, P. I., & Silveira, D. (2016). Sharing regulatory data as tools for strengthening health systems in the region of the Americas. *Revista Panamericana de Salud Pública, 39*, 245–254.

Spencer, Sanders, Whitley, Lund, Kaye, and Dixon. (2016). Patient perspectives on sharing anonymized personal health data using a digital system for dynamic consent and research feedback: A qualitative study. *Journal of Medical Internet Research*. 18(4), e66. doi: 10.2196/jmir.5011.

Ssembatya, R., & Kayem, A. V. D. M. (2015). Secure and efficient mobile personal health data sharing in resource constrained environments. In *2015 IEEE 29th International Conference on Advanced Information Networking and Applications Workshops* (pp. 411–416). IEEE. doi: 10.1109/WAINA.2015.113.

Staccini, P., & Lau, A. Y. S. (2018). Findings from 2017 on consumer health informatics and education: Health data access and sharing. *Yearbook of Medical Informatics, 27*(01), 163–169.

Stanford Medice. (n.d.). Big data = Big finds: Clinical trial for deadly lung cancer Launched by Stanford Study. Retrieved from https://scopeblog.stanford.edu/2013/09/27/big-data-big-finds-clinical-trial-for-deadly-lung-cancer-launched-by-stanford-study/.

Stauss, B., & Mang, P. (1999). Culture shocks. In inter-cultural service encounters? Journal of Services Marketing, 13(4/5), 329–346. doi: 10.1108/08876049910282583.

Steinhubl, S. R., Muse, E. D., & Topol, E. J. (2013). Can mobile health technologies transform health care? *JAMA*, 310(22), 2395–2396.

Stephanidis, C. (2001). User interfaces for all: New perspectives into human-computer interaction. User Interfaces for All-Concep*ts, Methods, and Tools*, *1*, 3–17. Mahwah, NJ: Lawrence Erlbaum Associates. ISBN 0-8058-2967-9.

Stephanidis, C., Akoumianakis, D., Sfyrakis, M., & Paramythis, A. (1998). Universal accessibility in HCI: Process-oriented design guidelines and tool requirements. In *Proceedings of the 4th ERCIM Workshop on User Interfaces for all* (pp. 19–21). Stockholm, Sweden.

Steyn, K., & Damasceno, A. (2006). Lifestyle and related risk factors for chronic diseases. In D. T. Jamison, R. G. Feachem, M. W. Makgoba, E. R. Bos, F. K. Baingana, K. J. Hofman, & K. O. Rogo (Eds.), *Disease and Mortality in Sub-Saharan Africa*. Washington (DC): World Bank. 2, 247-265.

Stoewen, D. L. (2015). Health and wellness. *The Canadian Veterinary Journal, 56*(9), 983–984.

Street, J. (1991). Personal data protection in health and social services. *Journal of Medical Ethics, 17*(1), 53–54. doi: 10.1136/jme.17.1.53.

Sulthana, M. Z., & Habeeba, S. (2014). Assurance of patient control towards personal health data. *International Journal of Advanced Research in Engineering and Science, 2*, 1660–1665.

Swan, M. (2009). Emerging patient-driven health care models: An examination of health social networks, consumer personalized medicine and quantified self-tracking. *International Journal of Environmental Research and Public Health, 6*(2), 492–525.

Tang, C., Plasek, J. M., & Bates, D. W. (2018). Rethinking data sharing at the dawn of a health data economy: A viewpoint. *Journal of Medical Internet Research, 20*(11), e11519.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records. *Journal of the American Medical Informatics Association, 13*(2), 121–126. https://doi.org/10.1197/jamia.M0978.

Taylor, K. (2015). *Connected Health: How digital technology is transforming health and social care*. London, UK: Deloitte Centre for Health Solutions.

Tikkinen-Piri, C., Rohunen, A., & Markkula, J. (2018). EU general data protection regulation: Changes and implications for personal data collecting companies. *Computer Law & Security Review, 34*(1), 134–153.

Topac, V., & Stoicu-Tivadar, V. (2011). Patient empowerment by increasing information accessibility in a telecare system. In MIE (pp. 681–685). *Stud Health Technol Inform*. 2011;169:681-5.

Ummels, D., Beekman, E., Moser, A., Braun, S. M., & Beurskens, A. J. (2020). Patients' experiences with commercially available activity trackers embedded in physiotherapy treatment: A qualitative study. *Disability and Rehabilitation, 42*(23), 3284–3292. doi: 10.1080/09638288.2019.1590470.

United Nations. (n.d.). Convention on the rights of persons with disabilities (CRPD). Retrieved from https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html.

US Environmental Protection Agency (US EPA). (2013). *What Is section 508?* Retrieved from https://www.epa.gov/accessibility/what-section-508.

Vahdat, S., Hamzehgardeshi, L., Hessam, S., & Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: A review. *Iranian Red Crescent Medical Journal, 16*(1). doi: 10.5812/ircmj.12454. pp. 1-7.

Vahidhunnisha, J., Balasubramaniam, T., & Ramas, A. (2014). Improving privacy in sharing of personal health data storage on cloud. *International Journal of Innovative Technoly and Research, 2*(3), 940-944.

Van Gorp, P., & Comuzzi, M. (2013). Lifelong personal health data and application software via virtual machines in the cloud. *IEEE Journal of Biomedical and Health Informatics, 18(*1), 36–45.

Van Panhuis, W. G., Paul, P., Emerson, C., Grefenstette, J., Wilder, R., Herbst, A. J., Burke, D. S. (2014). A systematic review of barriers to data sharing in public health. BMC Public Health, 14(1), 1144. doi: 10.1186/1471-2458-14-1144.

Ventä, L., Isomursu, M., Ahtinen, A., & Ramiah, S. (2008). *'My phone is a part of my soul' – How people bond with their mobile phones.* In Proceedings of the Second International Conference on Mobile Ubiquitous Computing, Systems, Services and Technologies (UBICOMM '08). IEEE Computer Society, USA, 311–317. doi:https://doi.org/10.1109/UBICOMM.2008.48.

Vergados, D. D. (2010). Service personalization for assistive living in a mobile ambient healthcare-networked environment. *Personal and Ubiquitous Computing, 14*(6), 575–590.

Verplanken, B., & Holland, R. W. (2002). Motivated decision making: Effects of activation and self-centrality of values on choices and behavior. *Journal of Personality and Social Psychology, 82*(3), 434–447. https://doi.org/10.1037/0022-3514.82.3.

Voigt, T. H., Holtz, V., Niemiec, E., Howard, H. C., Middleton, A., & Prainsack, B. (2020). Willingness to donate genomic and other medical data: results from Germany. European Journal of Human Genetics, 28(8), 1000-1009. https://doi.org/10.1038/s41431-020-0611-2.

W3C. (n.d.). Accessibility. Retrieved from https://www.w3.org/standards/webdesign/accessibility.

Wachter, S. (2018). Normative challenges of identification in the internet of things: Privacy, profiling, discrimination, and the GDPR. *Computer Law & Security Review, 34*(3), 436–449. doi: 10.1016/j.clsr.2018.02.002.

Wass, S., Vimarlund, V., & Ros, A. (2019). Exploring patients' perceptions of accessing electronic health records: Innovation in healthcare. *Health Informatics Journal, 25*(1), 203–215.

Web content accessibility guidelines (WCAG) 2.1. Retrieved from https://www.w3.org/TR/WCAG

Weick. K. E. (1984). Theoretical assumptions and research methodology selection, 111, 132.

Weitzman, E. R., Kaci, L., & Mandl, K. D. (2010). Sharing medical data for health research: The early personal health record experience. *Journal of Medical Internet Research, 12*(2), e14. doi: 10.2196/jmir.1356.

Weitzman, E. R., Kelemen, S., Kaci, L., & Mandl, K. D. (2012). Willingness to share personal health record data for care improvement and public health: A survey of experienced personal health record users. *BMC Medical Informatics and Decision Making, 12*(1), 39.

Wells, S., Rozenblum, R., Park, A., Dunn, M., & Bates, D. W. (2014). Personal health records for patients with chronic disease. *Applied Clinical Informatics, 5*(02), 416–429.

Weng, C., Friedman, C., Rommel, C. A., & Hurdle, J. F. (2019). A two-site survey of medical center personnel's willingness to share clinical data for research: Implications for reproducible health NLP research. *BMC Medical Informatics and Decision Making, 19*(3), 70-76.

Whiddett, R., Hunter, I., Engelbrecht, J., & Handy, J. (2006). Patients' attitudes towards sharing their health information. *International Journal of Medical Informatics, 75*(7), 530–541.

White, K. L., Frenk, J., Ordonez, C., Paganini, J. M., & Starfield, B. (1992). Health services research: An anthology. Pan American Health Organization, Pan American Sanitary Bureau, Regional. ISBN 92-75-11534-6.

Whitehead, M. (1991). The concepts and principles of equity and health. *Health Promotion International, 6*(3), 217–228.

World Health Organization (WHO). (2018). *Non communicable diseases*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases

World Health Organization (WHO). (2020). Data and statistics. World Health Organization. Retrieved from https://www.euro.who.int/en/health-topics/Health-systems/health-workforce/data-and-statistics.

World Health Organization (1997). *WHOQOL: Measuring Quality of Life.* Retrieved from https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/.

Willison, D. J., Schwartz, L., Abelson, J., Charles, C., Swinton, M., Northrup, D., & Thabane, L (2007). Alternatives to project-specific consent for access to personal information for health research: What is the opinion of the Canadian public? *Journal of the American Medical Informatics Association: JAMIA vol. 14,6 (2007): 706-12. doi:10.1197/jamia.M2457.*

Wilson, M., Scalise, K., & Gochyyev, P. (2015). Rethinking ICT literacy: From computer skills to social network settings. *Thinking Skills and Creativity* 18:65–80.

World Health Organization. (n.d.). *WHO, accessibility*. WHO. Retrieved from https://www.who.int/gender-equity-rights/understanding/accessibility-definition/en/

World Health Organization. (1946). Preamble to the constitution of World Health Organization as adopted by the International Health Conference, New York, 19-22 June 1946 by the representatives of 61 states; signed on 22 July 1946 by the representatives of the 61 states. Official records of the World Health Organization., 2, 100.

Wu, S.-W., Cheng, P.-H., Chiang, W.-C., Lin, J.-K., & Lai, J.-S. (2011). Categorized level management agent with forest-based data structures for accessing personal health records. In *TENCON 2011-2011 IEEE Region 10 Conference* (pp. 1207–1211). IEEE. doi: 10.1109/TENCON.2011.6129304.

Wu, Z., & McGoogan, J. M. (2020). Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China: Summary of a report of 72 314 cases from the Chinese Center for Disease Control and Prevention. *JAMA*, *323*(13), 1239–1242. doi: 10.1001/jama.2020.2648.

Yin, R. K. (1994). Discovering the future of the case Study. Method in evaluation research. *Evaluation Practice, 15*(3), 283–290. Sage Publications.

Yin, R. K. (2013). Validity and generalization in future case study evaluations. *Evaluation*, *19*(3), 321–332.

Yu, Y., Li, X., Hu, G., Liu, H., Mei, J., Ni, Y., Xu, W. (2017). Personal health self-management in a data perspective. *Studies in Health Technology and Informatics, 245*, 1244-1244.

Zang, J., Dummit, K., Graves, J., Lisker, P., & Sweeney, L. (2015). Who knows what about me? A Survey of behind the scenes personal data sharing to third parties by mobile apps. *Technology Science*. Retrieved from https://techscience.org/a/2015103001/.

Zargaran, A., Ash, J., Kerry, G., Rasasingam, D., Gokani, S., Mittal, A., & Zargaran, D. (2018). Ethics of smartphone usage for medical image sharing. *Indian Journal of Surgery, 80*(3), 300–301.

Zhang, D., Guo, B., Li, B., & Yu, Z. (2010). Extracting social and community intelligence from digital footprints: An emerging research area. Ubiquitous Intelligence and Computing. UIC 2010. Lecture Notes in Computer Science, vol 6406. pp 4-18. Berlin, Heidelberg, Springer. https://doi.org/10.1007/978-3-642-16355-5_4.

Zhou, C., Su, F., Pei, T., Zhang, A., Du, Y., Luo, B., Xiao, H. (2020). COVID-19: Challenges to GIS with big data. *Geography and Sustainability, 1*(1), 77–87. doi: 10.1016/j.geosus.2020.03.005.

Ziefle, M., Halbey, J., & Kowalewski, S. (2016). Users' willingness to share data on the internet: Perceived benefits and caveats. In Proceedings of the International Conference on Internet of Things and Big Data - IoTBD, 255-265, 2016 , Rome, Italy. pp. 255–65.

Zins, C. (2007). Conceptual approaches for defining data, information, and knowledge. *Journal of the American Society for Information Science and Technology, 58*(4), 479–493. doi: 10.1002/asi.20508.

Appendices

Table 14. Overview of the elements, publications, and evidence.

PHD access		
Elements	Publications	Evidence[1]
	P2, P3, P4	
PHD in relation to perceived definition of health	P2	Table II.
Data types & formats	P2	Table II.
	P4	Patients were dissatisfied receiving materials concerning their rehabilitation process mostly on paper: "The pamphlets were there, but you can't ask questions to a pamphlet!" "I don't want to write back and forth, and I don't want to read 400 pages of paper from this place. (rehabilitation center)" Conclusions pointed out interrelated information needs between stakeholders (subject in rehabilitation, healthcare professionals and informal caregivers)
Perceived value related to usability: - Medical language/terminology - Visualizations - Interfaces	P2	Participant #8 "Because everything is in doctor terminology so you need to take a little step back and think what it actually means." Participant #6 "…although I speak Danish, there are things especially like medical things the way that are written like that you can't really understand." Participant #6 "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 …" Participant #7"...it's a tough problem having to deal with all these formats. So that would be some way of visualizing and predicting future health outcomes...". Participant #2 "One challenge would be in Sundhed.dk, as I've mentioned before I had [tried] 3 links to find my appointments and on was working..."

PHD sharing

Elements	Publications	Evidence[1]
	P2, P5, P6	
Data privacy	P2	Participant #2 “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”
Conditions to share	P5	Figure 1. and Table 2.
Willingness in relation to digitalization of countries	P5	Figure 1. and Table 2.
Willingness per age	P5	Figure 2.
Willingness per education level	P5	Figure 4.
Willingness per occupation type	P5	Figure 5.
PHD in comparison to other types of personal data	P6	Table II, RQ1
How the new GDPR affected users’ online behavior	P6	Table II, RQ2

[1] The number of tables and figures correspond to those in the published papers

Table 15. Questionnaire survey results per category.

Category	No	I don't know	For public interest	For scientific research	For extra services or individual service	I would be paid for it
Total	29.78	13.64	11.86	22.63	7.85	14.23
	(2384/8004)	(1092/8004)	(949/8004)	(1811/8004)	(628/8004)	(1139/8004)
Finland	32.54	7.15	7.46	38.36	5.27	9.22
	(651/2000)	(143/2000)	(149/2000)	(767/2000)	(105/2000)	(184/2000)
Germany	35.67	12.79	10.86	17.67	7.73	15.28
	(715/2004)	(256/2004)	(218/2004)	(354/2004)	(155/2004)	(306/2004)
The Netherlands	25.37	14.45	15.47	16.95	12.23	15.55
	(507/2000)	(289/2000)	(309/2000)	(339/2000)	(245/2000)	(311/2000)
France	25.54	20.16	13.67	17.54	6.20	16.89
	(511/2000)	(403/2000)	(273/2000)	(351/2000)	(124/2000)	(338/2000)
Male	30.41	12.63	11.46	20.97	8.69	15.85
	(1193/3922)	(495/3922)	(449/3922)	(822/3922)	(341/3922)	(622/3922)
Female	29.68	14.37	12.37	24.47	6.61	12.50
	(1188/4002)	(575/4002)	(495/4002)	(979/4002)	(265/4002)	(500/4002)
18-34 y	22.06	12.40	12.89	25.27	11.17	16.22
	(565/2561)	(318/2561)	(330/2561)	(647/561)	(286/2561)	(415/2561)
35-44 y	26.86	15.96	10.35	21.58	8.89	16.35
	(408/1521)	(243/1521)	(157/1521)	(328/1521)	(135/1521)	(249/1521)
45-65 y	36.55	13.53	11.77	21.19	5.04	11.92
	(1433/3922)	(531/3922)	(462/3922)	(831/3922)	(198/3922)	(467/3922)
City	29.84	11.03	14.05	24.26	6.89	13.93
	(955/3202)	(353/3202)	(450/3202)	(777/3202)	(221/3202)	(446/3202)
Town/Urban area	31.58	10.41	11.17	24.99	7.96	13.90
	(859/2721)	(283/2721)	(304/2721)	(680/2721)	(217/2721)	(378/2721)
Countryside	31.28	14.52	10.83	19.39	8.63	15.35
	(551/1761)	(256/1761)	(191/1761)	(341/1761)	(152/1761)	(270/1761)
Compulsory education	30.91	16.39	12.01	19.55	6.63	14.50
	(619/2001)	(328/2001)	(240/2001)	(391/2001)	(133/2001)	(290/2001)
Academic education	32.16	8.55	12.70	26.78	7.35	12.45
	(360/1121)	(96/1121)	(142/1121)	(300/1121)	(82/1121)	(140/1121)
[a] Other education	29.77	11.40	12.08	23.86	8.25	14.65
	(1382/4642)	(529/4642)	(561/4642)	(1108/4642)	(383/4642)	(680/4642)
Category	No	I don't know	For public interest	For scientific research	For extra services or individual service	I would be paid for it

Managerial position / Senior	31.74 (432/1361)	6.89 (94/1361)	12.47 (170/1361)	24.55 (334/1361)	10.73 (146/1361)	13.62 (185/1361)
Junior white collar	31.77 (280/880)	10.86 (96/880)	11.10 (98/880)	24.09 (212/880)	8.10 (71/880)	14.08 (124/880)
Worker	27.19 (588/2162)	14.52 (314/2162)	14.03 (303/2162)	22.70 (491/2162)	7.47 (162/2162)	14.09 (305/2162)
Self-employed or sole trader	30.73 (148/480)	10.88 (52/480)	8.69 (42/480)	22.79 (109/480)	11.61 (56/480)	15.31 (73/480)
At school or student	26.21 (126/480)	9.12 (44/480)	9.35 (45/480)	32.30 (155/480)	7.78 (37/480)	15.25 (73/480)
Pensioner	39.17 (376/960)	11.95 (115/960)	11.62 (112/960)	23.13 (222/960)	2.48 (24/960)	11.63 (112/960)
[b] Other	28.14 (405/1441)	18.29 (264/1441)	12.09 (174/1441)	18.48 (266/1441)	6.95 (100/1441)	16.04 (231/1441)

[a] Other education: corresponds to vocational education, matriculation or other types of education, [b] Other: corresponds to other types of jobs or status, such as at-home mother/father

Original publications

This dissertation is based on the following publications, these are referred to in the text as P1–P6. The publications are reproduced at the end of this dissertation with the type of permission from the publisher.

I Karampela, M., Ouhbi, S., & Isomursu, M. (2018). Personal health data: A systematic mapping study. *International Journal of Medical Informatics*, *118*, 86–98. doi.org/10.1016/j.ijmedinf.2018.08.006

II Karampela, M., Grundstrom, C., & Isomursu, M. (2018). Personal health data: access and perceived value in Denmark. In *Proceedings of the 40th Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC)* (pp. 4081–4084). doi: 10.1109/EMBC.2018.8513407.

III Karampela, M., Grundstrom, C., & Isomursu, M. (2018). Personal health data: Accessibility and value in a Danish context. In B. Andersson, B. Johansson, S. Carlsson, C. Barry, M. Lang, H. Linger, & C. Schneider (Eds.), *Designing Digitalization (ISD2018 Proceedings).* Lund, Sweden: Lund University. ISBN: 978-91-7753-876-9. http://aisel.aisnet.org/isd2014/proceedings2018/eHealth/7.

IV Karampela, M., Porat, T., & Mylonopoulou, V. (2019). Needs of head and neck cancer patients and stakeholders during rehabilitation. In *Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare* (PervasiveHealth'19) (pp. 415–421). Association for Computing Machinery, New York, NY, USA. DOI: https://doi.org/10.1145/3329189.3329236.

V Karampela M., Ouhbi, S., & Isomursu, M. (2019). Connected health user willingness to share personal health data: Questionnaire study. *Journal of Medical Internet Research*, *21(*11), e14537. doi: 10.2196/14537.

VI Karampela, M., Ouhbi, S., & Isomursu, M. (2019). Exploring users' willingness to share their health and personal data under the prism of the new GDPR: Implications in healthcare. In *Proceedings of the 41st Annual International Conference of the IEEE Engineering in Medicine and Biology Society (EMBC)* (pp. 6509–6512).

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