



Designing Respectful Health Data Flows Centred on Data Contributors' Perspectives

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Designing Respectful Health Data Flows Centred on Data Contributors' Perspectives

PhD Thesis

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PhD Thesis
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Preface

This PhD thesis represents the culmination of a 3-years doctoral project to fulfil the requirements for acquiring a PhD degree at the Technical University of Denmark (DTU). The research was supervised by Dr. Kevin Doherty, Prof. David Coyle and Prof. Jakob Bardram.

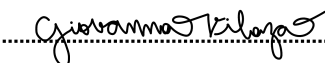
The PhD work was conducted at the Department of Health Technology (February 2019-February 2022) and the Department of Applied Mathematics and Computer Science (October 2018-January 2019). An external stay took place at the Insight Centre for Data Analytics, University College Dublin, in Ireland (September 2019-December 2019).

The project was a part of the Technology-Enabled Mental Health Innovative Training Network (TEAM-ITN), funded by the European Union's Horizon 2020 Research and Innovation Programme, under the Marie Skłodowska-Curie grant agreement 722561.

This thesis includes the following published research papers:

1. Vilaza, Giovanna Nunes and Bardram, Jakob (2019). *Sharing Access to Behavioural and Personal Health Data: Designers' Perspectives on Opportunities and Barriers*. In Proceedings of the 13th EAI International Conference on Pervasive Computing Technologies for Healthcare.
2. Vilaza, Giovanna Nunes et al. (2020). *Futures for Health Research Data Platforms From the Participants' Perspectives*. In Proceedings of the 11th Nordic Conference on Human-Computer Interaction: Shaping Experiences, Shaping Society.
3. Vilaza, Giovanna Nunes (2020). *What is the Future of Data Sharing for Research?* ACM interactions 27, 4, 54–56.
4. Vilaza, Giovanna Nunes and McCashin, Darragh (2021). *Is the Automation of Digital Mental Health Ethical? Applying an Ethical Framework to Chatbots for Cognitive Behaviour Therapy*. Frontiers in Digital Health 3, 689736.
5. Vilaza, Giovanna Nunes et al. (2021). *Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey*. Journal of Medical Internet Research 23, 10, e31294.

Giovanna Nunes Vilaza


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Signature

..... February 21st, 2022

Date

Abstract

The increased use of digital health data has been praised as a revolutionary turn for the practice and study of medicine. Among the diverse range of health data sources, a significant percentage of research has focused upon data generated by citizens and recipients of healthcare services. This broad category comprises information as diverse as data collected within clinical infrastructures, during treatment, and throughout individuals' daily lives. A growing interest in digital health data has led to the creation of shared-access repositories that allow multiple stakeholders to utilise available data sources simultaneously. One of the primary aims of these repositories is to overcome challenges related to recruiting participants for research studies. A further ambition is to store mobile and wearable data to observe and learn from human behaviour at a population scale.

Although digital health data may contribute towards an in-depth understanding of human subjects, the choice of allowing data access to multiple users is not exempt from fundamental ethical considerations. If identifiable data used to monitor stigmatised health conditions is leaked, individuals may suffer the consequences of social discrimination. Health data can be abused if utilised to enable commercial profit from individual vulnerabilities or inform governments' authoritarian control over citizens. There is also a risk that unregulated data analysis is biased and invalid research findings ultimately affect how patients are treated in the future.

Given the undeniable gravity and significance of such ethical concerns, there is a need to consider more responsible data sharing practices within healthcare to protect individuals. This thesis aims to inform the design of future health data ecosystems by providing evidence in addition to a portfolio of approaches to support the prioritisation of ethical design choices aligned with the values of citizens and patients. The overarching goal of this work is to investigate how we can discover ethically-oriented and data contributor-centred requirements for designing health data interfaces. This research is grounded in Human-Computer Interaction (HCI) and user-centred design traditions while building upon the concept and practice of ethical design. Given this orientation, the methodological approach of this thesis work includes and connects literature reviews, user studies (both qualitative and quantitative), critical appraisals of technology and the prototyping of user interfaces.

This thesis makes the following contributions. First, this PhD delivers a review of state-of-the-art health data repositories and discusses factors key to their acceptance. Second, it presents findings from a scoping review yielding a coherent up-to-date mapping of ethical thinking and doing in HCI. Third, it provides an in-depth understanding of data contributors' and technology creators' attitudes towards sharing data with and through health data repositories. Fourth, it illustrates in practice the application and teaching of ethically-centred approaches to the design of health data interfaces. Finally, it presents a set of design considerations supporting the future development of increasingly ethical health data flows. Overall, this PhD demonstrates how requirements for respectful health data flows can integrate ethical and contributor centred.

Dansk Resumé

Den øgede brug af digitale sundhedsdata er blevet set som en revolutionerende retning indenfor klinisk behandling og forskning. Blandt de mange forskellige kilder af sundhedsdata fokuserer en signifikant del af forskningen på data genereret af borgere og modtagere af sundhedsydelser. Denne brede kategori kan omfatte indsamlede informationer i kliniske infrastrukturer, under behandling eller gennem ens daglige liv. Den voksende interesse for sundhedsdata har ført til oprettelsen af arkiver med delt adgang, der tillader flere interessenter at tilgå den tilgængelige data. Et af de primære formål med disse arkiver er at overvinde udfordringer relateret til rekruttering af deltagere til kliniske studier. Et andet formål er at observere menneskelig adfærd i detaljer ved indsamlingen af data fra mobile og bærbare enheder.

Selvom personlige sundhedsdata kan bidrage til en dybdegående forståelse af menneskelig aktivitet, så er sundhedsdata ikke undtaget fra de grundlæggende etiske overvejelser. Data fra mobile og bærbare enheder kan fx. bruges som en indikator for mentale sundhedstilstande, der er stigmatiserede, hvilket kan føre til social diskrimination eller kompromittere den fremtidige beskæftigelsesegnethed. Tidligere studier har også fremhævet manglen på etisk begrundelse for at bruge menneskelige data til at gavne de virksomheder, der bygger robuste adfærdsmodeller ved at udnytte og tjene på individernes sårbarheder. Tidligere arbejde har også fremhævet manglen på etisk begrundelse for at bruge menneskelige data til at tjene virksomheder, der drager fordel af individuelle sårbarheder og regeringer, der udøver autoritær kontrol over borgerne. En lav indsats for at rekruttere en bredere mangfoldighed af bidragsydere til dataindsamlingen kan også medføre til en bias i datasæt og en uretfærdig fordeling af sundhedsydelserne.

I betragtning af den ubestridelige alvor og vigtigheden af disse etiske bekymringer, er der behov for at overveje mere ansvarlig datahåndtering indenfor sundhedsvæsenet. Denne ph.d.-afhandling har til formål at informere designet af digitale økosystemer i sundhedsvæsenet ved at levere evidens og en portefølje af tilgange til at prioritere etiske designvalg tilpasset borgernes og patienternes behov. Det overordnede mål er at undersøge, hvordan vi kan understøtte opdagelsen og handlingen af etiske krav såvel som krav fra bidragsydere ifm. dataindsamling ved design af interfaces til sundhedsdata. Arbejdet er funderet i menneske-computer-interaktion og brugercentrerede design traditioner, og er baseret på begrebet etisk design. Denne vinkel inkluderer en metodisk tilgang, som anvender en gennemgang af litteraturen, brugerundersøgelser (kvalitative og kvantitative), kritiske vurderinger af teknologien og prototyping af brugergrænseflader.

Dette projekt har følgende bidrag. For det første præsenterer denne ph.d.-afhandling en gennemgang af databaser og arkiver med sundhedsdata og diskuterer faktorer, der er nøglen til deres accept. For det andet bibringer ph.d.-afhandlingen en scoping-gennemgang, der giver en sammenhængende og opdateret kortlægning af etisk tænkning og handling i menneske-computer-interaktion. For det tredje giver afhandlingen en dybdegående forståelse af bidragsydernes til dataindsamling sammenholdt med teknologiskabernes holdninger til at dele data gennem arkiver med sundhedsdata. For det fjerde illustrerer afhandlingen i praksis, hvordan man anvender og underviser i værdi-centrerede tilgange til design af grænseflader for sundhedsdata. Endelig præsenterer afhandlingen et sæt designovervejelser, der understøtter den fremtidige udvikling af anvendelsen af sundhedsdata. Overordnet søger denne afhandling at demonstrere, hvordan etiske og bidragsydercentrerede perspektiver kan inddrages ved opstilling af krav til design af brugergrænseflader for sundhedsdata.

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Much work, care and thought were put into turning this PhD project into a thesis. Nevertheless, none of the following pages would have become a reality without the support and love of many people. I list the following acknowledgements to thank those who have been fundamental in this journey.

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Thanks to the Marie Curie programme and the CACHET network, I could meet and learn from many academic colleagues who share the same goals, interests and frustrations as me, especially at TEAM and during my stay at UCD. I hope we keep growing together.

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List of Acronyms

ACM	Association for Computing Machinery
AI	Artificial Intelligence
CBT	Cognitive Behavioural Therapy
CHI	Conference on Human Factors in Computing Systems
DTU	Technical University of Denmark
EMA	Ecological Momentary Assessments
GDPR	General Data Protection Regulation
HCI	Human-Computer Interaction
IoT	Internet of Things
IRB	Institutional Review Board
ML	Machine Learning
RRI	Responsible Research and Innovation
SIGCHI	Special Interest Group on Computer-Human Interaction
UX	User Experience
VSD	Value-Sensitive Design

Part I

Introduction to the Paper Collection

1 Introduction

1.1 Context

Data is a precious resource for the healthcare sector. In recent years, the increased digitisation of medical records has made possible more informed decision-making by health professionals, care facilities and financing institutions (Dash et al. 2019). Through the collection of personal sensing data reflecting patients' experiences, habits, and lives, technology has opened up a plethora of possibilities for Artificial Intelligence (AI) and Machine Learning (ML) also to personalise treatments, optimise costs and automate processes (Odone et al. 2019). Practitioners, researchers and academic journals of medicine have praised the increased use of digital data as a revolutionary turn for the care and study of human health (Meskó et al. 2017; Mohr et al. 2018). The coronavirus (COVID-19) pandemic has further underscored the vital role of public health data to support rapid and effective responses (Foraker et al. 2021).

Amidst the vast diversity of health data sources, previous research has often focused upon data generated by citizens, patients and the recipients of healthcare services (Li et al. 2019b; Mentis et al. 2017; Ostherr et al. 2017). This broad data category comprises information collected inside clinical infrastructures (for example, electronic health records), during treatment (for example, therapeutic disclosures) or throughout individuals' daily life (for example, habits tracking). These data sources can be extracted both passively (for example, through mobile sensing) or actively (for example, through self-reporting of symptoms). Novel technology devices are continuously expanding data gathering possibilities in this regard. Computers and smartwatches now accompany wearables, bio-sensors and Internet of Things (IoT) devices for health surveillance (Kristoffersson et al. 2020; Rahaman et al. 2019).

A variety of diverse uses likewise exist for this category of health data, ranging from personal and social to clinical and public applications. For instance, many individuals self-monitor sleeping hours, step counts and heart rate for their own personal purposes, seeking to acquire knowledge in support of their well-being (Epstein et al. 2015; Fleck et al. 2010; Khan et al. 2017). Health practitioners and clinicians, in turn, can utilise similar data to gain a fuller understanding of patients' routines in-between consultations (Malu et al. 2017; Chung et al. 2015). Patient groups and communities may also find social uses for health data by, for instance, sharing their symptoms via social networks as a means to obtain assistance, inspiration and encouragement (Wicks et al. 2010; Malu et al. 2017). Finally, one of the most prominent examples of health data usage lies in scientific research employing health data to improve prevention and treatment procedures for the general population (Collins et al. 2015). This last application of health data is the main focus of this thesis.

Therefore, while health data possesses the vast potential to support healthcare and scientific research, collecting and maintaining these data sets creates significant challenges in terms of high recruitment costs and the considerable effort associated with large scale data collection. This difficulty has led to the creation of shared-access repositories allowing multiple stakeholders to utilise data simultaneously, especially to support research initiatives (Broes et al. 2017; Hossain et al. 2016). The first among these repositories emulated the concept of bio-banks storing biological samples and genetic materials (Lo 2015; Broes et al. 2018), whilst the most recent also strive to enable the aggregation of

digital sources of information (for example, from mobile and wearable sensing). Examples of such shared-access platforms range from the extensive All of Us Research Programme sponsored by the United States government (Collins et al. 2015) to the European COVID-19 Data Platform quickly created amidst the pandemic (Harrison et al. 2021). Smaller enterprises include the global open-data community Open Humans as maintained by its members (Greshake Tzovaras et al. 2019).

Health data in such a shared-access ecosystem is not static but rather ‘flows’ across entities interested in data access for different purposes and uses. Data collected from citizens and patients alike (data contributors) is valuable to multiple and many kinds of data consumers (researchers, clinicians, governments), meaning that it might be worthwhile maintaining data in repositories for future re-use (See Figure 1.1). The control of collected, stored, and shared data in such a fluid state usually occurs through user interface components employed by the stakeholders involved at each stage of these processes. These health data interfaces may consist, for instance, of mobile apps used by patients for personal data collection or web portals from where researchers obtain access to data sources. The institution of boundaries on these health data ‘flows’ as entailed in the design of the corresponding health data ‘interfaces’ is a goal at the very heart of the work of this PhD thesis.

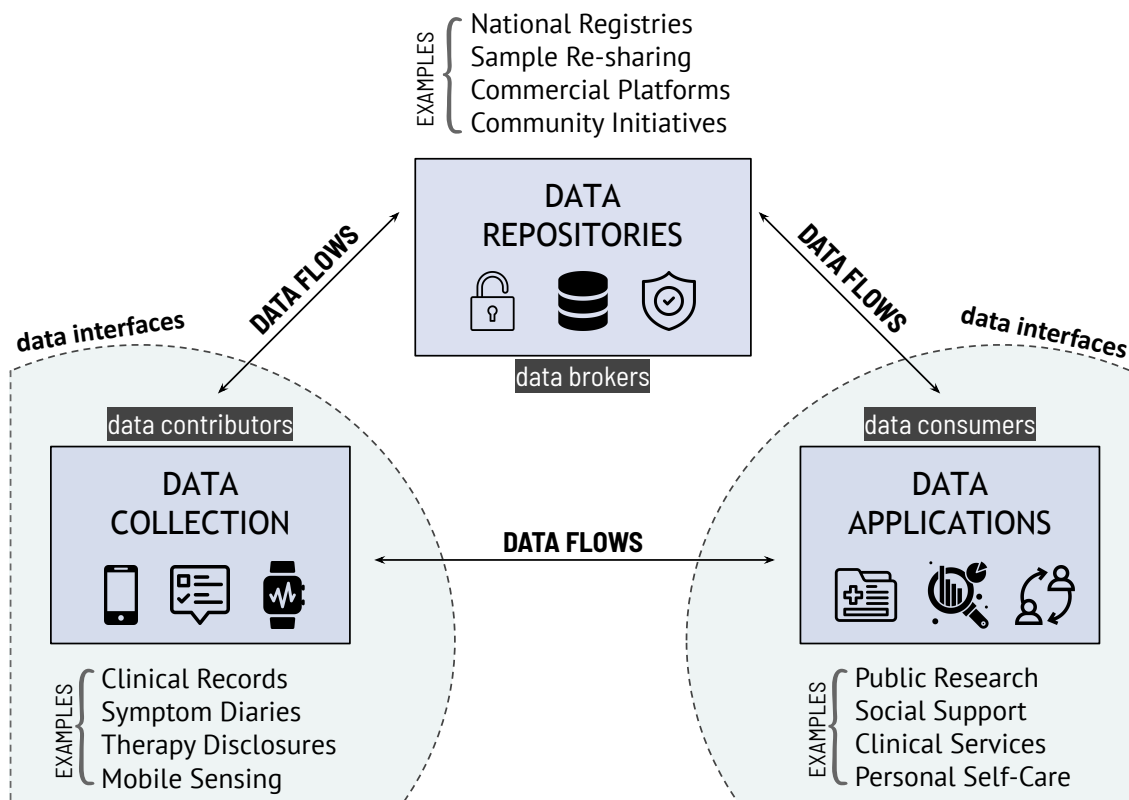


Figure 1.1: Infographic summarising the concepts of health data flows and interfaces

1.2 Motivation

As discussed above, the opportunity to research and gain an in-depth understanding of human behaviour comprises one of the primary drivers for collecting and storing health data. However, many have argued that the predominant vision for shared-access repositories over-emphasises the value that data can bring to researchers, clinicians and gov-

ernments — consequently undermining the associated risks to the individuals disclosing their personal data (Kostkova et al. 2016). The intimate observation of affective states, behavioural changes and daily habits are in stark contrast to less invasive information more often employed within healthcare (for example, the number of hospital admissions, the working patterns of practitioners or even physiological data such as blood pressure examined in-clinic). Facilitating access to sensitive data sources can have alarming consequences for the safety, well-being and freedom of data contributors, as explained next (Petelka et al. 2020; Klingler et al. 2017).

First, a wide variety of well-informed perspectives have drawn attention to the commonplace neglect of individual privacy rights within health surveillance initiatives, especially when it comes to debilitating diseases and living conditions that individuals may prefer not to disclose (Rooksby et al. 2019). For instance, the leakage of identifiable information connected to stigmatised mental health conditions can lead to social discrimination and harassment (Murnane et al. 2018). Beyond possible damages to one's reputation, the consequences of undesirable exposures can include cyberattacks and stalking that put individuals' physical and financial safety at risk (Christin et al. 2011).

Another set of concerns often raised by academics and patient advocates alike pertains to issues of social justice and the exclusion of marginalised groups from digital health innovation (Sankar et al. 2017). A lack of significant and genuine efforts to recruit a broader diversity of data contributors is said to only contribute to the historically unfair distribution of benefits across populations, especially when it comes to conclusions derived from unfairly constructed datasets (Klingler et al. 2017). Perhaps worst of all, the abuse of data by authoritarian governments, insurance providers, recruitment agents and forensic investigators can prove unfairly more risky to vulnerable groups (Middleton et al. 2019).

Finally, past work has also highlighted a lack of ethical justification for human data being employed to serve businesses that build robust behavioural models to unlock profit-making opportunities from personal vulnerabilities (Lupton 2014; Zuboff 2019). Drug advertisers, for example, may have a strong commercial interest in obtaining access to detailed information about patients and family members' diagnoses (Wilkes et al. 2000; Perera et al. 2011). Public concerns regarding such scenarios of data misuse can also directly affect individuals' willingness to contribute health data, which further hinders broad acceptance and aggravates this extant lack of data fairness (Skirpan et al. 2018c).

It is a significant challenge, therefore, to realise the potential benefits of health data sharing while also protecting data contributors from short and long term harm (Iakovleva et al. 2019; Eyre et al. 2020; Clark et al. 2019). Contemporary research argues that any vision for more respectful and ethical health data flows must start by acknowledging and addressing sources of discomfort among those who agree to disclose their most personal information (Sankar et al. 2017). However, a lack of attention to these data contributors' perspectives currently hinders the creation and conception of health data technologies better able to attend to individuals' expectations, preferences and concerns (King 2019). This knowledge gap comprises an obstacle for appropriately understanding both the current perception of risks and positive attitudes individuals may hold towards the prospect of health data sharing.

Besides a more robust engagement with data contributors' perspectives, integrating ethical thinking into the conception of health data repositories could further help address the crucial issues that motivate this research. However, the consideration of ethical implications during technology design processes remains one of the most significant and fundamental challenges of the field of HCI, and not only concerning the context of digital

health (Frauenberger et al. 2017). Many argue that because ethics itself has remained widely perceived as rigid, static and formalised in nature, its embodiment in digital systems development has proved slow. Professionals reportedly struggle to know how to go about putting ‘ethical design’ into practice (Stahl et al. 2016; Gray et al. 2021). Excepting a small number of argumentative essays (Nebeker et al. 2019; Roossien et al. 2021; Geneviève et al. 2019; Martinez-Martin et al. 2020), there exist few resources guiding how to translate ethical insights into concrete design alternatives for digital health applications — the second gap in knowledge motivating the work of this thesis.

1.3 Research Questions

As seen above, even though current data sharing practices within digital health intend to benefit society, it is still unclear how the conception of health data interfaces might better respect the preferences of the individuals exposing themselves to risk (data contributors). Therefore, this thesis aims to inform the design of technology ecosystems entailing health data flows by offering evidence and a portfolio of approaches to support technology creators’ prioritisation of citizens’ needs. The following overarching research question drives this PhD thesis:

“How might we discover and act upon ethical and data contributors’ requirements to design respectful health data flows?”

In particular, we were interested in the specific case of designing user interfaces that can mediate data contributions for health research. As seen above, health data is increasingly being used for scientific investigations, making it a timely research topic. Therefore, in order to answer this overarching research question, we conducted a series of interconnected investigations that investigated the following sub-questions:

RQ1. What is the current landscape of data sharing for health research, and which are the contribution options for participants?

RQ2. How can technology creators surface, reflect and act upon ethical requirements for user interfaces mediating health data contributions?

RQ3. Which technology acceptance factors, core values and ethical principles can guide the design of respectful health data interfaces?

Each of these sub-questions adds a fundamental piece to the overarching goal of this work. The investigations carried out to answer these questions aim to provide a deeper understanding of existing health data repositories, how they currently shape data contribution, and how ethical thinking and data contributors’ values could support technology creators in the conception of more respectful data exchanges in this context. The following section describes the methodology chosen to guide the research work.

1.4 Methodology

The work of this thesis stands on HCI and human-centred design traditions (Sharp 2003) while building upon the growing thread of ‘in-action’ ethics research (Frauenberger et al. 2017). In particular, this research focuses on the user group composed of those invited to contribute their data (citizens and patients) to health data repositories. Given this user-centred orientation, the methodological approach of this thesis includes and connects literature reviews, user studies (both qualitative and quantitative), critical appraisals of technology, conceptual design and user interface prototyping (See Figure 1.2). Adopting these different data gathering and analysis techniques aims to attain a deeper understanding of users to inform the initial stages of the interaction design process - establishing

requirements and proposing alternatives (sharp2003interaction). The following section describes the application of each specific method throughout the PhD course.

1.5 Thesis Outline

This thesis is composed of two parts. The first part (Chapters 1 to 10) provides the summary of the content from the research papers included in the thesis (See Figure 1.2). In this first part, chapters 1 to 8 summarise and connect context, motivation, research questions, methods, results and contributions of each of these research papers, setting the stage for the manuscripts found in their entirety in Part II. Then, chapters 9 and 10 close this first part and discuss implications for future works. The second part of the thesis presents the eight manuscripts (See Papers 2.1 to 2.8), either published or submitted, produced during the PhD project. The complete bibliography can be found at the end of this second part. An outline of the chapters is described next.

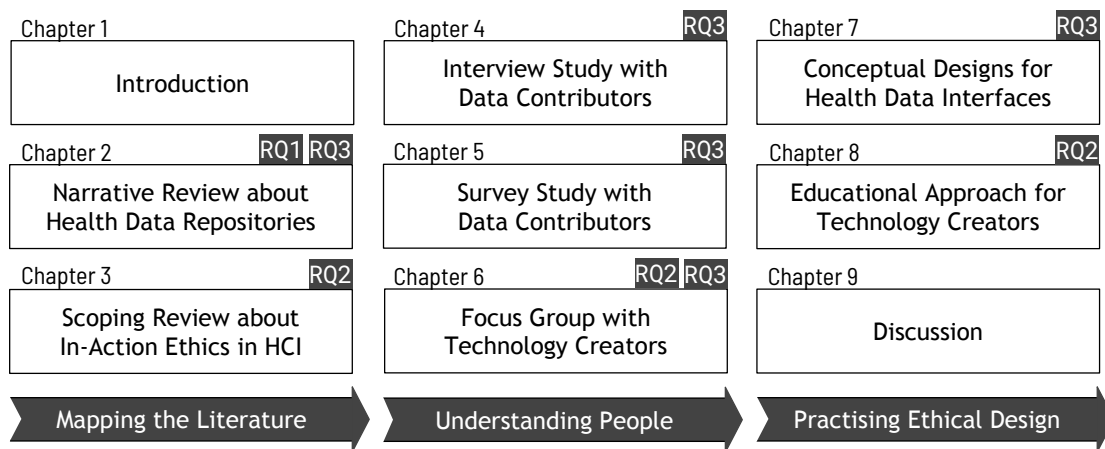


Figure 1.2: Diagram describing the thesis outline across chapters and research questions

Following this introductory chapter, Chapter 2 reviews a broad set of examples of health data repositories, including how these repositories configure different styles of data contribution for scientific investigations. Chapter 2 furthermore presents a comprehensive narrative review of factors for willingness to share data that have significant relevance to the acceptance of health data technologies. This chapter thus provides an in-depth look into the literature on digital health research and the importance of trust, privacy and reciprocity to this context. This chapter is based on the Papers 2.2 and 2.3.

Chapter 3 contributes a scoping review yielding a coherent up-to-date mapping of ethical thinking and doing in HCI. This review provides an overview of ethical concerns related to technology development and introduces methods, theories, and practical recommendations for putting ethics into action. Review findings constitute the foundation for the subsequent chapters, as they illustrate how to apply and explore matters of ethics in user-centred design. This chapter is a summary of the Paper 2.1.

Chapters 4 and 5 follow a mixed-methods approach to eliciting data contributors' attitudes towards data sharing with health data repositories and discovering which factors govern their decisions to participate. First, Chapter 4, based on the Paper 2.2, describes a qualitative investigation (interview study) illuminating what matters to 12 young adults when they are presented with a request for sharing different types of data with health research repositories. Then Chapter 5, based on the Paper 2.3, extends and complements these findings by engaging a much larger sample (1600 participants) through an

online survey generating a quantitative understanding of principal sources of motivation, reasons for concern and data sharing preferences. Chapter 5 also contributes a comparison between two national contexts (Brazil and Denmark) and the impact of demographic characteristics on contributors' attitudes.

Chapter 6 then moves to the perspectives of designers and developers (technology creators) working on the conception of new digital health technologies. This chapter enabled an understanding of what this stakeholder group considers critical factors in data contributors' acceptance of data sharing through a focus group study. The enablers and barriers identified in this study complement the insights gathered from data contributors' perspectives, as the focus group points to particular areas where technology creators require support to conceive systems that respect data contributors' values. This chapter summarises the Paper 2.4.

Chapter 7 turns to more concrete design explorations, building again upon the findings of previous chapters. This chapter first engages with Value-Sensitive Design (VSD) to guide the application of ethical insights in the form of a prototype for a health research mobile app. This chapter then contributes several design reflections regarding yet another type of health data collection interface (psychotherapy chatbots), engaging with an AI-ethics framework to illustrate how the issues involved in sensitive data disclosures during digital therapy might be appraised. This chapter presents the insights from the Papers 2.5 and 2.6.

Chapter 8 returns to engaging technology creators through a pilot study conducted with university students to examine their learning about ethical User Experience (UX) design. This chapter, based on the Paper 2.7, provides insight into (future) technology creators' experiences when engaging with ethical principles for designing a smartwatch app to collect and share heart monitoring data with clinicians and researchers. This chapter thus contributes a report on the students' impressions after employing ethical frameworks, which expands the insights about ethical design practice acquired through our own first-person experiences described in Chapter 7.

Finally, Chapter 9 discusses the overall implications of the work of this thesis and presents a vision for ethical acceptance based on the Paper 2.8. In particular, this chapter presents a compilation of design recommendations for health data interfaces based on the findings of the user studies. It also features deliberations concerning how ethics can be applied and integrated into user-centred design methodologies, considering our learnings and reflections on the limitations of individualised ethical action we observed throughout this work. Chapter 10 then concludes this first part of the thesis with some final remarks.

1.6 Contributions

This PhD thesis provides the following contributions. First, it delivers an in-depth understanding of the health data repository context, including a review of crucial technology acceptance factors. Second, it provides a coherent mapping of pathways for ethical thinking and doing drawn from the HCI literature. Third, it presents various insights concerning the practice of health data sharing as directly expressed by data contributors and technology creators. Finally, this thesis illustrates how we might teach and apply ethically-centred approaches to user interface design. This combined evidence makes possible a more informed and critical discussion of alternative futures for health data technologies. Through these contributions, this PhD demonstrates how ethical and contributor centred perspectives can be integrated to support the design of more respectful health data flows.

2 Mapping the Literature | Health Data Repositories

As digital technologies enable ever-expanding access to information regarding human health, behaviour and well-being, many have looked towards developing data repositories to support the assimilation and re-use of datasets, especially for research purposes. Each type of repository has its style of enabling data transference, thus configuring different kinds of relationships between its users. These systems may offer significant advantages, yet their acceptance by data contributors depends on several factors.

In order to characterise this technological context - the main focus of the user studies described later in this thesis - this chapter presents an overview of types of data repositories primarily built to support health research. The chapter also summarises the challenges to public acceptance of these systems. This content draws from two cross-cutting papers: *“Futures for Health Research Data Platforms From the Participants’ Perspectives”* (Vilaza et al. 2020) and *“Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey”* (Vilaza et al. 2021a), available in Part II as the Papers 2.2 and 2.3.

2.1 Introduction

Data about human health is fundamental for the progress of health sciences, as medicine strongly relies on the observation of connections between habits, symptoms and the effect of interventions (Bowling et al. 2005; Pagoto et al. 2013). Data sources for health research may come in different forms, from blood tests to medical images, but very often, researchers and clinicians gather data through in-person interviews and paper-based self-reports (Stone et al. 2007). In this regard, digital technologies are an appealing novelty, allowing the collection, storage and management of many and diverse kinds of information more efficiently than ever before (Hripcsak et al. 2015). Mobile apps employed to enable Ecological Momentary Assessments (EMA), for example, can sample patients’ self-reported status in real-time (Van Berkel et al. 2017), with wearable sensing systems additionally extracting indicators of health from mobility to physiological signals (Trifan et al. 2019). Such digital data sources are now used in combination with traditional observations to support future improvements in care (Dinh-Le et al. 2019).

Thanks to these recent achievements of health digitisation, shared-access data repositories have increasingly emerged as means to facilitate the use of longitudinal data from patients and healthy individuals alike (Dey et al. 2017; Pencina et al. 2016). These platforms allow multiple clinicians, researchers and projects to make use of the same data for a wide variety of purposes (Veličković et al. 2017; McPadden et al. 2019). In particular, shared-access platforms offer advantages of reduced recruitment and data collection costs while still providing the information desired by clinicians, researchers and public workers (Song et al. 2010; Hamer et al. 2020). Configurations and designs of health data repositories are diverse, each posing challenges and opportunities. In this next section, we provide an overview of the types of data repositories currently implemented, in which data is used primarily (but not exclusively) for research purposes.

2.2 Existing Platforms and Shared-Data Styles

A significant percentage of research has been conducted about the diversity of data collection technologies (Van Berkel et al. 2017; Kumar et al. 2020) and possible personal and



Figure 2.1: Infographic explaining health data research repositories

social uses of health data (Wood et al. 2015; O’Doherty et al. 2016; Frost et al. 2008). However, a gap lies in research focused on the repositories that enable data to be re-shared between multiple users, particularly health researchers. The following literature review aims to address this gap.

In order to develop a broad understanding of this technology ecosystem, we gathered and reviewed a set of existing health data platforms. The complete details of how we searched for examples of platforms can be found in the Paper 2.2. In particular, to shed light on the many possible styles of data contribution, we categorised the platforms we found according to the level of agency repository owners provide to data contributors. We referred to as ‘top-down initiatives’ the projects focused on attending to the demands of governments, institutions and researchers for access to large-scale, population-level data. In turn, we described as ‘participant-driven initiatives’ those attempts to bring participants, patients, and volunteers closer to data sharing practices by empowering these stakeholders to adopt a more active role in their participation. Next, we present specific examples of each of these broad categories.

2.2.1 Top-down Initiatives

Notable initiatives include national programmes that aim to gather representative samples of a country’s population. An influential example is the UK Biobank, a repository that back in 2010 already had records of 500,000 patients (Sudlow et al. 2015). Denmark is also widely known for its well-established national registry, which digitally stores public health data from the entire Danish population (Schmidt et al. 2014). Other countries have similar national databases in development, including India (Sahay et al. 2020) and China (Li et al. 2019a). More recently, the All of Us Research Programme in the United States has been described as a pioneer for its aims to store not only clinical and hospital records but also patient-generated data from mobile devices and wearables (Sankar et al. 2017).

Other examples include repositories that re-purpose previously collected data. For instance, the mobile personal health tracking app ‘Achievement’ invites its users to voluntarily share daily behaviour logs with researchers associated with the privately-owned platform Evidation (Clay 2020). This approach comprising user ‘opt-in’ can also be found in the commercial DNA testing service 23andMe (King 2019) and the social network PatientsLikeMe (Wicks et al. 2010). Similarly, non-commercial repositories enable the re-use of data from previously conducted clinical trials, such as the non-profit Vivli (Li et al. 2019b) and the European Union’s COVID-19 Data Portal (Alamo et al. 2020). These platforms function as data brokers, connecting researchers with the de-identified raw data samples from past studies (Bierer et al. 2016).

In general, these ‘top-down initiatives’ are platforms for which data access is typically granted to institutions selected by repository owners without the participation of data contributors. In some instances, additional data consumers and stakeholders may later request access to data. In both situations, permissions are usually approved internally by those managing the repository, which means that those who contributed their data have little involvement in the process. Such practices prioritise the needs of the higher-level institutions behind the platforms, which raises ethical concerns regarding how much autonomy is given to data contributors to express their concerns and choices over data use (Kostkova et al. 2016). Another ethical issue is that commercial and national databases might have the potential to produce unfair applications, should, for instance, governments or companies hide an agenda that goes beyond employing data for healthcare purposes (Zuboff 2019).

2.2.2 Contributor-driven Initiatives

In contrast with these so-called top-down initiatives, other data repositories are configured and hosted by the individuals who collect data for their own personal use and choose to make their data available to others. Examples of these ‘participant-driven’ platforms include the community-based Open Humans project (Greshake Tzovaras et al. 2019), in the case of which users contribute to open-access projects analysing Fitbit, Twitter and Apple Health data. The idea of the Open-Humans project is to function as a community through which members propose ideas for data explorations and share tools and tips for data analysis.

Similarly, although less community-focused, in the Project Baseline (Maxmen 2017), the initiative to contribute to a data repository begins with the volunteers who independently access the platform select which studies to join. Project Baseline also attempts to get contributors more involved in data collection and sharing by offering data-driven insights and information about the research. A small number of other crowd-sourcing projects present similar features, such as participatory disease surveillance surveys in which individuals provide data to support epidemiological controls (Neto et al. 2020). The surge of COVID-19, for example, has triggered many more of such collaborative ‘citizen science’ projects in the last years as an attempt to boost access to population data (Garg et al. 2020).

One particularly prominent ethical challenge with such participant-driven platforms is that they often display low recruitment rates, thus compromising cohort diversity. The Open-Humans project, for instance, had 6,800 users in 2019, a stark contrast to the more than 500,000 patients of the UK Biobank (Estrada-Galiñanes et al. 2020). In addition, crowd-sourcing projects may have fewer mechanisms for privacy control, as compared to the tight filters applied by national programmes that pre-screen who gets to access data (Anhalt-Depies et al. 2019). Ideally, health data repositories should be able to successfully balance the broader reach of national programmes with the active participation of data contributors. The critical factors involved in a broader adoption of these systems is often studied through the lens of ‘public acceptance’ or ‘technology acceptance’, which is the topic of the second literature review we conducted.

2.3 Factors Influencing Willingness to Share Data

The above overview of platforms revealed the organisational and political characteristics of a set of health data platforms. In order to shed light on the human-centred and experiential factors, we reviewed previous related work focused on enablers and barriers for willingness to share data. It is crucial to understand prior research around data sharing to develop more ethical practices that respect the reasons why data contributors

may feel uncomfortable disclosing information and prioritise their expectations for fair data exchanges (Nadal et al. 2020; Barkhuus 2012).

We gathered a comprehensive set of previous works presenting examination and discussion of what matters most to those collecting, sharing and re-sharing personal health and behavioural indicators (See Table 2.1¹). These works include studies extending beyond the context of health data repositories to broadly illuminate data contributors' key concerns, expectations, and values. Details on the review and analysis process are available in the Paper 2.2.

Factors	Effects	References
Motivation	Motivation decreases if data collection is burdensome	Cohen et al. 2015; King et al. 2006
	Motivation decreases if the purpose is perceived as not useful	Kraft et al. 2018; Tan et al. 2018; Ziefle et al. 2016; Barkhuus et al. 2003
Privacy	Some types of data carry social stigma	Kelley et al. 2017; Rooksby et al. 2019
	Some types of data are perceived as sensitive	Rudnicka et al. 2019; Bhatia et al. 2018; Garcia-Ceja et al. 2018
Trust	Trust can be damaged by previous experiences	Anderson et al. 2012; Corbett et al. 2018; Adjekum et al. 2018
	Trust can be harmed by data misuse and lack of transparency	Middleton et al. 2019; Murmann et al. 2017
Consent	Consent forms are lengthy and complex	Luger et al. 2013; Ostherr et al. 2017
	Consent forms do not offer flexible options	Hardy et al. 2018; Kaye et al. 2015; Nurgalieva et al. 2019

Table 2.1: Factors affecting willingness to share data

2.3.1 Motivation

The review revealed motivation to be essential for willingness to share data. One prominent reason why motivation is important is that it is challenging to keep individuals consistent with data collection requests in the long term if they do not have solid reasons for doing so (Rotman et al. 2012; Choe et al. 2014; Cohen et al. 2015). Understanding what motivates data contributors can lead to benefits more aligned to what is most valuable for them.

Previous research indicates that motivation can stem from *altruism* and a desire to contribute to a cause. Such charitable reasons include supporting science (Wiggins et al. 2019) and helping future patients (Gatny et al. 2012). The engagement of participants in decisions about research projects is also deemed as a motivating incentive (Shippee et al. 2015; Anderson et al. 2012). On the other hand, a different source of motivation discussed in prior studies refers to the practice of offering monetary incentives in the form of gift vouchers or cash (Lacetera et al. 2013; Benndorf et al. 2018). These types of incentives contrast in that some focus more on societal benefits whilst others target personal gains.

¹Based on Table 1 by Vilaza et al. 2020

Previous works have further discussed the role of other types of personal benefits in increasing motivation. For instance, getting access to DNA test results is often the primary motivation for individuals to share data with services such as 23AndMe King 2019, in a similar fashion that well-being maintenance is the driver of most individual self-tracking of behaviour (Fleck et al. 2010; Chung et al. 2017; Kersten-van Dijk et al. 2016). Despite benefits arising from such sources, others have warned about potential harms of such ‘self-focused’ approaches such as performance anxiety (West et al. 2016; Epstein et al. 2016; Chua et al. 2016).

2.3.2 Privacy

Privacy is known as a significant barrier to personal data sharing, especially when it comes to behavioural and health-related data (Kostkova et al. 2016; Nurgalieva et al. 2019). Prior research has highlighted as prominent fears among data contributors that the leakage of sensitive diagnoses can lead to social discrimination, given that some types of personal data are challenging to be anonymised entirely, such as DNA samples (Middleton 2018). Government surveillance and undisclosed commercial interests are other significant concerns that may increase unwillingness to share data (Lemke et al. 2010; Middleton 2018). When data is used beyond the limits individuals have agreed upon, ‘contextual integrity’ is said to be broken, as information gathering and dissemination become untied to the governing norms of specific contexts (Nissenbaum 2011).

For these reasons, individual participants have often expressed a desire to impose limitations and boundaries to protect their autonomy (Raento et al. 2008; Rooksby et al. 2019) and social reputation (Kelley et al. 2017; Palen et al. 2003; Leary et al. 1990; Petelka et al. 2020). The process of data collection can also trigger feelings of paranoia and loss of freedom, which are direct harms to well-being (Vaizman et al. 2018; Saunders et al. 2017; Caine et al. 2012). The idea of a ‘privacy paradox’, however, states that there can be a mismatch between expressed willingness to share data and actual behaviours (Norberg et al. 2007). Regardless of the attitude of data contributors, privacy protection in respect of others’ physical, emotional, and social integrity is known as a fundamental care commitment (Bagnasco et al. 2020).

Prior research shows that individuals may be willing to disclose certain information if they believe it can be useful to society and themselves (Ludford et al. 2007; Sannon et al. 2019; King 2019; Barkhuus et al. 2003). Agreeing to share personal data may depend, however, on the perceived sensitivity of the data request (Rudnicka et al. 2019). For instance, audio recordings (Di Matteo et al. 2018), browser history (Bhatia et al. 2018), social media activity (Garcia-Ceja et al. 2018), camera pictures (Rooksby et al. 2019), financial status (Weitzman et al. 2012), home address (Ludford et al. 2007), and sexually transmitted diseases (Weitzman et al. 2012) are among the information points perceived as least comfortable to disclose by data contributors.

2.3.3 Trust

The analysis shows that trust is fundamental for the acceptance of data sharing. When it comes to data repositories, trust in the institutions, organisations and companies managing that data is a significant factor for data contributors’ willingness to share (Anderson et al. 2012; Pratap et al. 2019; Leon et al. 2013; Joinson et al. 2010). Previous research has found that academic institutions are trusted more often than insurance companies, governments and companies (Domaradzki et al. 2019). The freedom to choose what information is shared with whom can increase trust among individuals and is considered more ethical conduct than denying this right (Abdelhamid 2018; Petersen 2018; Kostkova et al. 2016).

The literature lists other ethically motivated enablers of trust which are particularly relevant to digital systems: customisable features, engaging interfaces and honest communication (Adjekum et al. 2018). In general, transparency has been frequently associated with trust, as previous works extensively promote the role that transparent information can play in promoting data sharing acceptance and ethics (Domaradzki et al. 2019; Murmann et al. 2017). Trust, however, is not a static construct. The development and maintenance of trust is a long term process, and it is not uncommon that public perceptions of trustworthiness change with time (Corbett et al. 2018). Evidence of data misuse can, for instance, damage trusting inclinations and decrease willingness to share data (Middleton et al. 2019).

2.3.4 Consent

Before data collection and sharing, it is the usual and ethical practice to obtain voluntary consent from data contributors. The European General Data Protection Regulation (GDPR) has more strongly reinforced this requirement by demanding that any digital technology that collects personal data must obtain user consent (Voigt et al. 2017). At a minimum, consent forms should inform users about which information is being collected, how it will be shared and why the data is needed (Harari et al. 2016). However, previous research has emphatically argued that there is an ethical need to improve consent practices beyond these measures (Brehaut et al. 2012; Hutton et al. 2018). Consent forms are criticised for being overly lengthy and complex (Luger et al. 2013; Ostherr et al. 2017), whilst users are often not provided with flexible options (Hardy et al. 2018; Kaye et al. 2015; Nurgalieva et al. 2019).

2.4 In Summary

This chapter contributes an overview of multiple and diverse examples of health data repositories, accompanied by a review of factors identified as critical to the acceptance and willingness to share personal data. Although many have studied and proposed maximising technology adoption, if we solely focus on public acceptance and the possibility that people may share data despite disagreeing with terms and conditions, we might overlook critical ethical issues. This review already pinpoints a few ethical challenges caused by large-scale repositories' restrictive contribution style, including, for instance, the negligence of data contributors' autonomy. From a user-centred perspective, the experience of contributing to a health data repository should be comfortable and respectful. For this reason, to develop more acceptable and ethical health data research platforms, we need to understand how others have 'actioned' ethics in practice. In order to step ever closer to the aim of supporting the design of more ethically-informed health data flows, the next chapter presents a scoping review of ethics across HCI.

3 Mapping the Literature | Ethics and HCI

As seen across the previous chapters, to realise publicly acceptable systems that respect contributors' autonomy, well-being, and privacy, it is imperative to examine the conception of health data technologies through an ethical lens. For this reason, this chapter presents a scoping review conducted to develop a synthesis of just how the literature has examined and proposed the application of ethical reflection to research and design processes. As HCI is the academic discipline where human-centred design reflections are most often discussed, we focused this review on papers published within this key domain. Developing such a broad overview of ethical thinking and doing across this knowledge field consists of an ideal starting point for selecting and applying appropriate methodologies and theories to conceive more ethical systems. The content of this chapter is derived from the full paper titled "*A Scoping Review of Ethics Across SIGCHI*", currently under review and available as the Paper 2.1 in Part II.

3.1 Introduction

Over the years, ethics has consistently proved a fundamental focus of human-centred design (Molich et al. 2001). Historically, user research ethics has been primarily studied in terms of respect for the persons involved in research processes (Benford et al. 2015). Today, ethics remains one of the grand technology design challenges, as illustrated by contemporary debates around algorithmic bias, data misuse, and deceptive user interfaces (Durrant et al. 2018; Davis 2020).

However, engaging in ethical decision-making in practice remains a challenge for technology creators (Barry et al. 2020). Ethics is in itself a complex philosophical subject with a varied history not always known in detail by computing professionals (Stahl et al. 2016). In broad terms, ethics seeks to address questions of human conduct by utilising conceptions of right and wrong, desirable and detrimental, which are already very difficult reflections in any context (Baggini 2018).

Formal approaches to ethics, such as the Association for Computing Machinery (ACM) Code of Ethics and Professional Conduct (Gotterbarn et al. 2018) and Institutional Review Board (IRB) procedures, aim at providing official guidance for ethical action. However, these are criticised for being overly bureaucratic, detached from the needs of research in the field, and insufficient for accounting for different oversight requirements across jurisdictions (Frauenberger et al. 2017; Benford et al. 2015). The reality is that the circumstances of each project can vary, leading perhaps to situations not predicted by top-down commandments (Nathan et al. 2016; McNamara et al. 2018).

Therefore, the continuous and proactive integration of critical perspectives during design processes is a necessary step to enabling ethical doing in practice (Shilton et al. 2017; Frauenberger et al. 2017). Technology creators, researchers and UX design professionals may find support for this task by consulting the academic literature. Scientific publications serve as formal sources of knowledge as to how to take an abstract concept such as ethics and integrate it into the cycle of the design, development and adoption of digital technologies (Tolmeijer et al. 2020). Previous systematic reviews, for instance, have discussed ethics in relation to a wide range of technologies, such as autonomous systems (Tolmeijer et al. 2020; Vandemeulebroucke et al. 2018; Zoshak et al. 2021), assistive devices (Ienca et al. 2018; Burwell et al. 2017), and technologies for children (Van Mechelen et al. 2020).

Despite consisting of important sources of knowledge, findings from these previous systematic reviews are limited to their target application domain. A systematic review of computing ethics across Computer Science journals indexed by Scopus, as conducted by Stahl et al. 2016 comes closest to an aggregation of academic resources from multiple domains that could support researchers, designers and professionals in navigating ethical decision-making in their work. However, the authors of this previous review did not capture publications from important HCI conferences, where the majority of human-centred ethical reflections are likely published.

Given the relevance of ethical reflections spanning the field of HCI to human-centred design (Stephanidis et al. 2019), and the possibility that there might exist variable standards and expectations for ethical thinking across academic communities, there is therefore a need to conduct further reviews to complement current literature accounts. With this purpose in mind, a scoping review of ethics was conducted, focusing on how ethics is understood, employed and discussed within the HCI literature. The main goal of this review was to serve as a starting point for the process of designing new digital technologies and to provide insight into the ethical creation of health data ecosystems alike. The following research questions motivated and guided this literature review:

1. Which ethical considerations, technologies and user groups have been the subjects of previous papers?
2. Which approaches, methods and theories have been employed to explore ethical considerations?
3. Which practical recommendations for putting ethics into action have been reported and discussed?

3.2 Method

Seeking to answer the research questions above, we conducted a *scoping review*, which is a systematic literature review procedure used to produce a description of the scope of previous research about a topic (Munn et al. 2018). We followed the scoping review methodology established by Arksey and O'Malley (Arksey et al. 2005) and, in order to maintain rigour, we followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR by Tricco et al. 2018) to structure our process. The complete description of the procedure conducted to select eligibility criteria, information sources, search queries and data items for analysis can be found in detail in the Paper 2.1.

This review targeted papers published at conferences sponsored by the ACM Special Interest Group on Computer-Human Interaction (SIGCHI). The motivation for focusing the search to SIGCHI venues came from the need to produce a diverse set of papers on where human and user-centred work is published within computer science while keeping the process manageable and transparently delimited instead of attempting to capture all HCI papers about ethics. Therefore, we searched the ACM Digital Library for full papers published from January 1st 2010 to December 31st 2020, containing the keyword 'ethic*' within the title, abstract or authors' keywords list in order to identify papers with ethics as their core focus. Data was charted in a spread-sheet, and tables, visualisations and text-based narratives were used to describe the results.

3.3 Results

This review comprises a broad and diverse compilation of sources of knowledge and inspiration serving as a foundation for the ethical design of digital technologies broadly,

and in the context of the work of this thesis, health data ecosystems in particular. The initial search produced a corpus of 461 papers. Preliminary screening then excluded papers not peer-reviewed, full-length archival publications (314 manuscripts). The remaining 147 papers were subsequently assessed according to the inclusion criteria previously defined, resulting in the removal of 18 papers. This process then led to a final sample of 129 papers comprising the source of evidence for this review (See Figure 3.1¹). The following section summarises the main findings of the review, and those more closely related to the thesis are more strongly emphasised. The complete description of results can be found on Paper 2.1.

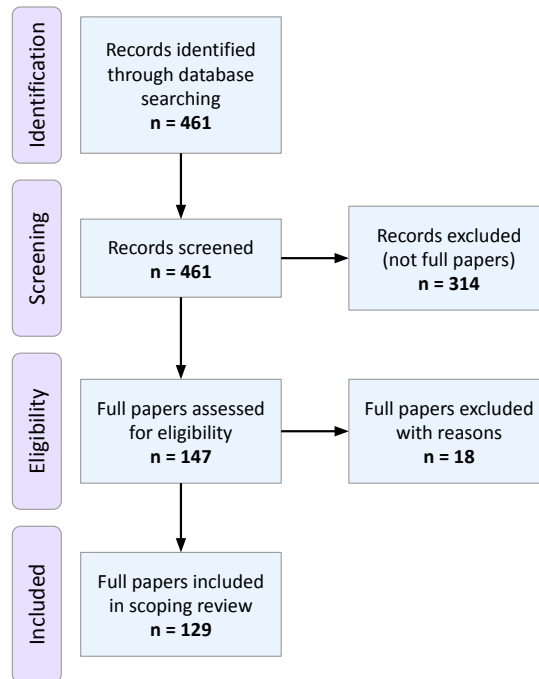


Figure 3.1: PRISMA diagram displaying the process of selecting sources of evidence

3.3.1 Characteristics of Sources of Evidence

This sample consisted of 129 full-length papers published at SIGCHI-sponsored venues. The vast majority were published in the last three years: 2018 (17%, n=22), 2019 (20.9%, n=27) and 2020 (28.6%, n=37). Overall, most of the papers (59.6%, n=77) were published at Conference on Human Factors in Computing Systems (CHI). Figure 3.2² shows the distribution of papers across publication venues and years in detail.

3.3.2 Objects of Ethical Consideration

Several types of technology proved the targets of ethical consideration (See Paper 2.1 for the complete list). Of particular interest to the work of this thesis are those papers (highlighted in bold for improving the reading experience) focused on **personal health** (Wärnestål et al. 2014; Shapiro et al. 2020; Rooksby et al. 2019; Barry et al. 2017; Purpura et al. 2011; Dahl et al. 2012; Sanches et al. 2019), web and mobile technologies used to collect **data for research** (McMillan et al. 2013; Morrison et al. 2012; Bowser et al. 2017; Snyder 2020; Pinder et al. 2017), **biosensors** (Howell et al. 2018; Fox et al. 2019; Curmi et al. 2014) and **DNA repositories** (Baig et al. 2020). The presence of papers directly related to the research topic of this thesis serves to highlight digital health data

¹Figure extracted from Paper 2.1

²Figure extracted from Paper 2.1

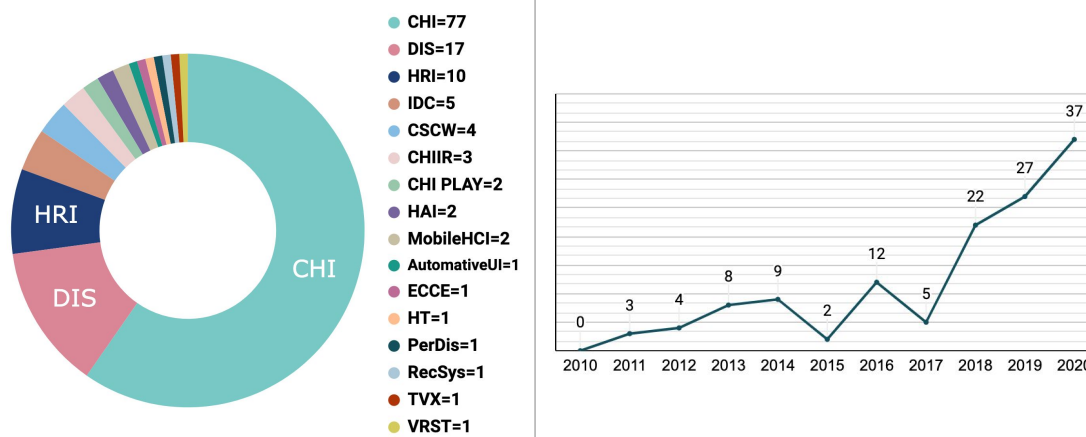


Figure 3.2: Sample distribution according to publication venue (left) and year (right)

technologies as a primary source of broadly relevant ethical concern. Several papers also emphasised the importance of examining the relationship between ethics and technology creators - another key thesis subject. The sample included several papers about **HCI researchers** (Munteanu et al. 2015; Moncur 2013; Hirsch 2020), **industry professionals** (Gray et al. 2020; Chivukula et al. 2020), and **students** learning about technology design (DiPaola et al. 2020; Bilstrup et al. 2020; Foley et al. 2020; Shapiro et al. 2020; Sabie et al. 2019).

The review of these papers underlines a set of ethical concerns that technology creators need to consider in their design commitments to respect end-users genuinely. Those papers concerning digital health systems highlighted in particular **harms to well-being** and adverse psychological effects (Sanches et al. 2019; Hodge et al. 2020; Foley et al. 2020; Barry et al. 2017; Toussaint et al. 2020). Unsurprisingly, concerns regarding **privacy invasion** and security breaches were most often discussed in relation to passive sensing (McMillan et al. 2013; Morrison et al. 2012; Curmi et al. 2014; Bowser et al. 2017; Toussaint et al. 2020; Pierce et al. 2020; Seymour et al. 2020; Fritsch et al. 2018; Sailaja et al. 2018; Knowles et al. 2019), shared-access data repositories (Sun et al. 2019; Baig et al. 2020; Lin et al. 2020) and social media networks (Andalibi et al. 2020; Lyckvi et al. 2018). Concerns around **social injustice** most frequently referred to flawed AI decisions (Troiano et al. 2020; Madaio et al. 2020; Strengers et al. 2020; Veale et al. 2018; Wächter et al. 2018; Wu et al. 2019; Ekstrand et al. 2018), and were most often raised by studies examining the issue of the digital divide (Rodil et al. 2020; Sultana et al. 2018; Harvey et al. 2014; Irani et al. 2016). Stigma and social discrimination were very often discussed by those papers focused on individuals with mental illnesses (Snyder 2020; Rooksby et al. 2019; Sas et al. 2020) and sexual minorities Strengers et al. 2020).

3.3.3 Approaches to Ethics in Design Research

The findings of this review furthermore highlight how ethical considerations have been approached, explored and engaged with by the HCI literature. Most papers report empirical studies employed to consult stakeholders directly, although several design methods were also encountered which propose the possibility of being conducted without stakeholders' presence. In addition to empirical approaches, many other papers employ and engage with a wide variety of philosophical and theoretical frameworks. With these findings, we compiled the following vast portfolio of options for technology creators to apply in their

work.

Empirical Approaches

Many user studies across this sample employed well-known user research methods, such as interviews (Seymour et al. 2020), questionnaires (Skirpan et al. 2018c), focus groups (Lazar et al. 2016), and co-design workshops (Foley et al. 2020), conducted in the lab and the field (the complete list of methods can be found on Paper 2.1). Participants in these studies included previous or current end-users (Seymour et al. 2020), potential end-users (Scheutz et al. 2016, close contacts of end-users (Wärnestål et al. 2014), and technology creators and researchers (Moncur 2013). The majority of papers reported participatory workshops (21.7%, n=28), followed closely by field and interview studies which are also featured frequently (19.3%, n=25).

Speculative design was frequently employed to surface, extrapolate through, and raise awareness of how technologies can imbue values, ideologies and behavioural norms. Fictional scenarios and provocative prototypes are several of the most-common formats through which speculations are expressed (Toussaint et al. 2020; Pierce et al. 2020; Encinas et al. 2018; Snyder 2020; Knowles et al. 2019; Troiano et al. 2020). A small number of field studies go a step further, proposing ‘activist systems’ to realise societal changes in the real world (for example, systems targeting fairer conditions for Amazon’s Mechanical Turk workers by Irani et al. 2013; Barbosa et al. 2019; Kasunic et al. 2019).

Distinct from approaches entailing the direct involvement of stakeholders, other papers promote the use of ‘expert-only’ methods: empathy-building tools, personas, stakeholder matrices and card-based materials to facilitate self-reflection and collaboration in teams (Sas et al. 2020; Ballard et al. 2019; Madaio et al. 2020). Critical appraisals of user interface features and scenarios have also been reported (Purpura et al. 2011; Fox et al. 2019; Lacey et al. 2019), as well as content analyses of online forum discussions (Ma et al. 2018) and manifestos (Fritsch et al. 2018). Several papers take stock of the literature and past projects to discuss ethical issues without involving stakeholders through argumentative essays (Brown et al. 2016; Mirnig et al. 2019), case studies (Irani et al. 2016) and literature reviews of specific subject areas (for example, a review of affective computing in HCI by Sanches et al. 2019).

Theoretical Approaches

Several papers discussed perspectives drawn from the domains of moral and social philosophy, in addition to political and design theory — composing approximately one-third of the sample. VSD was the framework most frequently found (10%, n=13). VSD theory proposes designers to accounts for ‘human values’ in a systematic manner (Dahl et al. 2012; DiPaola et al. 2020) by conceptualising as an agreed-upon vocabulary to guide and frame ethical reflection (for example, by considering how design decisions can affect the value of physical safety). Another perspective well-represented in the sample is Critical Theory (6.9%, n=9), an approach that challenges assumptions about power relations in society, often taking the form of Critical Design (Bardzell et al. 2013). Critical stances often question the role product design plays in social and cultural spheres and strive to foster debate in relation to an often-felt prioritised commercial focus (Irani et al. 2016).

Although less frequently, Care Ethics was also represented in the sample (for example, Sabie et al. 2019), which is a philosophical lens that shifts the moral focus towards embodied, situated and emergent relationships of mutual care (La Bellacasa 2017). When applied to design, Care Ethics foregrounds mutual commitments as fundamental for decision-making, in contrast with outlooks centred on norms and duties. Utilitarian ethics was encountered equally infrequently (for example, Niforatos et al. 2020). Utilitarianism holds that an optimal ethical choice can be achieved by ‘calculating’ the greatest good for the

greatest number of people (Boutilier et al. 2015). Given the difficulty of weighing positive and negative outcomes, utilitarianism risks turning decisions into ‘moral arithmetic’ (Mirnig et al. 2019).

Other theoretical orientations appear even more rarely within this sample. A small number of papers engage with Social Justice theory (Dombrowski et al. 2016), describing Social Justice-Oriented Interaction Design as a framework to help designers commit to plurality, advocacy, and political considerations. Similarly, Queer and Feminist theories appear only twice in regard to issues of inequality in design (Strengers et al. 2020; Nguyen et al. 2020). Virtue Ethics, which emphasises the cultivation of ethical wisdom through personal experience, appears in a single paper calling for greater scrutiny of the subjective assumptions underlying design choices (Barry et al. 2017). Biopolitics was likewise employed in a single instance as an analytical lens applied to question the authority of biosensing systems (Howell et al. 2018).

Similarly, Foucault’s theory of ‘care of the self’ was used to emphasise technology’s epistemic dangers as a source of power (Kou et al. 2019). Thanato-sensitive design was introduced as an approach to integrating the inevitability of mortality such that design can be more sensitive to this part of life (Massimi et al. 2011). Likewise, Somatic Ethics was explored in a single paper, positioning ethics as an experience to be lived through the body, not only the mind (Eriksson et al. 2020). Finally, amidst a predominant emphasis on Western ethical frameworks across the sample, Confucian Ethics was the sole non-Western perspective encountered, employed by a single paper exploring individual roles as sources of collective ethical obligations (Williams et al. 2020). Duty-based ethical frameworks were not explicitly applied by any single paper within the sample, although studies describing normative rules could be interpreted as examples of this deontological perspective, such as categorised guidelines (McMillan et al. 2013) and checklists (Knowles et al. 2019).

3.3.4 Recommendations for Putting Ethics into Action

Finally, the review also presented several practical recommendations for tackling ethical concerns as they arise. Approaches spanned broad research participation, design choices, and responsibility roles. Therefore, this sample of the HCI literature provides examples of practical wisdom and knowledge that can be further applied to our goal of eliciting and acting upon ethical requirements in the context of health data ecosystems.

Ethics as Participation in User Research

The ethical involvement of people in design research is a major topic discussed across the sample. The following suggestions are particularly relevant for health data ecosystems design because they refer to protecting the best interests of individuals contributing with data for research. First, the literature shows a turn towards promoting an active engagement of participants concerning the configuration of projects (Vines et al. 2013; Bell et al. 2019). This recommendation includes that researchers make sure participants benefit from being part of a study, for example, by acknowledging participants as co-creators (McNally et al. 2016; Hodge et al. 2020), negotiating compensation options (Howard et al. 2019) and gifting working prototypes (Hodge et al. 2020). Some papers also propose ways for researchers to become more involved with the communities they study, for example, by volunteering with organisations (Foley et al. 2020).

Many other suggestions identified are noteworthy in that they would not always be considered by standard research procedures, such as writing consent forms in an easy to understand language (Sitbon et al. 2020), granting participants enough time to get acquainted with the technology before a study (Waycott et al. 2016), and allowing data access to be

revoked anytime (Peacock et al. 2018; Benford et al. 2012). In the case of the re-use of publicly available data, several papers advise reducing the risk of re-identification (for example, Abbott et al. 2019) and informing participants about the new usage of data (for example, Bowser et al. 2017). If participating in and conducting research becomes an emotionally charged experience, several papers proposed that researchers should be trained to minimise and recognise sources of distress during their research (for example, Hirsch 2020). In addition, the presence of domain experts, counselling, group discussions, and a healthy work-life balance are other noteworthy suggestions (Moncur 2013; Massimi et al. 2011).

Ethics as Design Choice

According to several of the reviewed papers, design choices can be the ‘vehicle’ through which ethical concerns are addressed (See Paper 2.1 for a broad and detailed overview of the forms these design choices can take). We focus here, for the sake of brevity, on those most clearly related to the practice of health data ecosystem design. This analysis of the HCI literature pointed towards transparent communication of system intentions and technical limitations as supporting of user autonomy and the capacity of making informed choices (Shi et al. 2020; Baig et al. 2020). Privacy concerns, it is likewise suggested, may be managed should user interfaces provide mechanisms for data control (Rooksby et al. 2019; Sun et al. 2019). Interactions that trigger obsession, performance anxiety, and the over-optimisation of behaviour should be avoided in order to preserve user well-being, others argue (Howell et al. 2018; Andalibi et al. 2020).

Other papers furthermore comment that designers can attend to issues of social justice by prioritising the engagement of those misunderstood, misrepresented or expressing cultural difference, who are often subject to marginalisation (Sultana et al. 2018). Concerning this goal, the deployment of ‘activist systems’ is recommended as a fruitful way to start tackling social challenges (Barbosa et al. 2019). On the other hand, other papers argue that fairer practices of user interface design might not be sufficient to tackle social justice challenges, as the complex relationships between technologies and their surrounding socio-economic and political contexts can prove strong opposing forces (Veale et al. 2018; Madaio et al. 2020). These assorted challenges, despite initial solutions, serve to highlight just how complex the design of more respectful digital health systems can be should they strive to address such ethical challenges.

Ethics as Taking Responsibility

Another recurrent theme we found in the papers reviewed is the apparent expectation that professionals should adopt measures against unethical practices as part of their work (for example, Correll 2019). Papers also point to the need for researchers in academia to be responsible for ethical conduct beyond that which is anticipated by institutional ethics approval (for example, Munteanu et al. 2015). On the other hand, it is also discussed that individuals alone might have a limited capacity to act against business goals and roles within hierarchies (Chivukula et al. 2020; Gray et al. 2019).

Education is also encouraged as a path to supporting ethical awareness among individuals (Gray et al. 2018; Chivukula et al. 2019). One paper describing an open-ended project with local organisations shows how an ‘ethics of care’ was configured between students and users (Sabie et al. 2019). Similarly, another paper demonstrates that collaborative and self-experimentation classroom activities can initiate reflection about harmful data collection and visualisation practices (Shapiro et al. 2020). The use of cards to ignite group debate in regard to moral dilemmas and the creation of prototypes is yet another educational technique found within the sample (Bilstrup et al. 2020). The importance of enhancing end-users’ critical gaze in relation to issues of ethics is also discussed (Di

Geronimo et al. 2020). Examples of how to achieve this include an immersive theatre experience (Skirpan et al. 2018b), a bio-metric mirror as provocative demo (Wouters et al. 2019) and an activity to examine the values embedded in a popular video-streaming platform (DiPaola et al. 2020).

In contrast, very few papers explicitly invoke responsibility from the public sector or urge the creation of more robust policies. Current regulations are, in fact, criticised by some, as overarching lists of rules said to be ultimately ineffective, given the challenge that it is to define guidelines in advance that multiple contexts can adopt (Figueiredo et al. 2020; Madaio et al. 2020). An exception to this argument can be found, however, in a paper praising the idea of Responsible Research and Innovation (RRI) as a valuable top-down framework to guide the implementation of ethics in HCI research (Grimpe et al. 2014). Questions of policy are equally relevant to health data repositories of all scales, particularly those about data misuse and accountability structures.

3.4 In Summary

The review presented in this chapter provides a valuable foundation for future works taking the abstract concept of ‘ethics’ and seeking to putting it into practice through technology design processes. The next step in the work of this thesis is to return our focus to the specific application context of health data ecosystems, using the knowledge sources identified in this review to support rich and informed engagement with participants, and develop a unique understanding of their expectations, preferences and values. The next chapter thus describes a user study conducted to examine the attitudes of health data contributors when presented with the scenario of contributing their personal information to a health data platform.

4 Understanding People | Interview Study with Data Contributors

As part of a user-centred research agenda, this chapter turns towards the people at the heart of the health data technology ecosystem: data contributors. We conducted a qualitative interview study to build upon the knowledge gained during the first stage of this research process (mapping the literature) and capture what matters most to this user group. In this study, we asked young adults about their motivations and concerns when presented with the opportunity to share different types of personal information with a health data platform. The study reported in this chapter has been published as “*Futures for Health Research Data Platforms From the Participants’ Perspectives*” (Vilaza et al. 2020), and is attached to this thesis as Paper 2.2.

4.1 Introduction

As seen in the previous chapter, the acceptance of health data technologies can be compromised by ethical concerns, a lack of motivation to contribute, and trust issues. A lack of public acceptance has negative consequences; without broad inclusion and diversity, the potential benefits achieved through the use of health data may furthermore be unfairly distributed across populations (Sankar et al. 2017; Ienca et al. 2020). Therefore, it is critical to understand data contributors’ perspectives on collecting, sharing, and re-sharing personal health data. Previous research has investigated volunteers’ willingness to contribute to bio-repositories (Domaradzki et al. 2019; Middleton et al. 2019; King 2019); however, there remains a gap in our understanding of users’ willingness to contribute health data repositories that may store in particular more sensitive types of data, such as mobile sensing and behavioural monitoring. To address this critical gap in knowledge, we conducted the following study.

4.2 Method

This study employed a semi-structured interviewing method – a well-established design research methodology also suitable for investigating ethical concerns, as seen in Chapter 3. Interviews included a card sorting activity for inquiring participants about their comfort level with sharing specific data types (See Table 4.1¹). The study was exempt from ethical approval, although conducted according to established ethical standards (informed consent, confidentiality, participant well-being) and followed Denmark’s national code of scientific conduct.

In conducting this study, we chose to focus on young adults, given that this demographic group was found to be less open than other (older) groups to the idea of sharing health data (Goddard et al. 2009). There were 12 participants, being four females and eight males (age mean=23, std=1.8), from the United States, China, Hungary, Spain, France, Italy, Netherlands, and Scotland. In broad terms, participants were asked about their attitudes about eventually contributing to a health data repository that primarily stores and shares (de-identified) data for research purposes.

Data analysis employed an inductive approach, following Braun & Clarke’s Thematic Analysis method (Blandford 2013; Braun et al. 2012) and identifying three main themes: rea-

¹Table extracted from Vilaza et al. 2020

sons to contribute health data to shared-access research repository, the ideal characteristics of a trustworthy repository and personal criteria for feeling comfortable with the prospect of sharing different types of information. The complete description of this study protocol is in the Paper 2.2.

Calls/text content	Financial status	Relationship
Mental illness	Address	Contagious illness
Genetic disorders	Emotional status	Family
Sleep patterns	Places visited	DNA
Alcohol/tobacco	Food	Local ambience
Current weather	Distances	Partner health
Physical status	Leisure	Physical illness
Physical exercises	Heart rate	Toilet habits
Hygiene	Blood/urine	On-screen time
Academic/work performance	Apps used	Calendar

Table 4.1: Data types comprising each card for the sorting activity

4.3 Results

4.3.1 Motivations to Contribute Data

Two main reasons to contribute data to health data repositories were identified: supporting public benefits and receiving personal benefits.

Public benefits

All participants praised how valuable the concept of a health data platform seems to be: *“There could be a lot of good for a lot of people if healthcare providers could have more access to information about people’s lives”* (P3). Helping patients and researchers was a motivation to contribute expressed by most: *“I would share my data with the idea that it can help research and it can help other people to be cured”* (P9).

Personal benefits

The majority also felt motivated by the prospect of obtaining personal benefits, such as access to data to improve their health: *“If you have all the information about me, you can give me more specific tailored care, maybe even like getting life recommendations”* (P3). In contrast, monetary compensation was not perceived as essential by most: *“I don’t think I would ask for financial compensation, I think it is more volunteering type of work”* (P7), unless there is a strenuous time commitment *“Probably if it takes a lot of time, it should be rewarded, it should be paid”* (P1).

4.3.2 Trust in the Platform Governance

Two main enablers of trust were mentioned recurrently in the interviews: more transparent communication and more choices for data control.

Transparency

Most participants mentioned that they would want to know who was managing the platform: *“I need to know who are the people behind the programme. Is it the university, is it an external research centre, is it for hospitals?”* (P2). It was also described as crucial by most to know in detail the purposes for data use in the future: *“It is not good to share anything if we do not know how it can be used in the future”* (P11). Others expressed that they would like to receive updates about research outcomes: *“I would be interested to know if I helped and what conclusions were drawn as a result”* (P8). Most commented that they

would like to be informed about the security protocols in place: *“Knowing some technical stuff would make me comfortable even though I don’t understand that type of information”* (P4). They would also like to know whether their data were to be stored anonymously: *“If it is already anonymised in the database, then I would use the platform because I know that I am just going to be one in the millions”* (P4).

Choice

Some participants expressed a desire to be asked for permission for their data to be re-used on a case-by-case basis: *“If they have new research and want to have access to my data, I want them to ask me if I want to release to the new research or not”* (P7). Others added that they would also like to block access to specific data receivers: *“I want to choose if I disagree with one of the studies and say: ‘with this one I don’t want to share’ ”* (P10). Many also noted that they would prefer to be able to pause data collection or delete previously collected data: *“Maybe in some situations, it is useful to stop recording some data. If you go to some places where you don’t want to be followed, for example, you don’t want people to know you are there”* (P2). Other future possible data contributors expressed that they would feel more comfortable if their data were shared in the least detailed form necessary: *“If it just to know what you are going to do in your day, how many hours you are walking, something like that, is fine”* (P10).

4.3.3 Criteria for Sharing Each Data Type

Insight into data contributors’ motivations and perceptions of trust enables the understanding of critical factors for public acceptance. However, it is also important to understand how these values relate to the prospect of being solicited to share different data types. Participants shared the criteria that would guide their decision to share or refrain from sharing an extensive list of information (See Table 4.1). These criteria included: evidence of the importance of the data type for research, perceived risk in case of a data leak (material loss and reputation damage), the burden of continuous data collection and the potential privacy invasion of their relatives, partners or colleagues.

Relevance for research

Most participants shared that they would be willing to share data if they knew why data of that type was essential for research: *“I would be happy to share that food consumption information. For me, that has a very tangible connection to health”* (P3). However, participants had divergent opinions regarding the relevance of different data items, with some willing to share items that others would not, as seen in the card sorting activity.

Potential for material damage

Many were concerned about the risk of physical attacks, for instance, if their location was leaked to malicious actors: *“If I am going back home at this time, then someone is just waiting for me at the door and just breaking into my room”* (P7). Participants also expressed that cyber-attacks are also concerning for them: *“Financial situation, no, because people maybe know how much money I have in my bank account and they would see if it is worth hacking it”* (P7). Both attacks could perhaps lead to financial loss, which is another reason they mention that contributes to fearing data sharing: *“If hackers are working for an insurance company, and they sell data to them, they could propose different plans”* (P6).

Risks to reputation

Each participant had their own set of data types that they believed posed risks to their reputation. Many were concerned about others knowing of their substance use or abuse: *“Alcohol, tobacco, I do not want people to know how much I drink because I drink too much”* (P8); particularly in the context of their work environment: *“I am afraid that in a potential data leak, my employer gains access and discriminates me in my employment”* (P11).

Invasion of others' privacy

The privacy of others was also an essential criterion for several participants: *“I think sharing calls and text content overlaps with the privacy of other people”* (P2). These participants believed that consent should be obtained from others in these cases: *“When it comes to the condition of my partner, it is tricky because I feel like it is their decision to share the information”* (P3).

The effort of data collection

Several participants also raised concerns regarding the burden of the commitment to collect data in the first place: *“I do not want to share data when I'm low on my battery or when I am short of data. I would not like this data to interfere with my daily life”* (P2); and perhaps particularly when in a vulnerable state: *“If someone is really sad or depressed, I think it is harder to share that”* (P10).

4.4 A Conceptual Framework

These findings show how data contributors reason about the prospect of eventually sharing their personal data with a shared-access repository for health research. The factors outlined above are critical to understanding what is essential for public acceptance. An ethical health data ecosystem design should elevate the experience of contributing by attending to these factors.

To highlight those factors shaping acceptance of health data platforms by data contributors, we developed this conceptual framework (See Figure 4.1²). This framework serves as a tool to support technology creators' reflection on ethical health data ecosystem design. By understanding how different factors may affect acceptance at different stages, technology creators can be better equipped to make decisions that will more strongly support the values of those contributing their data. A core property of this framework is that it emphasises that technology acceptance is a continuous process that evolves with time, which means that it becomes necessary to consider the maintenance of users' trust after the initial phases (Nadal et al. 2020).

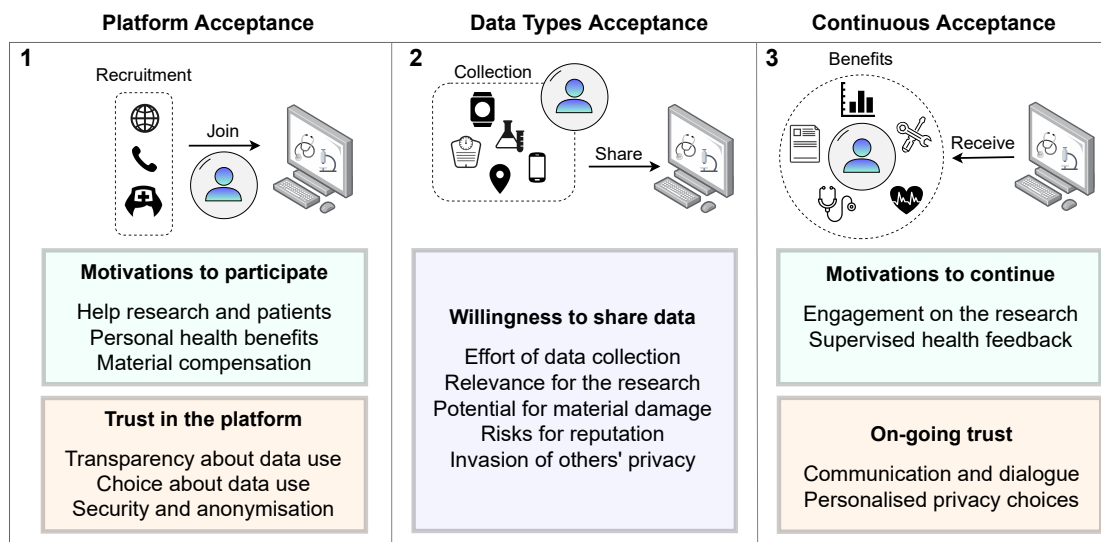


Figure 4.1: Conceptual framework for acceptance based on the interview findings

This conceptual framework describes how the experience of contributing to a health data repository can be understood as a sequence of acceptance phases: from the moment a

²Figure from Vilaza et al. 2020

participant is first introduced to the possibility of contributing to the actual collection and sharing of data that comes with the commitment to participate. In the first phase, individuals seek reassurance that being part of a research platform will benefit themselves and others (motivation) without posing significant risks in their lives (trust). Once individuals agree to participate, they ponder which information types they feel comfortable sharing (willingness to share). Each participant applies different selection criteria during this deliberation process, based on their personal boundaries and risk perceptions. As participation in the repository progresses, individuals may change their perceptions of sharing data according to the initial conditions. For this reason, as highlighted in the framework, the maintenance of motivation and trust is a long-term process, requiring designers and researchers, from an ethical standpoint, to consider their impact on acceptance fluctuations.

4.5 In Summary

This chapter contributes a list of factors expressed by data contributors as critical for their acceptance of personal health data sharing with health data platforms. Results highlight the existence of clear motivations to contribute, potential enablers for trusting the platform and varied willingness to share each specific data type. To facilitate the process of translating these qualitative insights into design recommendations for future platforms better attend to contributors' needs and values, we proposed a conceptual framework (see Figure 4.1) connecting each of the identified factors to sequential stages of acceptance. The next chapter builds upon these findings by providing a complementary quantitative perspective on data contributors' attitudes expressed by a much larger and diverse sample.

5 Understanding People | Survey Study with Data Contributors

To better understand data contributors' attitudes, we next sought to expand the qualitative insights outlined in the previous chapter with a broader sample and a quantitative approach. This survey study was motivated by our need to ground our design suggestions not only in the perspectives of a target set of individuals but also in evidence collected from more diverse data contributors. We also wanted to compare the strength of specific sources of motivation, data access preferences, willingness to share digital and non-digital data items, and reasons for privacy concerns between contributors with different characteristics. The results reported in this chapter have been published in the form of the full-paper *“Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey”* (Vilaza et al. 2021a), available as Paper 2.3.

5.1 Introduction

This study builds upon the interview study described in Chapter 4 to gain a more nuanced understanding of the acceptance factors considered crucial by interview participants. As seen in our review of approaches to engaging with ethics (Chapter 3), surveys help make solid arguments for the existence and prevalence of ethical concerns across populations (Skirpan et al. 2018a). Surveys also allow the statistical analysis of relationships between individual characteristics and acceptance factors, which can be very relevant when considering differences between user groups. The survey study described next provided robust evidence on data contributors' attitudes.

5.2 Method

5.2.1 Recruitment

This collected responses from two national contexts: Brazil and Denmark. Recruitment occurred between March 2020 and December 2020, primarily targeting young adults but not prohibiting other age groups' responses. The link to the survey was distributed online via university forums and newsletters, email lists and social media (Facebook, Twitter, Whatsapp). A recruitment event was also organised at Technical University of Denmark (DTU), during which participants were compensated with a cup of coffee.

5.2.2 Survey Design

The design of the survey questions drew on several sources of knowledge, including the findings of the study described in the previous chapter (Vilaza et al. 2020; Middleton et al. 2019; Patil et al. 2016; Sanderson et al. 2017; Lemke et al. 2010; Ahram et al. 2014; Trinidad et al. 2012; Rathi et al. 2012; Papoutsi et al. 2015; Luchenski et al. 2012; Zanaboni et al. 2020; Porter et al. 2014). Survey development was iterative and informed by feedback from experts (researchers, clinicians, statisticians) and members of the target audience (young adults). At the beginning of the survey, the following short description of a health data repository was provided: *“A research data repository is an online database containing data collected during research studies. In such repositories, de-identified data is to be re-used in the future by other research studies”*. The survey was deployed using the LimeSurvey platform, and data was hosted on a secure server at the DTU. More details on the rationale for each of the questions can be found in the Paper 2.3.

5.2.3 Procedure

The study was considered exempt from ethical approval in Denmark, although it received approval from the Institutional Review Board of the Universidade Federal do Rio Grande do Norte (UFRN). Participants were asked to provide consent at the beginning of the survey, in line with the European General Data Protection Regulation (GDPR) and following standard ethical conduct principles for online research. Participation was anonymous.

Data analysis and visualisation were conducted using the R Project for Statistical Computing (software for statistical computing and graphics). This analysis included frequency distributions, bivariate associations and binary regressions. Reference values followed that an odds ratio below 1.5 was considered weak and above 5.0 strong (Chen et al. 2010); and for a 95% confidence interval, results were significant if $P < .05$. Missing values from questions skipped were removed from the analysis.

5.3 Results

5.3.1 Participants' Characteristics

The survey was answered by 2299 participants, out of which 1963 completed all questions (1963/2299, 85.38%). For data analysis, only data from participants residing in Brazil (1017/1600, 63.56%) and Denmark (583/1600, 36.44%) were included (1600/1963, 81.50%). The majority of participants in the target sample were between 18 and 27 years old (933/1600, 58.31%), identified as being female (891/1600, 55.69%), had at least a university degree (992/1600, 62.00%), were in good, very good or excellent health (1407/1600, 87.94%) and were moderately, very, or extremely interested in health topics (1088/1600, 68.00%). The vast majority of the sample owned and used smartphones (1562/1600, 97.63%) and computers (1537/1600, 96.06%).

5.3.2 Experiences, Awareness and Attitudes

The vast majority of the sample positively perceived the type of health research data repository described in the survey that stores de-identified data (1339/1600, 83.69%). Approximately half of the participants had participated in a health research study already (763/1600, 47.69%), and those who participated were more likely to have a moderate to high interest in health topics (OR 2.35, 95% CI 1.88-2.93; $P < .001$). A small portion of the sample was aware of examples of research data repositories (459/1600, 28.69%), and those aware of examples were more likely to have a moderate to high interest in health topics (OR 3.02, 95% CI 2.30-3.96; $P < .001$) and to have been participants in previous health studies (OR 3.36, 95% CI 2.66-4.23; $P < .001$). Those who held a positive perception were also more likely to be aware of examples of research data repositories (OR 3.26, 95% CI 2.17-4.90; $P < .001$). Significant factors influencing participants' current perceptions of digital health research repositories were: an interest in health topics (OR 1.49, 95% CI 1.10-2.02; $P = .01$), previous participation in health research studies (OR 1.70, 95% CI 1.24-2.35; $P = .001$), and awareness of examples of existing repositories (OR 2.78, 95% CI 1.83-4.38; $P < .001$). The complete results of this logistic regression can be found on Table 2, Paper 2.3.

5.3.3 Motivation to Participate

The majority of participants felt very or extremely motivated regarding the prospect of helping future patients (1366/1600, 85.38%), helping researchers (1253/1600, 78.31%), receiving health results concerning themselves (1170/1600, 73.13%), and receiving general research results (1063/1600, 66.44%). Only a minority felt very or extremely motivated by financial compensation (505/1600, 31.56%). Those who positively perceived health data repositories were more likely to be motivated by all incentives suggested, except financial compensation. Those interested in health topics were more likely to be motivated

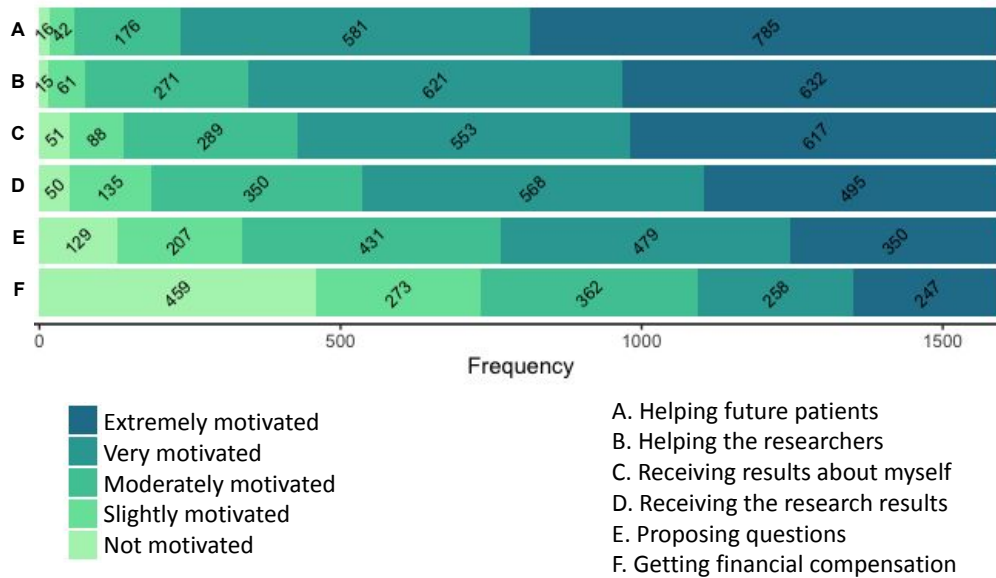


Figure 5.1: Distribution of answers for each motivation source

by receiving the results of research (OR 2.25, 95% CI 1.65-3.06; $P < .001$) and proposing questions to be investigated (OR 2.53, 95% CI 1.97-3.24; $P < .001$). The youngest segment (18-27 years old) was more likely to feel motivated by receiving financial compensation (OR 1.92, 95% CI 1.57-2.35; $P < .001$). Figure 5.1¹) shows the distribution of responses.

5.3.4 Reasons for Concern

The majority of participants felt very or extremely concerned about their data being used for unethical projects (1219/1600, 76.19%) and profit-making without their consent (1096/1600, 68.50%). Being a victim of cyberattacks was very or extremely concerning for 65.94% (1055/1600). Only a few participants felt very or extremely concerned about the burden of being asked to share more data in the future (527/1600, 32.94%). No significant associations were found between specific participant groups and different reasons for concern. (See Figure 5.2²).

5.3.5 Willingness to Share Different Data Types

Only a few participants felt uncomfortable sharing any data items (94/1600, 5.87%). Those who felt uncomfortable sharing any data items were more likely to have a negative or indifferent perception of health research repositories (OR 3.91, 95%CI, 2.49-6.14, $P < .001$). Most participants felt uncomfortable or very uncomfortable sharing the content of texts and calls (1206/1600, 75.37%). Fewer participants felt uncomfortable or very uncomfortable sharing the frequency of texts and calls (706/1600, 44.12%). Around half of the sample considered places visited (864/1600, 54%), apps used (775/1600, 48.43%) and DNA samples (750/1600, 46.87%) as uncomfortable or very uncomfortable data to share. On the other hand, most felt comfortable or very comfortable sharing the other data types: sleeping patterns, food consumption, alcohol consumption, diagnoses of physical illness, physical activity levels, stress levels, family health history, distances travelled, diagnosis of mental illness, blood samples and time spent on screen. Figure 5.3³ shows the

¹Figure extracted from Vilaza et al. 2021a

²Figure extracted from Vilaza et al. 2021a

³Figure extracted from Vilaza et al. 2021a

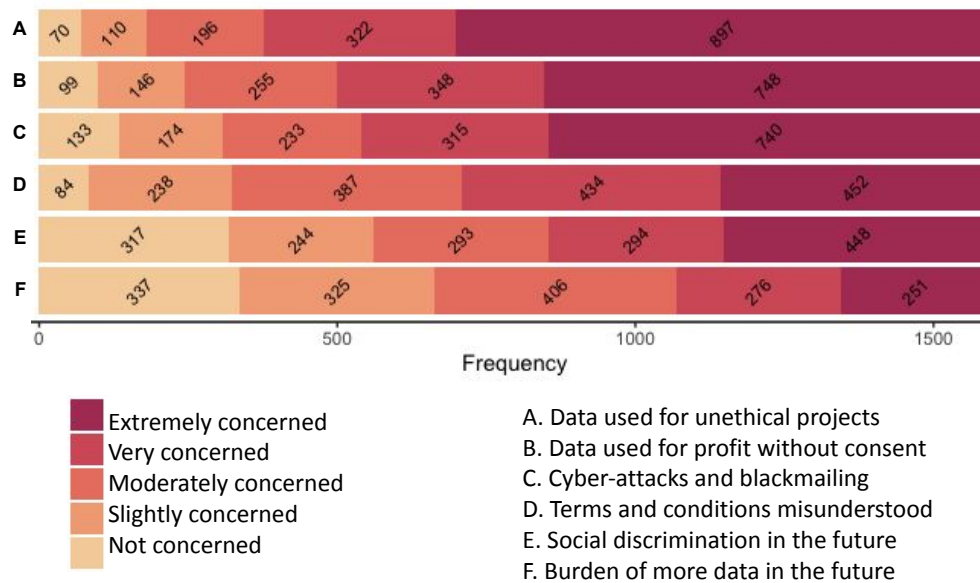


Figure 5.2: Distribution of answers for each reason for concern

distribution of responses.

The following findings highlight that participants' willingness to share different data types can vary significantly. Those who had a positive perception of health research repositories were more likely to feel comfortable or very comfortable sharing all of the data items, except the content of calls and texts. Those concerned about being discriminated against were more likely to feel uncomfortable sharing data about diagnoses of mental illness (OR 2.26, 95%CI, 1.66-3.07, $P < .001$). Those uncomfortable sharing data about app usage were more likely to be concerned about data being used for profit (OR 2.57, 95%CI, 1.91-3.46, $P < .001$) and not understanding terms and conditions (OR 2.22, 95%CI, 1.71-2.87, $P < .001$). Those not motivated or only slightly motivated by the possibility of receiving results about themselves were more likely to feel uncomfortable sharing their alcohol consumption (OR 5.76, 95%CI, 3.63-9.13, $P < .001$), distances travelled per day (OR 3.31, 95%CI, 2.29-4.80, $P < .001$), stress levels (OR 6.46, 95%CI, 4.43-9.44, $P < .001$) and physical activity levels (OR 6.78, 95%CI, 4.52-10.17, $P < .001$).

Age (OR 2.16, 95%CI, 1.28-3.70, $P = .004$), digital device ownership (OR 1.90, 95%CI, 1.14-3.26, $P = .01$), health status (OR 2.28, 95%CI, 1.24-3.98, $P = .01$) and current attitude regarding digital health research repositories (OR 3.77, 95%CI, 2.24-6.26, $P < .001$) were significant factors affecting participants' willingness to share any data with a health research repository. The complete results of this logistic regression can be found on Table 3, Paper 2.3. These findings highlight that participants' willingness to share different data types can vary significantly according to demographic factors, health status and current attitudes.

5.3.6 Preferred Data Access Options

The majority of participants stated they would like to receive information about which projects access their data in the future (1334/1600, 83.37%) and to be able to decide who obtains access to which aspects of their data (1181/1600, 73.81%). Never being contacted was desirable or very desirable to only 25.5% (408/1600), and allowing the owners of the repositories to decide who can access the data was desirable or very desirable only to 23.62% (378/1600). Giving public or academic institutions access to their

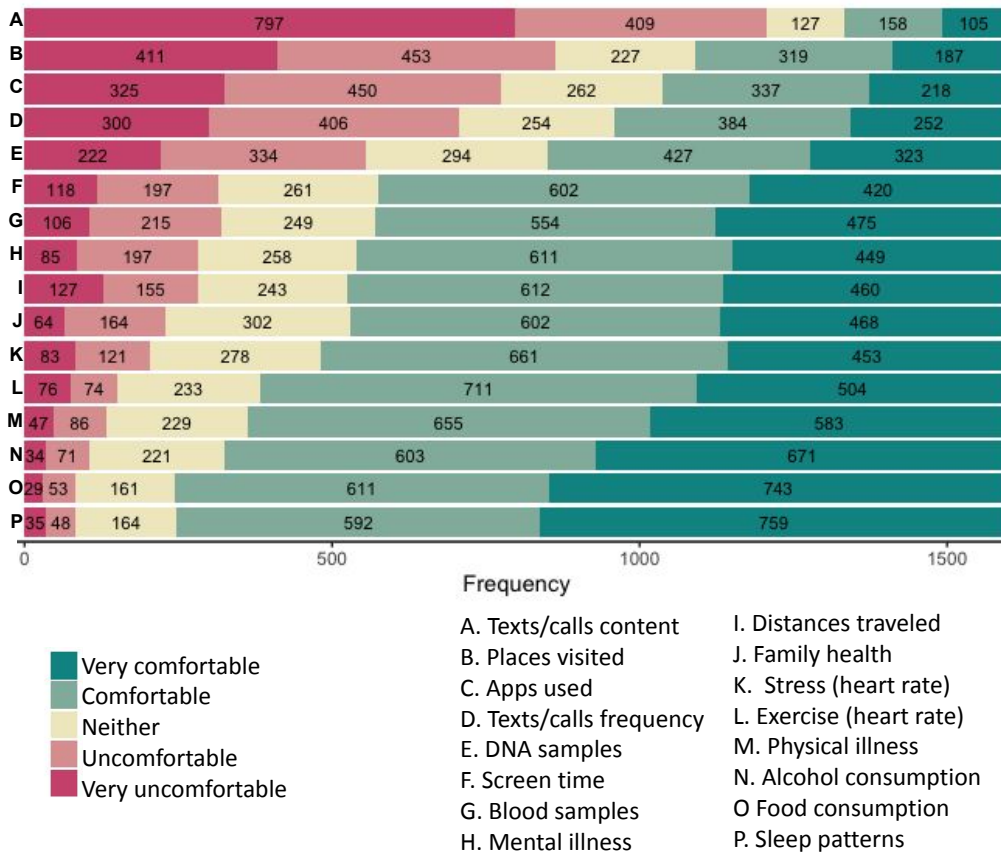


Figure 5.3: Distribution of willingness to share across different data types

data was perceived as desirable or very desirable by 48.93% (783/1600) of participants, although allowing private labs and companies access was considered desirable or very desirable by only 13.43% (215/1600). Figure 5.3⁴ shows the distribution of responses.

Those who found it desirable to be informed about the identities of those using their data were more likely to have a positive perception of health data repositories (OR 2.45, 95%CI, 1.77-3.39, $P < .001$). Those concerned about data being used for unethical projects were more likely to find it desirable to have control over how their data would be used (OR 2.45, 95%CI, 1.80-3.42, $P < .001$) and to be informed (OR 3.09, 95%CI, 2.18-4.37, $P < .001$). Those concerned about data use for profit without their consent were more likely to find it undesirable to have private labs and companies access their data (OR 2.24, 95%CI, 1.69-2.96, $P < .001$).

5.3.7 Cross-country Analysis

No significant differences were found between the demographics distribution of participants residing in Brazil and Denmark, except that a higher percentage of females and a lower percentage of participants who had completed a higher education degree were present within the Brazilian sample. The vast majority of the Brazilian sample held a positive attitude towards health data repositories (927/1017, 91.15%), in contrast with a less significant majority in Denmark (412/583, 70.67%). The Brazilian sample was also more likely to feel motivated by receiving results about their health, proposing questions to be investigated, receiving research results, and helping researchers. The Brazilian sample was also more likely to be moderately, very, or extremely concerned by all options listed.

⁴Figure extracted from Vilaza et al. 2021a

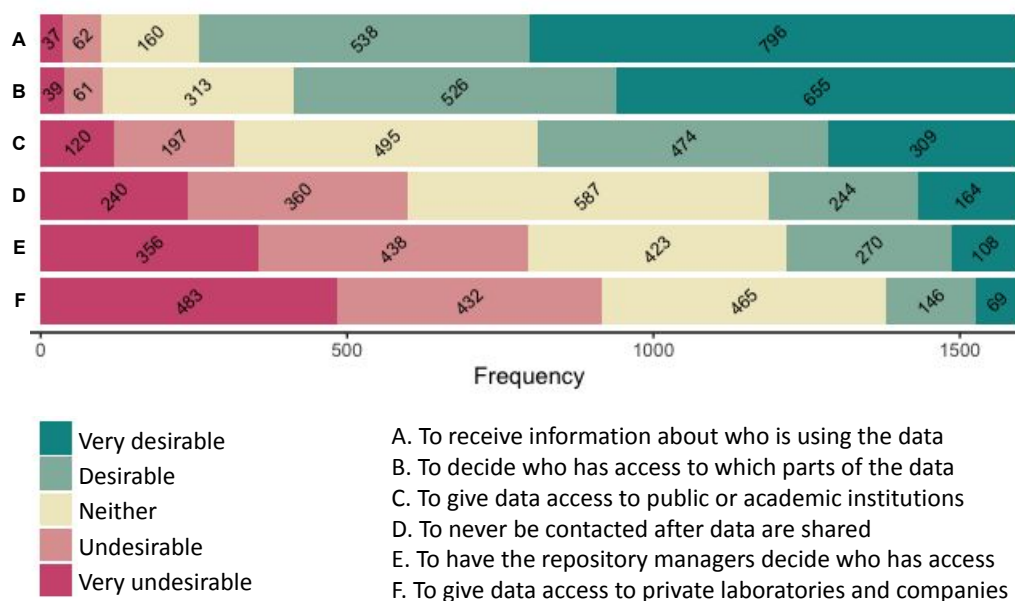


Figure 5.4: Distribution of answers for each access control option

Finally, the Brazilian sample was more likely to find it desirable to receive information about who is using their data (OR 5.51, 95% CI 4.12-7.37; $P < .001$), with most being more likely to find it desirable to never to be contacted (OR 3.63, 95% CI 2.87-4.60; $P < .001$). They were also more likely to find it desirable to enable repository managers to decide who gets access (OR 2.84, 95% CI 2.24-3.60; $P < .001$); and allow both private organisations (OR 3.73, 95% CI 2.77-5.04; $P < .001$) and public institutions to access data (OR 4.51, 95% CI 3.61-5.63; $P < .001$).

5.3.8 Overview of Survey Findings

Given the breadth of the variables contemplated by this study, we end this section by presenting a summary of results:

- A positive perception of health research data repositories is associated with higher levels of motivation and willingness to share. This positive perception can be further influenced by levels of personal interest in health, previous participation in health studies and awareness of examples of research repositories.
- The most potent sources of motivation for contributing data are: helping future patients, helping researchers and receiving results about personal health and research outcomes. On the other hand, receiving financial compensation appears as the weakest incentive.
- The most significant reasons for concern are the possibility of data being abused (for unethical research goals or profit) and the risk of cyber-attacks. The least concerning consequence is the possibility of being asked to provide more data in the future.
- The vast majority of participants state feeling comfortable with sharing at least one data item; however, most report feeling uncomfortable sharing the content and frequency of texts and calls, locations of places visited, and apps used.
- Those unwilling to share any data are more likely to have a negative perception of health research data repositories and low motivation levels; however, they are not

more likely to possess more substantial concerns than others.

- Those concerned about being discriminated against are more likely to feel uncomfortable with sharing data about mental illness diagnoses, with no significant associations being found between social discrimination and other data types.
- Those uncomfortable with sharing alcohol consumption, distances travelled per day, stress levels, and physical exercise are more likely not to feel motivated by receiving this information about themselves.
- The majority of participants find it desirable to know which projects access their data. Most also prefer to decide who gets access to their data. In contrast, not being contacted after providing consent is considered undesirable by most.
- Allowing public or academic institutions to access data is perceived as more desirable than allowing private labs and companies. Those concerned about unfair profiting practices are more likely to find it undesirable to grant data access to private organisations.
- The Brazilian sample is more likely to report a positive perception of health data repositories, higher motivation levels and higher levels of concern. The Danish sample is more likely to prefer not being contacted after providing consent and allowing repository managers to decide who can access data; however, the Danish sample is less likely to feel comfortable sharing alcohol consumption and stress levels.

The findings of this survey study confirm the importance of the factors derived from the qualitative study in Chapter 4, while they also expand our understanding of how motivating, concerning and desirable certain conditions for health data sharing can be. The implications of a more nuanced analysis of different factors include the possibility of fine-tuning design suggestions to focus on what matters most to potential contributors, thus supporting the work of technology creators. Overall, differences between national contexts and demographic groups demonstrate the need for data platforms to propose conditions for participation entailing diverse configurations of the contribution that may potentially accommodate the needs of a broad set of people. A more thorough discussion of how findings relate to previous literature can be found in the Paper 2.3 and a more detailed discussion of design recommendations derived from this study are available in Chapter 9.

5.4 In Summary

This survey study contributes novel insight into public attitudes regarding health data repositories in which data is used primarily for medical research; by enabling a quantitative understanding of that which matters to health data repository contributors. Together with the findings from Chapter 4, these results show that data contributors care about having their autonomy respected and are motivated about the benefits that might be offered to themselves and society. Findings from this research can be used to support design for health data technology acceptance, as well as more ethical use and sharing of health data. In order to further this work's contribution to the design of these systems and technology creators' capacity to action ethics, we next turn towards investigating the attitudes of those creating and managing digital health technologies - the topic of the next chapter.

6 Understanding People | Focus Group with Technology Creators

As this thesis has the overarching aim of supporting technology creators to build health data systems more attuned to data contributors' needs, we next turn to examine the technology creators' perspectives. To understand the enablers and barriers deemed most critical to supporting the acceptance of data contribution by this stakeholder group, we chose to conduct a focus group study. This additional viewpoint - as provided by interaction designers and software developers - expands and confirms findings derived from prior studies conducted with data contributors. The content of this chapter is based on the Paper 2.4: "*Sharing Access to Behavioural and Personal Health Data: Designers' Perspectives on Opportunities and Barriers*" (Vilaza et al. 2019).

6.1 Introduction

The health data ecosystem comprises many stakeholders whose needs and objectives can clash. Previous research has identified as the paramount necessity among those *consuming* health data for high data quality and robustness (Bourla et al. 2018; Kim et al. 2017). On the other hand, as seen in the previous chapters of this work, those *contributing* health data desire privacy protection and more flexible data sharing conditions. As argued in Chapter 2, the predominant vision of health data systems currently, however, caters primarily to the goals of researchers, clinicians and public workers, which at times means treating the needs of data contributors as of a lower priority.

Chapter 3 shows that engaging with those envisioning and building interactive systems is a meaningful way of putting ethics into practice. Professionals working on the conception of new health data technologies are often tasked with bridging the needs of data contributors and data consumers in order to create systems that capture what is essential for both (Marcu et al. 2011). In this context, technology creators can help raise technical limitations and design possibilities useful for devising future developments. However, previous health data repository research has rarely engaged with this stakeholder group. For this reason, we consulted a group of interaction designers and software developers to understand better their perspectives regarding the potential ethical benefits that health data repositories may yield and the factors that, based on their experiences, currently hinder such advances.

6.2 Method

A focus group study was conducted with six employees working at the Copenhagen Center for Health Technology. As they were part of the same research group, they were familiar with each other's work and had collaborated on projects ranging from a mobile app for depression treatment, a web-based tool for cognitive assessment and a heart rate sensor for monitoring patients with cardiovascular diseases. All participants had been working with digital health technologies for more than a year. Two worked as interaction designers (P2, P4) and four as software developers (P1, P3, P5, P6).

The focus group lasted for approximately two hours, was audio-recorded, and participants' notes during discussions were documented in the form of photographs (See Figure

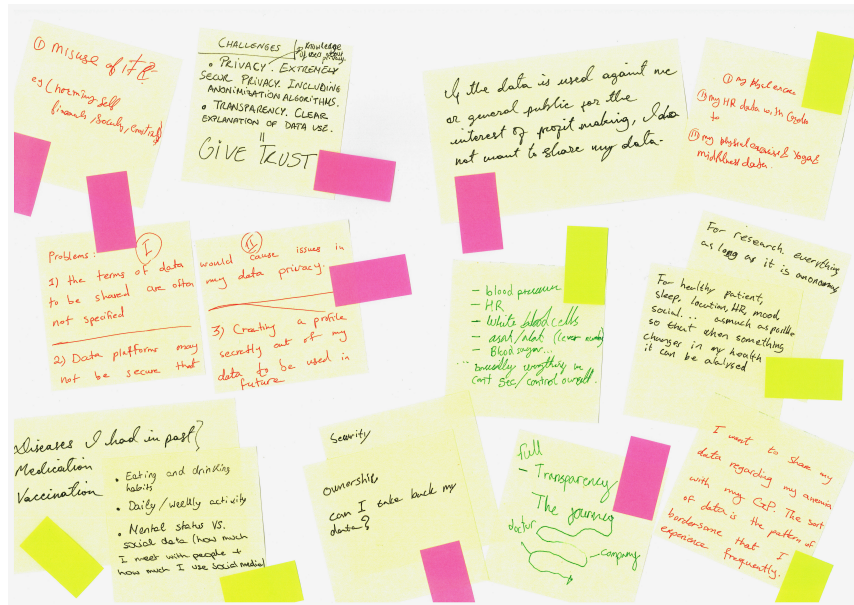


Figure 6.1: Participants' notes during the focus group

6.1¹). Audio data were transcribed and analysed using Braun & Clarke's Thematic Analysis Braun et al. 2012, in the process of which themes were inductively derived. More information on the study procedure can be found on the Paper 2.4.

6.3 Results

6.3.1 Data Should Be Used for Science

All participants believed that health data should primarily be used for increasing benefits for individuals and society: *“Good purposes, research purposes, which are going to benefit society in general, going to benefit the health sector”* (P5). Thanks to their technical knowledge, participants were able to articulate why data is an essential resource for health science: *“Sharing data can help others in a bigger way or solve a bigger problem. For example, if I share my heart data, how my heart is functioning, that can help to build an artificial intelligence algorithm which can automatically detect diseases or that can help to build some model”* (P3). They were also confident that even though data collected right now may not be relevant to healthy individuals, in the future, novel discoveries might be unlocked if people share data: *“We might not know what to do with the data right now, but in four years, I might go down with stress. Then we can look at the four years of data leading up to me having this stress, and we could maybe figure out what is causing it, more accurately”* (P4).

However, some participants admitted that entities with unethical purposes could also misuse health data: *“A company or organisation that has my data can create a profile secretly and use it in the future for data analysis. They may already know about my behaviour before they actually meet me because they have a lot of data about me so that they can predict my actions in the future”* (P1). One participant went further and stated that personal health data should not be used for profit: *“It has to be good for all the people, and not for profit making like all the big corporations are doing in some way or another”* (P2). Health developers' views on the merits of data sharing align significantly with those of health data contributors, as shared in the prior studies of this work.

¹Figure extracted from Vilaza et al. 2019

6.3.2 Users Are Reluctant to Share Data

All participants have experienced that some users are not willing to share health-related data despite the potential benefits: *“It is technically feasible, and we are very much looking forward to getting this kind of data because if you have more data, you can build more robust systems. But, that is the problem: you do not have the data because people are not willing to share it”* (P3). In particular, one participant mentioned that users from one of their previous projects were more reluctant to share data about their mental health: *“I think most people are happier sharing only physiological data, because of the stigma of sharing the mental data”* (P6).

Technology creators, however, were aware that the reason for such unwillingness to share data is that users would prefer to keep their mental illness diagnosis private: *“We take the data from all of these psychiatry patients, but these patients are afraid of other people knowing what is going on with their mental health”* (P2). One participant contrasted the collection of digital health data with traditional disclosures made during medical consultations: *“When you talk with your doctor, any data you share with your doctor, is confidential”* (P4). Such findings indicate that technology creators are conscious of their users’ concerns and aware of the reasons why users might be reluctant to share their data with digital repositories. This observation draws further evidence that data contributors often do not feel comfortable sharing data about their mental health, as indicated by the previous user studies in this thesis.

6.3.3 Health Data Systems Could Be Improved

Most participants were critical of standard practices in designing and developing data sharing systems. One participant drew attention to the lack of clarity of ‘terms and conditions’ documents: *“The terms are sometimes not clear: when they want to collect it, like what sort of data they want to collect, it is very general the data agreement”* (P1). The same participant also expressed frustration regarding the lack of real choice when it comes to consenting to access to data: *“Even if you read them you cannot say to the service ‘I will not give you consent’, then you do not have any option besides not to use it. You have to give away your data. It is like a trade-off”* (P1). This participant was also sceptical about the security measures taken by the developers of large-scale health data repositories, given that they had advanced knowledge of data protection techniques: *“I am not sure that the software developers covered all issues, or if privacy and security were also considered when developing this platform”* (P1).

Other participants described how health data systems could be improved in response to such critical views. One example was to increase transparency about data usage: *“The most important for me is the journey of the data, so who is going to use it, and at what point, who is going through the data”* (P6). However, even though most participants were vocal about their dissatisfaction with current standards for data sharing procedures, they felt they were not able to change them. Several expressed a belief that this should always be how things work: *“That is the point of sharing it, when you initiate it, you do not know what will happen next”* (P3). These comments stand in stark contrast to the enthusiasm about the new opportunities that health data could provide for building models and algorithms to support healthcare now and in the future.

6.4 In Summary

This chapter further supports the idea that ethical health data technologies must address contributors’ concerns and provide protective measures against data misuse. Findings show that technology creators had personally experienced that data contributors can be reluctant to share their personal data, especially when it comes to data referring to mental

health. Developers and designers were also critical of how data sharing requests often provided contributors little choice or transparency. However, acting on such findings in the practice of technology design and development remains a significant challenge in itself — participants felt sceptical that some data sharing standards could ever change, and they did not explicitly suggest initiating this movement. We next explore and experiment with different approaches to realising the ethical design of health data user interfaces, rooted on the results of the user studies in the last three chapters.

7 Practising Ethical Design | Health Data Interfaces

User-centred design guidelines propose that initial research for understanding users' needs should lead to the recommendation of actionable requirements for the conception of design alternatives (Sharp 2003). Taking some of the methods for ethical design highlighted in Chapter 3 and the insights elicited through the user studies described Chapters 4 and 5, we here explore means of leveraging the combination of these prior sources of knowledge in the design of health data interfaces. Therefore, this chapter aims to understand how the process of translating ethical requirements into user interfaces unfolds.

This chapter explores in particular two approaches advocated by previous research as well-suitable to eliciting ethical guidance (See Chapter 3): Value-Sensitive Design (VSD) and the critical appraisal of technology design. These approaches share similarities in that they both employ conceptual constructs (values and principles) to guide ethical analysis, yet they also differ in how these constructs are selected. Whilst in VSD, values usually emerge through so-called 'empirical investigations' (bottom-up approaches), critical appraisals can rely on pre-defined lists of ethical principles from established frameworks (a top-down procedure). We here describe how we applied these methods to the context of two unique design cases, highlighting how it is possible to adopt ethical perspectives in the configuration of health data interfaces respectful of data contributors' needs.

First, the framework of VSD was applied to the design process of a mobile app to be used for health research (StudyApp), and in particular, to guide the proposal of user interfaces aligned with the values expressed by data contributors. This part of the chapter draws from and expands upon the Paper 2.5 "*A Value-Sensitive Approach for Ethical Health Research Platforms*". Then, an AI-ethics framework (based on normative principles) was applied to analyse ethical improvements to the design of chatbots for psychotherapy, with particular attention being given to the question of data sharing. This second half of the chapter is a summary of the Paper 2.6 "*Is the Automation of Digital Mental Health Ethical? Applying an Ethical Framework to Chatbots for Cognitive Behaviour Therapy*" (Vilaza et al. 2021b).

7.1 Interfaces for Research: Designing a Mobile Study App

The design process described in this case study was part of the development of the StudyApp, a mobile application for health research studies, through which participants answer daily surveys and contribute passively collected data. This app design consists of an initial step in a much broader software development project that aims to build re-usable software components for a 'generic' data collection mobile app that will eventually cater for varied types of health research (Bardram 2020). This chapter describes the stage of developing conceptual user interface designs for this StudyApp to achieve the project's purpose while prioritising ethical perspectives.

To support this design task and enable the exploration of a specific approach to ethical design, we chose to adopt VSD. The rationale for selecting this framework started with observing that this is a popular framework employed often in HCI publications (See Chapter 3). We then thought that 'values' could suitably encapsulate the user studies' findings needed to inform the design process (See Chapters 4, 5 and 6). This way, VSD tied to-

gether with the investigation of data contributors' perspectives, was employed to support the proposal of user interface features for the StudyApp project, as described next.

7.1.1 Methods

Value-sensitive design (VSD) is a design framework focused on human values and “what is important to people in their lives”, with a focus on ethics and morality (Friedman et al. 2008). VSD argues that digital artefacts can shape human experience by enabling (or hindering) users' values. Values are posited as different from ‘user needs’ in that they represent conscious choices that are usually less volatile and circumstantial — they might be understood as core human aspirations rather than current human necessities (Hayes et al. 2009). Nevertheless, they are essential to human welfare.

Different stakeholder groups might have conflicting values. Navigating such value tensions is both a challenge for VSD and a way for providing constraints for the design process. In the case of digital health research platforms, there exists a tension between researchers' needs for high-quality evidence and contributors' concerns with privacy (See Chapter 2). Existing platforms have often attempted to overcome this tension by prioritising data collection while also employing data protection techniques to de-identify data and, thereby, protect participants' identities.

However, as seen in the findings of Chapters 4, 5 and 6, data contributors often have privacy concerns that can hinder their acceptance regardless of efforts to keep data secure. For this reason, there exists an opportunity to consider alternative approaches to data collection and sharing that emphasise participants' values such that they can feel more comfortable contributing. We aimed to craft a prototype that demonstrates an intention to respect what data contributors consider most important by engaging in the following VSD process.

7.1.2 Empirical Investigations

The VSD approach entails phases described as ‘conceptual, empirical and technical investigations’. Empirical investigations consist of the study of the human context in which technologies are situated and the perspectives of users and stakeholders. In this case, findings from the user studies carried out in the initial phases of this thesis served as our ‘empirical material’ and evidence source.

The interview study described in Chapter 4 and the survey study of Chapter 5 investigated how data contributors perceive participation in a digital health research repository and how comfortable they feel sharing different data items. These studies revealed that the main reasons to contribute to health data repositories consist of helping patients and researchers, although there is also a strong interest in receiving other personal benefits in exchange for data contributions. Data access options perceived as desirable by data contributors include the control of data collection and use, driven by significant variation in individuals' willingness to share different types of information. We translated these key insights into a set of values of importance to data contributors through the process described next.

7.1.3 Conceptual Investigations

According to VSD, conceptual investigations comprise analytic, theoretical and philosophical explorations of the constructs in focus, seeking to define, for instance, working definitions of values. During this phase, our conceptual investigations aimed to take our empirical findings and identify the values that would best characterise them through reflection. After carefully pondering over possible combinations of values, we decided to focus on two central aspects in our design process.

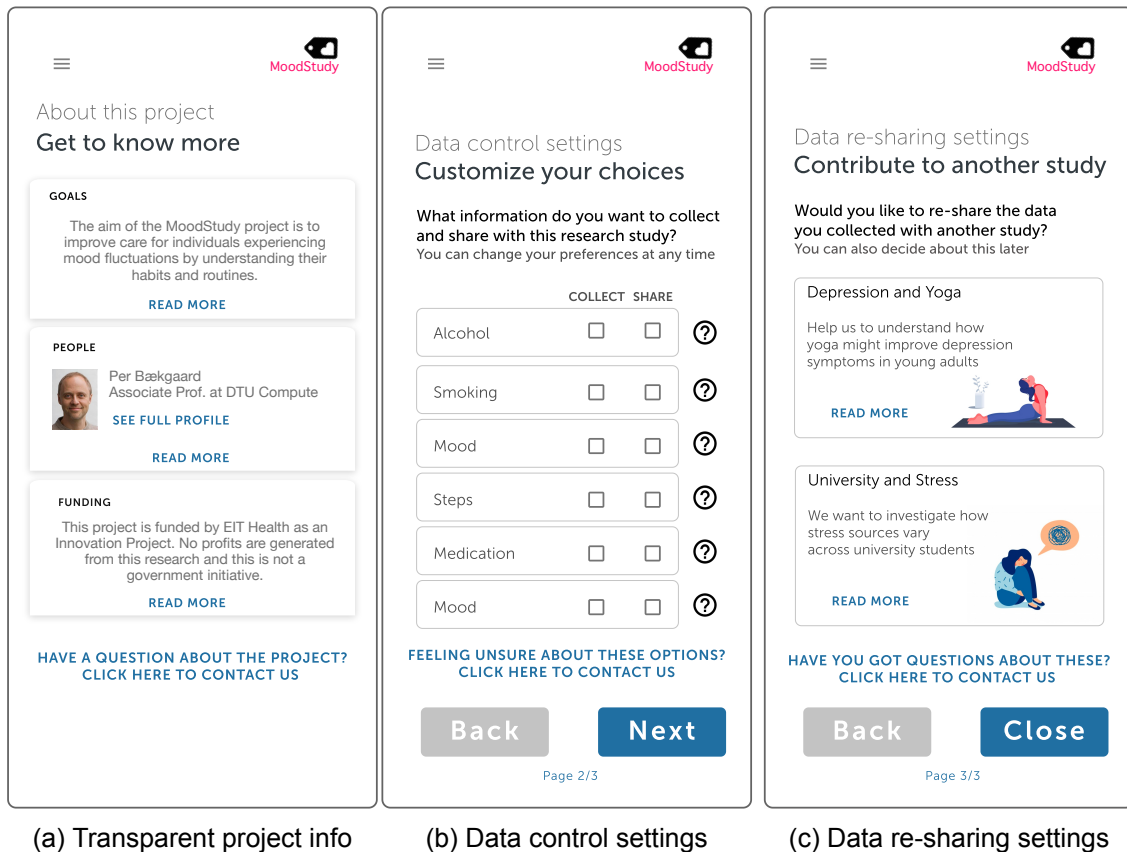


Figure 7.1: Health data interfaces supporting the value of agency

First, we defined users' desire for increased control and choice concerning the use and sharing of their data as best encapsulated through the value of *agency*. We conceptualised agency in our case as “the ability to influence or control outcomes” (Ahearn 2001). In digital environments, a user’s agency to take actions is often mediated through the affordances provided by computational systems and interface components (Harrell et al. 2009). In the context of digital health, user agency can thus be related to the mechanisms through which users can act upon choices over how data is collected, shared, and re-shared (Torous et al. 2019).

Second, we conceptualised users' desire to receive personal benefits, besides those societal in nature, in terms of the value of *reciprocity*. Reciprocity as a value here refers to the expectation of being rewarded for positive actions with other positive actions (Molm 2010). In the context of data contribution, reciprocity can take the form of material compensation; however, participants in our user studies often expressed an aspiration for more meaningful ways to be recognised for their contributions. They expressed interest in knowing how their data might be helpful to others, as well as a desire to build a relationship of mutual respect with data platform owners. Next, we describe how these two central values were used to inform a prototype created to illustrate our design proposal.

7.1.4 Technical Investigations

Technical investigations focus on how technologies can more readily support desirable values or render other values more challenging to realise. Value sensitive design proposes that technical inquiries may take the form of prototypes depicting how user interfaces support the values identified through conceptual and empirical investigations. We

took the values of agency and reciprocity as design rationales for the following prototyping process.

Following standard practices of user-centred design (Sharp 2003), we first sketched a low fidelity prototype to illustrate possible system features to enable agency and reciprocity. We used this low fidelity prototype to informally prompt discussions with another designer, a software developer and a researcher. Separately, we also showed the prototype to five young adults peers, unrelated to the project, asking for their input as potential beta users. Following feedback from these group discussions, we further designed a high fidelity interactive prototype to serve as input for the software developers' deliberations around the coding phase of the envisioned StudyApp.

Designing for User Agency

The value of agency led us to come up with health data interfaces to allow selection and customisation of the data to be collected, shared and re-shared (See Figure 7.1). First, an interactive form lets data contributors state their preferences about which data types they want to be collected and shared by ticking the respective checkboxes (See Figure 7.1b). This form also allows users to read more about why each data type is required for the research (clicking on the question-mark icon). Second, a similar form lets users express whether they would like to delete any data points from the platform permanently. Third, the value of 'agency' also drove the design of a data re-sharing request form to let users choose whether data already collected should be shared with other research projects (See Figure 7.1c).

In addition to these forms, a user interface informed the user about project goals, investigators, funding sources and the study duration (See Figure 7.1a). The 'read more' buttons display more detailed information in this interface. Users can contact the study owners at any time through the 'contact us' option in these interfaces. Users' agency was therefore enabled through choices regarding how data is collected, shared and re-used, while further supported by the possibility of contacting the research team at any moment.

Designing for Reciprocity

In terms of designing to foster a sense of reciprocity, we created several interfaces to allow users to more directly benefit from their contributions (See Figure 7.2). First, a personal health management interface provided visual summaries of the data collected, in line with the visions of personal health informatics, although not with the ambition to replace existing care structures (See Figure 7.2a). In addition to this feature and motivated by the need to support users regarding the interpretation of this data, we proposed another interface to allow users to schedule remote consultations with health experts best equipped to provide feedback on health indicators (See Figure 7.2c).

Reciprocity was also supported by channels for communication between researchers and study participants, thereby actively inviting data contributors to participate in the research process. The prototype included an interface displaying updates and news about the research projects and a button asking whether users would like to propose a theme for a research study (See Figure 7.2b). Other features to increase reciprocity and the feeling of being part of a community included social forums and learning materials. This design, therefore, pushed for a more participatory approach to health research studies by proposing user interfaces through which users could share their ideas and learn about the research. Similarly, the consent form was composed to show that participants are considered and respected as an integral part of the research process.

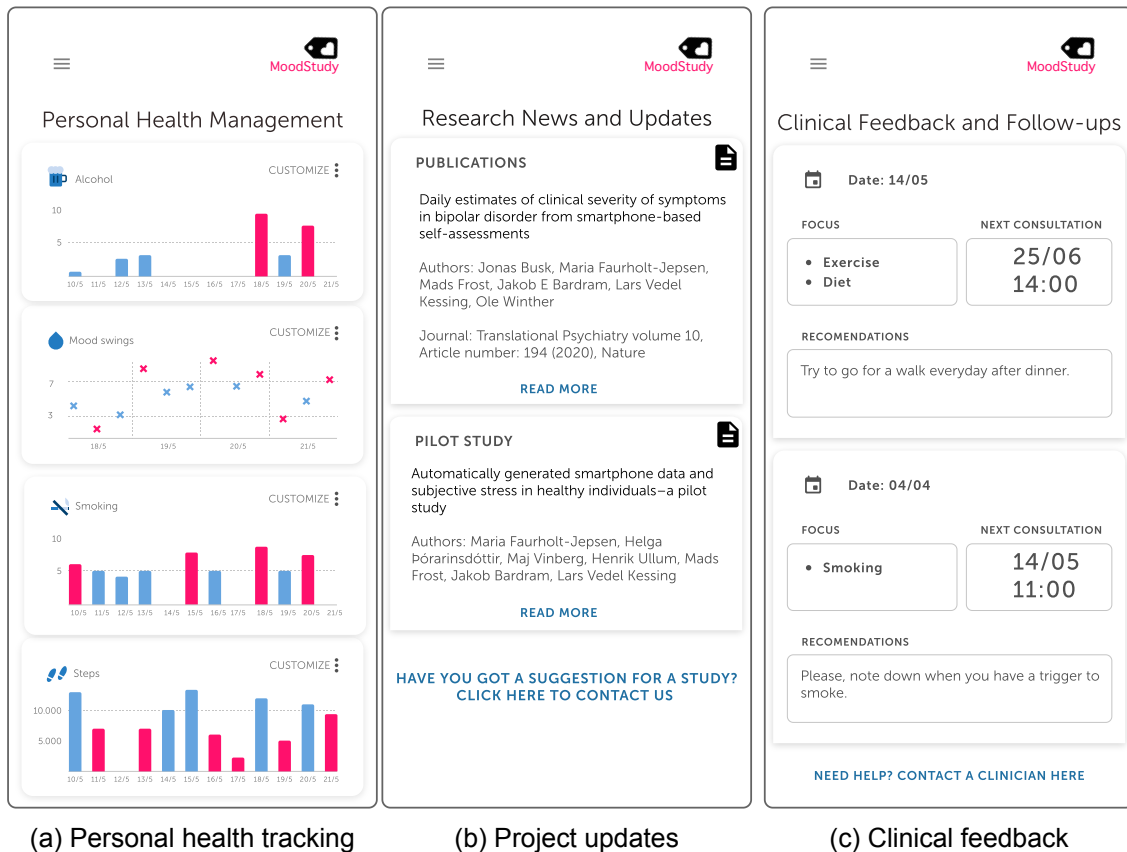


Figure 7.2: Health data interfaces supporting the value of reciprocity

7.1.5 Section Summary

This application of VSD to a specific and typical example of a health data technology shows how an ethically-grounded approach can orient designers' focus towards values otherwise not customarily emphasised. The result is a prototype used as the starting point for the conception of a functional app, serving as an example of the application of an existing design methodology to ethical design leveraging results from studies conducted with users. The features proposed here probably apply not only to the specific mobile app but other health data interfaces designed to support data collection and sharing for health research. We next describe how we explored a contrasting yet complementary approach employing a list of pre-defined principles to inform future developments.

7.2 Interfaces for Intervention: Analysing Chatbot Design

Another emerging and increasingly significant motivation for health data sharing pertain to disclosing emotions, symptoms, and personal events within a therapeutic context. As language modelling has become more sophisticated, a notable development in this space is the conception of conversational agents programmed to emulate the practices of psychotherapists (Lee et al. 2020). Chatbots for psychotherapy, especially for Cognitive Behavioural Therapy (CBT) are being increasingly promoted as credible tools that may enable broader access to psychological support and propitiate more comfortable means for self-disclosure (Inkster et al. 2018). Previous research has found, for instance, that end-users engage more with self-report and disclosure when interacting with automated virtual interviews (Lucas et al. 2017; Lucas et al. 2014). A well-known example of a chatbot for CBT is Woebot, which has had its effectiveness for depression and anxiety successfully

validated with a sample of university students (Fitzpatrick et al. 2017).

However, a recent review considered the responses of chatbots during suicide emergencies very limited and potentially harmful in nature (Vaidyam et al. 2019). Another particularly alarming issue related to digital interventions which collect sensitive information about mentally ill patients is the lack of trustworthy privacy policies (Mercurio et al. 2020). In the case of chatbots used for psychotherapy, disclosed symptoms and feelings represent confidential data sourced from individual lives that may lead to the realisation of those dangers discussed in previous chapters: data leaks potentially leading to cyber and physical attacks, social discrimination and data misuse without consent.

Ethical challenges, including inappropriate responses and data handling by these systems, make this an area in which users' well-being, and indeed lives, hinges upon the capacity to reflect on the critical requirements in this space. It is not surprising that the idea of automated psychotherapy is often met with scepticism by psychiatrists (Doraiswamy et al. 2020). There are increasing concerns regarding how AI developments can ever lead to safe, ethical and effective tools for psychological support (Thieme et al. 2020). Even though the primary goal of digital health interventions is to provide health support through digital interfaces, this data may be eventually re-shared for health research purposes, which points to all the ethical concerns extensively discussed throughout this thesis. Future developments, therefore, must consider these ethical issues if they are expected to be broadly and securely adopted by patients — as motivates the exploration described in this second part of this chapter.

7.2.1 Methods

The study of AI ethics has very often communicated and organised ethical considerations in terms of how they relate to core normative principles (Thieme et al. 2020). Previous research reviewing current AI ethics standards, guidelines and frameworks has argued that the debate over the impact of AI on society has primarily focused on five normative principles: beneficence, non-maleficence, autonomy, justice and explicability (Morley et al. 2021). In summary, it is commonly agreed that AI developments should strive to be beneficial to, and respectful of, people and the environment, robust and secure, respectful of human values, fair and explainable, accountable and understandable (Floridi et al. 2020; Royakkers et al. 2018). However, it is unclear how such normative principles might guide the appraisal of system features in practice.

For this reason, we apply an ethical framework to raise critical questions related to the specific context of automated psychotherapy using chatbots. As we also noted a similarity between using pre-defined 'principles' as a unit of ethical analysis and centring the design process around 'values', which we deemed as a valuable way to contrast these two approaches. The choice for which framework to apply was based on such a previous review of prevailing ethical principles present in AI-ethics frameworks in general (Morley et al. 2019). This framework served as a structure to guiding a group discussion between authors, who extensively brainstormed how each of the ethical principles might be unattended to by current systems and what future developments might take.

7.2.2 Results

Beneficence

The principle of beneficence entails providing positive value to individuals and society. Beneficence in the general context of digital health interventions is often connected to the prospect of spreading access to psychological support to more individuals in need (Roberts et al. 2018). However, the lack of regulation in the digital health market gives grounds for data to be used for other purposes that are not aligned with this understanding

of beneficence. For instance, the use of chatbots for the collection of sensitive personal data might have the goal of feeding profiling algorithms that in turn can be used in predatory advertisement and exploitative businesses (Gentsch 2019).

In addition, in the particular case of automated CBT, benefits can only be achieved if there is evidence of the efficacy of the intervention. However, the vast majority of digital psychology interventions are still in the testing phase or have only been evaluated for a short time (Provoost et al. 2017; Bendig et al. 2019). Although scarce, previous controlled research into clinical outcomes indicates that it is possible to demonstrate efficacy rigorously, but it can take time (Ma et al. 2019).

Besides restricting its goals to the supply of health support and perhaps clinical research, creators developing CBT chatbots should strive to inform users about the intervention's intentions and any indications of its efficacy in leveraging the principle of beneficence. Conversational dialogues, which are characteristic of chatbots, could be the channel to explain to users about such information items. Other interfaces surrounding this interaction (for example, textual content within the mobile app) could also contain informative materials.

Non-maleficence

The principle of non-maleficence advocates that not harming is just as important as doing good. Chatbots for CBT collect and use data voluntarily disclosed by users during therapeutic dialogues, yet the negative consequences of data leakage and misuse infringe the principle of non-maleficence. Even if accidental, the disclosure of intimate therapeutic content can lead to social discrimination due to the stigma attributed to mental illness (Corrigan 2000; Penn et al. 2003). Reduced employment opportunities and forensic investigations may harm individuals if data collected during psychotherapy by chatbots are made available to the government or companies (Martinez-Martin et al. 2018b).

Interaction with a chatbot can also be harmful, especially if responses might be inappropriate for the context (for example, if a user is disclosing thoughts about suicide). Chatbot failures are aggravated by the fact that after a negative experience, users might be less willing to engage with in-person clinical support as well (Bauer et al. 2017). Non-maleficence applied to the context of automated psychotherapy involves not only protecting data privacy but also considering if the feedback provided after a data disclosure might be detrimental to end users' health (Miner et al. 2017).

Above all, CBT-chatbots should strive to attend to non-maleficence by keeping data secure and private. In addition, unlike traditional in-person psychotherapy, many chatbots maintain a textual record of conversations, which means there should be ways to alert users of the risks this imposes. Chatbots' dialogues could be the vehicle for this type of communication, for instance.

Explicability

The principle of explicability refers to the capacity of outcomes to be made transparent and understandable. This principle has often been linked to privacy policies concerning data disclosures for digital health interventions. While some individuals may readily agree to use chatbots for digital psychotherapy, they might not fully understand the terms and conditions regarding using and re-using the data they disclose (Martinez-Martin et al. 2018a). Furthermore, it is not always clear to end-users the limitations of the responses of an artificial agent (Luger et al. 2016). In the case of psychotherapy chatbots, the lack of explicability to how dialogues are artificially produced might also have consequences for end-user's beliefs in therapeutic effectiveness.

As extensively discussed in previous chapters, past research has emphasised that word

choices and excessive length compromise the explicability of legal clauses and obfuscate aspects of high importance to users, such as how their identity is protected (Ostherr et al. 2017). For this reason, the consent provided is often deemed not valid if users do not grasp the data-sharing permissions entirely (Martinez-Martin et al. 2018a). Therefore, it is not sufficient to provide information to users - it is recommended that this information should come in language and a format that facilitates comprehension on behalf of all populations (Luger et al. 2013).

Autonomy

The principle of autonomy is related to the capacity of individuals to act and make choices freely. This principle is harmed when users cannot choose how data is used and re-used, as discussed in previous Chapters. To protect their autonomy, individuals may choose not to disclose certain aspects of their life out of fear of potential data breaches and disciplinary actions that might restrict their activities in the future (Rooksby et al. 2019). End-users should be offered ways to control how data is potentially shared beyond the therapeutic context. Data permissions could also possibly be requested through the chatbot dialogues.

Autonomy is also breached if users become liable to manipulation, as in the coercive selling of system upgrades so that users can get access to therapy (Gentsch 2019; Hille et al. 2012). Manipulation is a well-known form of unethical conduct in traditional psychotherapy, yet is currently less regulated within digital interventions (Koocher et al. 2008). A lack of autonomy can constrain the formation of a healthy therapeutic alliance grounded in trust, and for this reason, end-users should not be forced to accept conditions that may prove detrimental to their progress.

Justice

The principle of justice promotes equality, inclusiveness, diversity, and solidarity. The unequal inclusion of end-users from different backgrounds in research and development is a well-known source of algorithmic bias and injustice, leading to the creation of systems that fail to reflect the needs of minorities. In the particular case of chatbots, the data from which language models are built may be tainted with racist, sexist, and discriminatory speech that, if left unattended, can be harmful to end-users (Schlesinger et al. 2018). Such disrespectful health data interactions are aggravated by the absence of regulation and ethical standards for medical devices that attempt to present AI and health data use as innovative advantages (Martinez-Martin et al. 2018b).

The principle of justice can be understood in terms of responsibility attribution and accountability. Recent evaluations of AI ethics have highlighted that current regulations lack mechanisms to reinforce and punish negative consequences for ethics violations (Hagendorff 2020). Past research has pointed out that strict guidelines for the development of AI for medical devices are still missing as of today, thus further complicating matters of justice in this context (Bauer et al. 2017). Without definitive positions regarding accountability, it remains unclear which entities should be responsible for ethical issues related to therapeutic disclosures made through chatbot interaction (Berscheid et al. 2019).

It is challenging to consider the application of justice only in terms of user interface design. However, some choices that may help to attend to the principle of justice include the creation of datasets that respectfully address discriminatory speech and considering how pricing, hardware/software requirements, and language might hinder access to intervention. Another approach that goes beyond the design of user interfaces could be to adopt existing accountability and risk mitigation strategies employed by healthcare workers (Nathan et al. 2015).

7.2.3 Section Summary

Despite the strong appeal of automating psychotherapy, such endeavours must be considered with caution. In a similar fashion to the discussion of health data interfaces for *research purposes*, there are fundamental challenges to be tackled in the context of *health interventions*, which could be surfaced through the engagement with the five core principles. The use of the AI-ethics framework led to several suggestions pointing towards the use of chatbot dialogues as the interface through which general information and data permissions might be communicated and configured — an idea that avails of the specific features of this type of health data interface.

7.3 In Summary

In this chapter, human values and ethical principles allowed us to explore the unique circumstances through which data contributors may voluntarily disclose data through these interfaces. As a result of these methodological explorations, we contribute design implications for developing two specific health data collection interfaces: a mobile app designed to support health research studies and chatbots designed to enable psychotherapy. Regarding future research, the StudyApp will be developed further for a research project involving children with Obsessive-compulsive Disorder (OCD). A 9-week feasibility study will assess how ten families feel while using the app through the User Experience Questionnaire (Laugwitz et al. 2008) and Trust Scale (Gulati et al. 2019), and post-study semi-structured interviews will guide further iterations. Similarly, future projects concerning conversational agents for mental health intend to follow up on some of the challenges brought forth by the analysis of chatbots for CBT this time with the engagement of actual end-users.

Even though empirical findings and explorations of methods provide insight into ethically-oriented design, this may not be enough to shape practice. Technology creators might need to learn how and why to apply ethical thinking to user-centred design processes. Motivated by the vital role of educating future generations of technology creators, the next chapter turns to studying how others may learn and apply approaches similar to the one described in this chapter.

8 Practising Ethical Design | Educational Approach

As we have learned in our review of ethics across HCI presented in Chapter 3, computing ethics education is increasingly advocated for preparing university students for the complex design dilemmas they are likely to face in their future workplaces. Precisely how this can be best achieved, however, remains an open question. Our own experiences applying ethical thinking to technology design led us to explore how to teach others to do the same, thus contributing to the emergent ethics education efforts. We conducted a pilot study with engineering students from the Technical University of Denmark enrolled in an introductory UX Design class to observe how they engaged with ethical principles during a prototyping activity. This chapter describes the results of this pilot study and continues to move forward the work of this thesis by exploring technology creators' perspectives following their attempts to put ethical design into practice. The content of this chapter is drawn from the research paper *“Teaching User Experience Design Ethics to Engineering Students: Lessons Learned”*, currently under peer-review (See Paper 2.7).

8.1 Introduction

Ethics education comprises a much-needed foundation for the next generations of designers and developers (Skirpan et al. 2018a). The inclusion of 'computing ethics' in university programmes has been considered essential to preparing future professionals to face the increasingly urgent dilemmas on the role and impact of digital technologies in society (Gray et al. 2018; Chivukula et al. 2019). Pedagogical approaches for teaching ethics have included: first-hand experiential learning to facilitate empathy-building towards accessibility issues (El-Glaly et al. 2020), role-playing games for simulating the process of writing and adhering to privacy policies (Shilton et al. 2020), and science fiction writing to encourage moral imagination in relation to the drawbacks of AI (Burton et al. 2018).

Another possible teaching approach, however, less often explored by the literature pertains to the use of top-down ethical frameworks to guide students' design work. The development of 'ethics checklists' is an increasingly common practice among technology companies as means of attempting to alleviate the difficulty practitioners face when it comes to operationalising abstract principles (Madaio et al. 2020). Previous pilot studies indicated that ethical questions are a helpful starting point when it comes to exploring ethical considerations in the classroom, but similar approaches are yet to be evaluated in the context of health data ecosystems (Saltz et al. 2019). We conducted the following pilot study to understand how this approach might be applied to this application domain.

8.2 Teaching Context

The pilot study investigated how the students applied purposefully-designed teaching materials to support their design work during this one-week project. The study was conducted as a part of an introductory UX Design course, in which lean business models and design thinking were core components of the teaching program. Weekly classes consisted of one-hour lectures followed by 3 hours of supervised group work (with teaching assistants). After the class, students were asked to prepare and submit a set of deliverables (business model canvas, user story maps, interactive prototypes, a report on prototype evaluation) based on a design brief. The course was therefore structured using 'project-based learning' pedagogy (Kokotsaki et al. 2016).

The pilot study took place as part of a particular project in which students had to design in groups a prototype for a smartwatch app that would be used to collect, visualise and share heart rate data between patients, researchers and doctors (See Figure 8.1). The design brief was motivated by previous research arguing that wearable technologies can empower patients at risk by continuously monitoring their heart rate and alerting them and their doctors when episodes of cardiac arrhythmia arise (Kumar 2021). The assignment description also explained that data collected through the smartwatch was meant to keep clinicians informed about the status of their patients in between consultations and that data could serve as material for scientific investigations.

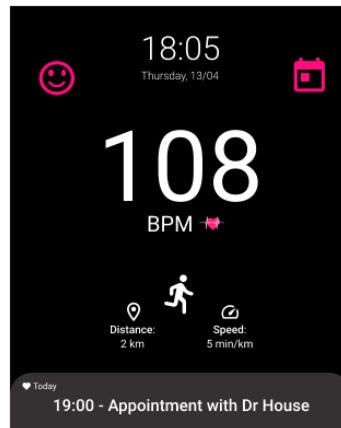


Figure 8.1: Example of a smartwatch prototype created by a group of students

8.2.1 Educational Materials

An essential part of this pilot study was the design of the teaching materials. Lecture slides were prepared with the goal of introducing students to the connection between ethics and UX design. The slides presented examples of user interface design choices that may infringe upon ethical principles as a way to illustrate why ethics is important. These examples of unethical design included interfaces that do not offer data sharing options, are not transparent about data use, attempt to exploit users for profit, actively exclude minorities and foster harmful behaviours, such as eating disorders. The principles being infringed upon in these instances were: choice, transparency, reciprocity, inclusion and well-being (See Figure 8.2¹).

This work further builds upon the ethical principles chosen to structure our critical analysis of CBT-chatbots (Morley et al. 2019) and the framework by Nebeker et al. 2019 for actionable ethics in digital health. We adapted the names of some of the principles to a more friendly vocabulary so that the students could more easily develop a shared understanding of these concepts. It was explained to the students that ethical principles are one way of engaging with ethics during the design process and that the primary goal of learning about these principles is to facilitate the articulation of ethical requirements.

In addition to the lecture slides, two templates² were designed as tools to support group discussion and self-reflection. Students were asked to use the templates at any stage of their design process (before or after designing the prototype) and adapt these ethical inquiry templates to the particularities of their own projects.

The first template consisted of a checklist (See box 8.1) containing items to remind the

¹Figure extracted from Paper 2.7

²Templates extracted from Paper 2.7



Figure 8.2: Infographic illustrating the five normative principles taught to the students

students of ways in which their prototypes could respect the above principles (“The system is transparent about how data is used and shared”). The second template was an online form (See box 8.2) that students could also adapt and send to their peers (or users) to collect external feedback, including questions such as “From not at all (0) to completely (7), how much do you think the system is transparent and clear about how it works? Why?”.

8.3 Method

The pilot study evaluating the educational approach described above was carried out after the students delivered the prototypes and reports for the class assignment. Semi-structured interviews were conducted with those who volunteered to participate in the evaluation study. The goal was to collect qualitative data from the students about their learning experiences.

Participants were 12 students at the Technical University of Denmark, taking a 13-week course on UX Design. A teaching assistant conducted interviews to ensure confidentiality from the professor responsible for the class. Audio recordings were transcribed, and an inductive Thematic Analysis was conducted following Braun and Clarke’s framework (Braun et al. 2012). Further details on how the study was conducted can be found on Paper 2.7.

8.4 Results

8.4.1 The Approach Raised Awareness

Across the sample, UX design ethics was described as a topic not yet examined by many of the students until the UX design course: *“It is the first time I hear about ethics in design”* (P2). Nonetheless, at least half of the students expressed being interested in the subject: *“I have not thought about it, but as soon as I read it, I was like, okay, this is important, it is something that I really want to address because ethics is something that I care about”* (P11). The educational materials were said to be effective in bringing the topic to the students’ attention: *“The lecture you gave raised some awareness. Since that lecture, ethics has been part of our work in the group”* (P1). The introduction to UX ethics also changed some of the students’ perspectives about UX design: *“We thought about ethics, but maybe not in a good way. We did the opposite with the previous courses. We thought:*

Choice

- The system allows users to choose and select their preferences
- The system does not force single options to users (for example, I accept)
- The system allows users to change their mind and select a different option later

Transparency

- The system provides enough information about how it works
- The system is transparent about how data is used and shared
- The system does not hide important information on purpose

Well-being

- The system is designed to help users to improve their well-being
- The system does not make users' well-being worst (for example, making them anxious)
- The system provides direct support to users in case they suffer physical or emotional harm

Inclusion

- The system is directly targeted to attend the needs of at least one marginalised group
- The system does not exclusively target only over-represented groups
- The system does not exclude people of different races, disabilities, gender and cultures

Reciprocity

- The system is useful by offering direct and significant benefits for the users
- The system does not use manipulation techniques to get users to spend money
- The system is not built to take advantage of users for business gains

Box 8.1: Checklist template

how can we be as evil as possible with this? How can we gather as much data? How can we blackmail the user the most? Now we think the opposite” (P6).

8.4.2 Principles Helped to Discover Concerns

Most students perceived the templates as helpful guides as to what to pay attention to when designing user interface features: *“What we did was to use the templates, and that is how we learned how to do it. Without the templates, we would not be able to know what to change”* (P5). Participants used the principles of the templates to discuss ethical issues as they attempted to prioritise ethical considerations in their prototypes: *“We tried to add more things to the smartwatch regarding transparency and freedom of choice”* (P4), and *“We were thinking about choice, being able to know what you are showing and having more settings. In the first app that we made, we did not have settings”* (P11). The students also discussed how they tried to address concerns related to potential harms to well-being: *“The whole point is trying to make the users not feel bad if they have not done something they should have done. The notification could like tell them to go out for a walk without trying to make them feel bad and just try to stay positive”* (P10).

8.4.3 Ethics Was a New Topic to Many

Given that the topic was a novelty to most, a lack of previous experience made the activity challenging: *“I feel hesitant, doubtful, concerned because I have never heard of the topic before”* (P2). The lack of specialised domain knowledge (healthcare) was also perceived as an obstacle: *“We felt a lack of knowledge because in this particular case, we need a doctor to say what is more important. Maybe it could be nice to have more health information because we know this is something we should take into consideration but we*

From not at all (0) to completely (7), how much do you think the system...

1. ... allows users to choose and select their preferences? Why?
2. ... is transparent and clear about how it works? Why?
3. ... promotes well-being and protects users from harm? Why?
4. ... can be used by diverse races, gender identities and physical mental abilities? Why?
5. ... provides mutual benefits for owners and users without manipulation? Why?

Box 8.2: Feedback form template

do not know the potential damage” (P4). In particular, a participant expressed feeling incapable of knowing how to design for disabled users: “I don’t know how to include the disabled. I think it is important, but I have no idea how. You must be the blind person to understand the blind person” (P2). Similarly, another student was also not aware of how blind users could use mobile phones: “One of the comments that we kept getting when we were reviewing each other’s solutions was that blind people would not be able to use this but are blind users even able to use apps?” (P1).

8.4.4 Some Perceived Ethics as Not Important

In contrast with the above findings, a small number of students commented that they believed that ethics should not be a priority in design: *“I think it was a good add on to the course, but I do not consider it being a high priority”(P1) . In their view, ethical ideals can hinder business opportunities: “I think it is rather unrealistic to incorporate ethics in such a corporate area. How would you ask big corporations or developing companies to be more aware of ethics if it is clear that their primary concern is money?” (P2). One participant, for instance, explicitly stated that ethics was an obstacle to profit: “Data is money, and all I ever wanted is to make money. So we need all the data even if you do not want to share it, that was our app’s logic: money” (P7). As one of the participants alternatively remarked, getting a high grade was ultimately their own most important motivation: “In the end, we were caring about a good grade, so I am not going to lie this was the reason behind” (P3).*

8.4.5 Group Members Had Conflicts

Social dynamics played a role in how group discussions were held within teams. A few students mentioned that it was challenging to reach a consensus in the group: *“We have been able to agree on many things, but we are a group of people who do not know each other very well, so we do not always turn out super compatible. It is hard to say: ‘I think you should change all the work you just did’ ” (P12). A reason for disagreements could be found in the different levels of interest each member of the group had: “We were more interested in it than the others. It is not that they were against it, they just did not care” (P12). One of the students mentioned that in order to handle such conflicts, the group resorted to the feedback of other peers: “The moment one has a question and asks the group, but we cannot agree in a few minutes, we decide to validate the concept with others” (P5).*

8.4.6 Time Pressure Was Frustrating

Given the requirements for weekly deliverables, time was a scarce resource, which meant that students had to decide what to prioritise. However, ethics was perceived by many as a topic that demands a longer time frame: *“At that point, we were too busy and concerned with the next hand-in. We were just going to leave it because we did not have much time. We were not making great philosophical discussions about everything, but if we*

had a longer time frame, we could do it” (P2). A suggestion made by one participant was to learn from examples in order to speed up the process: “Maybe we could see some examples of how to implement it more quickly” (P3). Besides a lack of time, a small number of participants expressed a desire to start the design process from a perspective of ethical deliberation rather than discussing ethics as an after-thought: “It felt stressful and frustrating because it was late in the process, and I feel like that is something that should have come earlier” (P11).

8.5 In Summary

This pilot study demonstrated the possibilities and limitations of teaching ethics by asking students to use ethical principles to guide their prototyping activities. Our pilot study effectively raised students’ awareness, and the structured templates (a checklist and feedback form) provided helpful guidance. On the other hand, the challenges students experienced during the process serve as valuable insights for future education efforts. It became clear that there is a need for more extensive teaching methods, complemented by real-world user engagement if possible, and exercises for empathy-building. This exploration of the teaching of ethics complements the other approaches to ethics explored in this thesis by recognising the impact of grounding design decision-making in ethical principles and supporting the education of technology creators that may develop future ethical health data ecosystems. The next chapter serves to provide further reflection on this approach to supporting ethical design, as those others presented, explored and promoted through the work of this thesis.

9 Discussion

One of the primary and most persistent challenges in technology development to date pertains to integrating ethical concerns into design processes, especially when it comes to technologies that directly affect collective matters of civic life. Throughout this thesis, we have identified, discussed, and applied a portfolio of approaches to raising ethical considerations in practice. The evidence gathered from our engagement with young adults and young technology creators allows the integration of research findings into design recommendations for health data interfaces that respect data contributors' values.

This final chapter connects the results of this extensive research project set to “discover and act upon ethical requirements to design respectful health data flows” (See Chapter 1). Our road map started from a thorough understanding of the socio-technological context at hand (See Chapter 2), which then served as the foundation for the subsequent user studies (See Chapters 4, 5 and 6). With the knowledge gathered directly from data contributors and technology creators, we could conceptually envision and critically assess health data interface designs (See Chapter 7). We then moved to promote what we have learned to future generations of designers, researchers and developers (See Chapter 8). Ethics was, therefore, the core thread uniting these investigations and this engagement with ethical thinking was majorly supported by the scoping review we conducted (See Chapter 3).

The following sections highlight key implications derived throughout this PhD project and discuss our reflections about the overall process. These insights are also further linked to the relevant literature. As for the more detailed consideration of methodological limitations, this can be found in the respective discussion section in each of the papers available in Part II of this thesis.

9.1 Understanding What Matters to Data Contributors

In our review of existing health data repositories, we have discussed how digital health has traditionally focused on the needs of those consuming data: clinicians, researchers and public workers (See section 2.2 in Chapter 2). As a consequence, those who store and use the data (not those who produced it) have traditionally retained the power and knowledge that comes with data ownership (Shilton et al. 2021). The work of this thesis in its collective form makes a case for turning the focus towards understanding in greater depth the perspectives of those contributing data — in itself an essential step towards more ethical health data ecosystem design.

This shift equally requires and results in a revised conceptualisation of ‘public acceptance’, according to which individuals ‘accept’ to contribute because they feel comfortable disclosing their personal data and believe this act will be beneficial both to society and themselves. Data contributors are vital to health data repositories, yet they are much more than objects to be observed or a collection of entries in a database (Doherty et al. 2020). The narrative review of contributors’ willingness to share data described in Chapter 2 and the combined work of the user studies presented across Chapters 4, 5 and 6 highlight and reinforce the critical nature of the three components for this ethically motivated acceptance: reciprocal exchange, privacy boundaries and trusting relationships.

9.1.1 Reciprocal Exchange

Ethical incentives are essential to communicating and realising the benefits of data sharing (See section 2.3.1 in Chapter 2). In contrast with usual research practices involving humans, the survey study conducted in this thesis work showed (across a sample of 1600 respondents) that material compensation does not represent the most appealing of motivations (See section 5.3.3 in Chapter 5). Options such as 'suggesting new research questions' were rated as very appealing for more participants than the possibility of receiving financial benefits, for example. Such evidence implies that ethical participation should probably entail meaningful incentives beyond money.

The prospect of helping future patients and future researchers appears as a powerful incentive. Both the survey and interview studies (See section 4.3.1 of Chapter 4) revealed that participants have a desire to help others through their data contributions, aligning with prior literature emphasising the importance of altruism and beneficence in motivating people to participate in research (Kraft et al. 2018; Tan et al. 2018; Ziefle et al. 2016). The focus group with technology creators conducted in the earlier stages of this thesis further complemented these findings with experts' commentary to a shared belief that generating scientific discovery should be the main reason leading people should agree with data sharing (See section 6.3.1 of Chapter 6). For this reason, it is crucial that data contributors are appropriately informed about how their contribution actually enables advanced clinical research.

Besides such demonstrations of selflessness, previous research about genetic data analysis has shown that learning about their own health can also be a significant motivation for volunteers (King 2019; Nobile et al. 2013). This observation was confirmed through the work of this thesis concerning a broader sampling of data types (for example, mobile sensing data). Participants in both the interview and survey studies demonstrated a strong interest in getting feedback about their health status. While this interest is likely connected to the innate human desire for growth and self-actualisation (Maslow 2013), the provision of personal benefits in return for data exchange points also to the value of 'reciprocity', as surfaced and discussed during the design of the StudyApp in the latter stages of this work (See section 7.1.4 Chapter 7). In the same way that individuals may therefore agree to disclose sensitive information with a chatbot to receive the benefits of therapy (See section 7.2.2 in Chapter 7), this thesis highlights reciprocal exchange as vital to the ethical acceptance of health data sharing; for research and intervention.

However, the way that personal health feedback is provided to patients and citizens must be mindful of individual preferences. A key finding of the survey study we conducted is that those uncomfortable with sharing alcohol consumption, levels of stress, and physical exercise are less likely to be interested in receiving feedback about themselves (See Chapter 5). Feelings of shame can probably explain this correlation, as participants in our interview study expressed feeling ashamed of their alcohol and tobacco consumption, for example (See Chapter 4). The technical students on our pilot teaching study have also observed that providing continuous heart rate measures for patients presenting cardiac arrhythmia can make them even more stressed and concerned (See Chapter 8). These findings together confirm that in order to return personal data in the form of health feedback ethically, technology creators must consider each individual's conditions, and a 'one-size-fits-all' generic design will probably not attend to such divergent needs (Bhat et al. 2020).

9.1.2 Privacy Boundaries

Much prior data sharing research has focused on the important question of privacy (See section 2.3.2 in Chapter 2). As part of this thesis, the interview and survey studies shed

light on data contributors' divergent views on the privacy risks associated with different data types, corroborating prior literature (Bhatia et al. 2018; Ahram et al. 2014). Our user studies extend these previous findings with a much more nuanced understanding of contributors' willingness to share both digital and non-digital sources of data. This analysis highlights that a desire for privacy protection is strongly related to the personal perception of risks - a finding elevating the need for technology creators to consider designs that target the specific reasons behind data contributors' reluctance to share each data type (Barkhuus 2012).

Data collected through mobile and wearable sensing technologies, for example, were perceived as uncomfortable to be disclosed by most, even more than the very revealing DNA samples (See section 5.3.5, Chapter 5). Our interview study indicated that participants were more reluctant to reveal information if they could not see a connection with research goals, and many were negatively surprised to learn that digital data sources, such as location tracking and texting patterns, are being used in scientific investigations (See section 4.3.3 in Chapter 4). This evidence is particularly relevant to digital health researchers intending to request access to mobile and wearable sensing data, as they might need to re-consider if the benefits of collecting such data sources surpass the discomfort people might have with this prospect.

Our survey results further indicated that the more granular the data types were, the more the contributors were unwilling to share them - even if the data was de-identified (See section 5.3.5, Chapter 5). The *frequency* of texts and calls was, for example, considered more comfortably shared than their *content* — participants in our interview study reasoning that such detailed data yielded additional risks to individual safety and freedom, including hacking and stalking concerns (See section 4.3.3, Chapter 4). Data contributors' discomfort sharing data sources that expose their location, social communication style, and phone usage can therefore compromise an ethical and broad public acceptance (Rooksby et al. 2019).

In particular, those unwilling to share data about diagnoses of mental illness were found to be more likely to fear social discrimination according to our survey study (See section 5.3.5, Chapter 5). Participants of our focus group study also raised the same concern, stating that end-users often perceive mental health data as a very sensitive type of information (See section 6.3.2 of Chapter 6). Similarly, we have also discussed the harms that the leakage of therapeutic disclosures made through automated psychotherapy technologies could represent to patients (See section 7.2.2, Chapter 2.6). When taking these insights together, it becomes evident that digital health innovations that target patients suffering with mental illnesses must consider what is at stake for these users who willingly open up about a part of their lives that can damage their reputation, employability and self-esteem (Murnane et al. 2018; Rooksby et al. 2019).

9.1.3 Trusting Relationships

This thesis shows that when it comes to designing health data flows, trust matters. Our survey study found that most data contributors fear that health data can be misused by unethical agents, which is a clear indication of lack of trust (See section 5.3.4 of Chapter 5). The Brazilian survey sample, in particular, perceived the idea of sharing data with public entities as less acceptable than the Danish one - a finding most likely related to the lower level of trust Brazilians display in government institutions (Zammar et al. 2010; Middleton et al. 2019). In contrast, people living in Denmark felt comfortable with the prospect of allowing repository owners to decide how their data is used (Duckert et al. 2022). These insights demonstrate that it is crucial for data contributors to believe that they can trust

those requesting access to their data for having ethical conduct, as negative experiences can erode trust as well as scandalous data abuse episodes (Murmann et al. 2017; Kizilcec 2016; Rieger et al. 2019).

Prior research frequently highlights transparency as a vital enabler of trust, especially when individuals have their initial expectations violated and need to clarify inconsistencies (Ziefle et al. 2016; Adjekum et al. 2018; Shklovski et al. 2014). Most of our survey respondents expressed a desire to receive continuous information about who is using their data (See section 5.3.6, Chapter 5). This finding can be explained on the basis that people often feel more comfortable if they know that their data will benefit the common good and not others' profit-making (Patil et al. 2016; Ostherr et al. 2017; Kraft et al. 2018; Bhatia et al. 2018). Our discussion about the principle of explicability concerning CBT-chatbot design (See section 7.2.2 of Chapter 7) also highlights that it is vital that technology can be seen to behave in ways that respect users' expectations. Therefore, the results of our studies with data contributors and technology creators in combination point to the urgency to consider transparent communication in future developments.

Another critical component for trust in this context is user autonomy. Comments made by data contributors across all phases of this work express the importance for them being allowed to have a choice over decisions made regarding who can use their data and for which goals (See section 4.3.2 of Chapter 4). Previous research has further emphasised that merely notifying individuals about possible data re-use is considered less acceptable by data contributors than requesting their permission for each new data usage - another evidence of the crucial role of respecting user autonomy (Ostherr et al. 2017; Ludman et al. 2010).

However, as shown by this thesis' review of health data repositories (See section 2.2, Chapter 2), most larger-scale initiatives still rely on a broad consent approach, which means that projects can use data at any time without contributors having any autonomy. For these reasons, we posit that shifting to more granular consent styles and increasing data control choices is vital in enabling freedom and choice. We explored such an idea in the design of the StudyApp (See section 7.1.4, Chapter 7) and the same way of thinking can probably be applied to other common forms of health data interfaces as well. In further exploring the translation of research findings to design implications, the next section expands recommendations for future developments for health data interfaces.

9.2 Designing Future Health Data Interfaces

The previous section emphasised and discussed the role of reciprocal exchanges, privacy boundaries and trustworthy relationships in fostering an ethical acceptance of health data technologies. Translating such abstract concepts into design choices is, however, a challenge in itself, as seen in our pilot study with technical degree students (See Chapter 8). This thesis offers paths forward by providing and discussing a set of broad but well-informed design alternatives based on the evidence gathered in the user studies and the literature. Whilst the subsequent implications for design might be particularly relevant to young adults, who were the main focus of the user studies conducted in this thesis, findings may still hold value to other populations, as findings appear much aligned with previous discussions in the literature.

The following design recommendations build upon an 'emancipatory' vision for the future of health data sharing. As outlined in the ACM Interactions Magazine article 2.8 (available in Part II), paths to public acceptance should be grounded upon the ethically justified need to collect personal data in the first place. Then, any initiative to collect, store and re-share

health data should act responsibly to correspond to the expectations of data contributors instead of attempting to coerce individuals to accept unfavourable terms of conditions. In this conceptual design vision, health data repositories position citizens and patients as ‘permanent owners’ of their personal health data, even after data is stored in a repository.

The evidence collected in this thesis serves as evidence for conceiving such respectful designs that may help achieve the desired societal benefit: better healthcare for all. Abusing this knowledge to coerce individuals to share data despite their concerns, merely to increase public acceptance, would not be an ethical path. The following recommendations aim to turn the experience of health data contribution into a rewarding interaction that prioritises individual well-being, safety, and freedom, as most of the existing platforms have so far focused on catering for the needs of data consumers - clinicians, researchers and public workers (See section 2.2 in Chapter 2).

9.2.1 Alternative Interface Modalities

The conceptualisation of health data as ‘flows’ and ‘interfaces’ allowed us to convey that when data ‘flows’ between entities, consumers and contributors interact with these flows through user interfaces. According to this abstraction, an ‘interface’ does not necessarily have to be materialised as a *digital* user interface such as the StudyApp we prototyped (See section 7.1.4 of Chapter 7). Non-digital options (for example, paper-based form and face-to-face encounters) can even potentially attend to a more diverse group of people who may not have access to digital devices, which is crucial to supporting inclusion and accessibility (De Sutter et al. 2021). Technology creators should stay open to blending digital and non-digital designs to realise optimal configurations for the interfaces composing health data ecosystems. Interfaces can consist of e-mails, letters, news, reports, landing web pages, chatbots (See Chapter 7) - each artefact thus mediating how people understand, take ownership of, and create value from data.

9.2.2 Transparent Communication

Regardless of the interface chosen, transparent communication is extremely important for health data interactions. Requirements surfaced through the user studies of this thesis include that the organisation(s) managing data repositories should be more transparent about: who is accessing data, the goals of individual projects and whether any entity might be profiting as a result. Moreover, most survey participants also expressed being interested in receiving updates about the outcomes of research conducted with their data (See section 5.3.3, Chapter 5). Depending on the setup of the health data repository and the preferences of its users, these information items could be transmitted through many different channels, such as web-pages, e-mail newsletters, data collection mobile apps and even paper-based postal correspondence. The most important is to provide this information in a way that data contributors can access it at any point, even after formally providing consent, in order to allow them to become aware of what is happening with their data and privacy (Duckert et al. 2022).

9.2.3 Interactive Learning Opportunities

There is also an opportunity for technology creators to use interactive learning materials creatively. Our interview study shows, for instance, that data contributors are intrigued about the connections between health outcomes and passively sensed behaviours (See Chapter 4), even though this seemed obvious to the technology creators in our focus group (See Chapter 6). The goal of adding easy-to-digest educational resources could be to invite data contributors to understand better how their contribution is relevant and become more aware of possible risks. In addition, even though it can be challenging to convey technical aspects of security and anonymisation protocols (Clark et al. 2019), our

user studies found that people desire to be able to understand how their data is protected and the potential risk of retracing personal identities. Insights and recommendations from science communication studies could further help on this endeavour, such as a stronger focus on not only conveying messages effectively but also engaging with the experimental, cultural and affective dimensions of the meaning-making process it triggers (Davies et al. 2019).

9.2.4 Personalised Health Feedback

The findings of this thesis furthermore underline the possibility of providing meaningful feedback in support of personal health goals, following the ‘quantified-self’ movement (Fleck et al. 2010). However, despite the appeal of data visualisation and quantitative measures of health, previous research argues that personal health tracking design should be careful not to trigger excessive self-scrutiny and low self-esteem (Chua et al. 2016; Murnane et al. 2018), especially among young adults who can become obsessed, anxious or deeply frustrated (Kelley et al. 2017). Some patients might also need the supervision of specialists to interpret health information appropriately, which means that simply giving people access to statistics and behavioural metrics can prove overly confusing and misleading (Mentis et al. 2017; West et al. 2016). Previous research has further advised against the promotion of an intense ‘datafication’ of well-being, as not every data point can be a reliable indicator of health (Chandwani et al. 2016; Bhat et al. 2020; Epstein et al. 2016). For these reasons, even though data contributors are interested in receiving personalised feedback and designing for that could be a way to promote ‘reciprocal exchanges’, it is fundamental to consider the arguments of this previous research before developing potentially harmful user interfaces.

9.2.5 Flexible and Continuous Data Control

Flexible data sharing is an option of significant public interest that surfaced in this work and the literature (Abdelhamid 2018; Kaye et al. 2015; Kuntsman et al. 2019). According to the user studies conducted in this thesis, data contributors desire to exert more control over which data is shared and with whom. Allowing such choices is a way to increase user autonomy (See Chapter 3) and an enabler for broader public acceptance (See Chapter 2). When contemplating specific ways to design for personalised data controls, however, it is important to avoid overwhelming contributors with requests, as not everyone shares the same desire to act upon their privacy choices and people can change their minds (Barkhuus 2012). For this reason, it might be wise to allow contributors themselves to choose how they prefer to express data access permissions, as discussed in the analysis of applications of technology in support of automated psychotherapy (See section 7.2.2 of Chapter 7). For instance, data contributors might choose to provide consent on a case-by-case basis or allow data to be always shared by default unless there is a specific receiver or purpose that the contributors might prefer to deny access permissions. Therefore, data contributors are allowed to flexibly decide which data types to share and how permissions for data re-sharing are to be solicited.

9.2.6 Active Community Engagement

Overall, the design implications discussed above suggest that data contributors should become more actively involved in the research process beyond simply sharing their data. The literature offers many other examples of meaningful opportunities for community engagement, including the possibility of proposing research questions, providing feedback on current projects and voting for research decisions - suggestions that the participants in our user studies have also endorsed (Bromley et al. 2015; Fleurence et al. 2013; Shippee et al. 2015). In the OpenHumans platform, for instance, members can engage in group discussions, browse through different projects and discuss ideas for data analysis (See

section 2.2 of Chapter 2). Inspired by health-related social networks, such as Patients-LikeMe, data contributors could also be interested in exchanging personal experiences with the platform with each other, clinicians or the repository owners (See section 2.2 of Chapter 2). Such additional features and communication channels would mean a shift from the traditional relationship between data contributors and data consumers towards a more balanced power dynamic, which is essential to enable ethical participation (Terry et al. 2011).

9.3 Supporting Technology Creators' Ethical Practices

The design implications discussed above serve as new and promising directions for an alternative and more ethical future for health data repository design. However, employing such insights in the real-world practice of design remains a significant additional challenge that requires engaging with and pondering methods, theories, and processes. This final discussion section contributes towards supporting the work of technology creators by offering reflections on the learnings acquired through first-person experiences and the extensive literature reviews conducted.

9.3.1 Reflections on Methodologies and Approaches

Ethical design is made complicated by the fact that technology creators need to make not only 'good' design decisions but also base these decisions on long-term consequences for users (Barry et al. 2017). Many have worried that it might be challenging to integrate even valid ethical reflections into the development of health data technologies due to a lack of professional awareness and willingness to incorporate ethical perspectives into the user-centred design process (Snyder 2020; Lupton 2014). The empirical user studies identified and conducted in this thesis surface noteworthy examples that corroborate the idea that, with proper motivation, it is possible to integrate an ethical perspective with commonplace user-centred design methods, such as interviews, surveys, and focus groups — the familiarity technology creators may already possess with these approaches proving an advantage (Sun et al. 2019; Figueiredo et al. 2020; Fiesler et al. 2018; Hirsch 2020; Skirpan et al. 2018c).

In this thesis, well-known user inquiry methods served as effective approaches to ethical design without requiring the complete remaking of research techniques and procedures. For instance, the design recommendations discussed in the previous section highlight not only the value that qualitative methods provide to understanding subjective, contextual, and intricate user experiences in terms of possible harms (See Chapter 4) but also how quantitative methods helped to reach a somewhat more objective basis for argumentation (See Chapter 5). Field studies evaluating ethically-informed designs 'in-the-wild' could further contribute towards the ecological validity of design suggestions, such as a future step planned for the StudyApp (See section 7.1 of Chapter 7).

Comparing and contrasting the two methods employed in Chapter 7, each allowed us to reflect on design choices differently. Using conceptual 'values' as anchors for the design rationale behind the StudyApp helped us to direct creativity towards enabling users to achieve their aspirations of higher agency and reciprocity through interactive elements within health data interfaces, such as data types selectors (See sections 7.1.4 and 7.1.4 of Chapter 7). Technology creators might find the VSD approach beneficial in their design processes, as it shifts the focus from user 'needs' to 'values', thus bringing a different, more ethically-engaged perspective on the definition of a 'system requirement'.

On the other hand, the employment of an ethical framework based on pre-established principles for the analysis of automated CBT led to the discovery of ethical considerations

beyond what might be addressed by user interface elements. Given that the AI-ethics framework we used was built from a previously acquired understanding of recurrent issues, this ethical analysis unfolded issues of justice and inclusion that the participants in our user studies did not state explicitly. However, this does not suggest a move away from attending to users but rather defend non-participatory approaches as also proving well-suited to facilitating earlier stage, conceptual, ethical discussions. Technology creators would do well to follow such procedures with empirical user studies, as developers and designers might not always fully grasp the lived experiences of end-users, as remarked by the students participating in our pilot study on the teaching of ethics (See Chapter 8).

9.3.2 Reflections on Theories and Design Philosophies

The range of theories, philosophies, and design orientations employed by HCI researchers to guide their engagement with ethics can prove immensely diverse, as seen in Chapter 2.1. Whilst some researchers argue that it is possible to make ethical decisions according to rational frameworks (McMillan et al. 2013), others construe ethics as an expression of care emerging from affective ties (Sabie et al. 2019). Some comment that perceptions of 'good' are born from individual virtue (Barry et al. 2017), while others emphasise the importance of socially established roles defining standards of conduct (Williams et al. 2020). Such disagreements, of course, predate HCI (Baggini 2018).

The lack of a definitive perspective on ethics, especially in a field as eclectic as HCI, can itself represent a risky position for technology creators, as without a common framework, it can be difficult to reach agreements, especially when it comes to controversial subjects (Horst 2007). However, learning from different perspectives can lead to richer discussions if arguments are grounded in explicit deliberation of how diverse theories might conflict or complement a point-of-view (Mirnig et al. 2019). The view put forward by this work is that ethical thinking requires first attuning to the diverse range of possible moral philosophies and then wisely and coherently arguing why specific ideas, moral principles and actions are relevant to particular contexts (Baggini 2018). Although no theory can be considered the 'best' for ethical design, an informed and critical engagement with ethical theories is fundamental to putting ethics into practice.

A related ethos corroborating this argument for ethical pluralism can be found in the form of VSD. The VSD framework includes moral and ethical sensibilities to its working definition of 'human values' while allowing researchers to engage with consequentialist, deontological or Confucianist positions if appropriate. This approach does not deny the importance of fundamental principles for human flourishing (for example, human autonomy), yet it also encourages exploration of the reasons underlying divergent ways of thinking. Interestingly, VSD is the theoretical framework most often employed in the papers identified through our scoping review Chapter 2.1, which can be an indication that HCI demands theoretical frameworks that can accommodate plural perspectives while still attaining to the importance of key ethical values, such as autonomy, beneficence and justice.

When it comes to design philosophy, another perspective often found in HCI is Critical and Speculative Design (Sas et al. 2020; Ballard et al. 2019; Purpura et al. 2011), as our scoping review of ethics across HCI showed (See Chapter 3). The value in integrating Critical Theory with design lies in the way in which it brings unexpected insights to the process while also supporting the expression of design ideas and raising public awareness of problematic ideologies (Bardzell et al. 2013). Speculation serves as a means to foreground potentially hidden issues and communicates alternative (more ethical) versions for future systems, which are goals that technology creators might strive for if they are to commit to ethical practice (Dunne et al. 2013). Our applications of critical perspectives

applied to conceptual interface design serve as concrete examples of how this might be achieved in practice (See Chapter 7).

9.3.3 Reflections on Teaching and Learning

Creating a more ethical future for digital health requires professionals to learn how to move from discussion and debate to ethical design in practice. Building upon previous research identified through the scoping review of ethics reported in Chapter 3, we have attempted to cultivate future technology creators ethical awareness regarding the design of a smartwatch for heart rate monitoring (See the pilot study in Chapter 8). On the surface, our experience with teaching ethics to health data ecosystems was successful. Students gained more awareness of ethical design practices, and they felt that the list of ethical principles was a valuable resource for their creative process, which corroborates with prior work concerning the teaching of machine learning ethics through thematic questions (Saltz et al. 2019).

Despite these seemingly supportive results, gaps in the students' diverse educational backgrounds and varied interest levels strongly affected their learning process. For instance, a student honestly stated that technology should be "as evil as possible", which only reinforces the importance of empathy development within technology creators. In particular, the ethical requirements that students had most difficulty approaching were related to accessibility and social justice, even though these are of undeniable importance for UX design (Inal et al. 2020; Costanza-Chock 2020). We have witnessed in practice how the navigation of ethical design has to be strongly tied with social awareness, goal setting and personal dispositions willing to embrace unavoidable complexities (See Chapter 8).

The work of this thesis serves equally to highlight a critical and yet pervasive challenge: respectful design cannot be achieved only through a series of deductive tasks or blind obedience to norms. It has been said that through consistent practice, individuals can eventually develop an 'ethical compass' that supports decision-making (Matchett 2009). This argument corroborates the idea that future and current technology creators probably need access to continuous and much more comprehensive ethics education to engage with ethical design genuinely. A concrete suggestion is for educational programs to combine theoretical exercises and hands-on classroom activities across several modules of university qualifications, thus going much beyond standalone lectures (Garrett et al. 2020). Another suggestion is to adopt such pedagogical approaches in the UX industry if suitable.

Furthermore, actively involving end-users in class could perhaps help technology creators and students understand the importance of learning about ethics. As demonstrated in a previous study, graduate students could develop an 'ethics of care' through a design project carried out in direct contact with communities and non-profit organisations (Sabie et al. 2019). As discussed in the first section of this chapter, the combination of participatory and non-participatory methods is probably the most advisable for a genuine engagement with ethics, and the evidence gathered through our studies points to the same conclusion. A single prototyping activity is far from sufficient to address personal misconceptions and cultivate an 'ethical designer character' (Lindberg et al. 2020). Finally, future researchers could examine further how to make ethical education an attractive topic to individuals who might not have previous experience with the open-ended and not straightforward nature of philosophical reasoning.

9.3.4 Reflections on Individual Responsibilities

This thesis and the literature in combination demonstrate that promoting engagement in ethical reflection requires that technology creators are provided not only with knowledge

but supportive environments favourable to the quest for more respectful designs. A challenge in this regard is that putting ethics in action is a demanding task for individuals, especially when it conflicts with dominant organisational goals (Gray et al. 2018). Previous studies have emphasised that the contexts in which technology creators are situated can hinder their capacity to act, as designing is usually an activity performed in teams, sponsored by business owners and funding agencies (Boyd et al. 2021). If ethical thinking is not supported by leaders, workplaces and the innovation culture, individuals might have to compromise their values (Friedman et al. 2019; Gray et al. 2020).

Therefore, although this thesis provides insight to support the enacting of ethical decision-making by research and design professionals, the responsibility for materialising ethical design, in reality, does not lie solely with these agents. As seen in the review of existing health data repositories, these platforms are often owned by national states, for-profit companies and research institutions (See Chapter 2). Without harmony across the roles of leaders, organisations, universities, governments and global entities to protect the interests of end-users, it becomes difficult to pursue and promote a broad ethical design agenda (Durrant et al. 2018; Shilton et al. 2017). In our focus group study, for instance, participants were not confident that data storage arrangements were secured entirely (See Chapter 6), which means that technical infrastructures probably need to be continuously evaluated and regulated by external entities (Horst 2007). Such regulatory frameworks do not necessarily need to become the overly rigid and bureaucratic structures criticised by previous research, but they are essential to strengthening ethical guidance in some jurisdictions that lack this foundation (Dow et al. 2019; Patil et al. 2016; Glerup et al. 2017).

Whilst the optimal role of regulations is still being consolidated and better understood by the professional community, it is paramount to find ways to protect data contributors from risk and empower technology creators to work towards more ethical designs. As health data has grown to become a resource with great value for many, this thesis calls for more substantial collective initiatives across academia, the public sector or as part of privately-owned endeavours. Suggestions include organising communities of practice sharing experiences and supporting leaders who promote working cultures that encourage critical thinking in design work. Further avenues for real-world change include developing communication tools to mediate ethical discussions across organisational hierarchies, including channels for citizens to express their concerns. In solidarity with the shared objective of improving healthcare for all, we hope this thesis serves as a source of inspiration, eye-opening perspective, and indeed hope for many others working towards the conception of more respectful health data flows.

10 Conclusion

In seeking to advance the development of health data interactions, this thesis has prioritised the position of data contributors to promote a shared understanding of how we might devise novel and respectful design possibilities rooted in user-centred research. Overcoming a prevailing stance that data sharing should primarily serve data consumers, the work carried out for this PhD has striven to offer an alternative vision in which those disclosing their personal data have their preferences and expectations prioritised. This thesis, therefore, serves as a step towards a future in which transparency, choice, mutual benefit, and trustworthiness are at the core of health data flow design.

The journey towards meeting this ambitious goal has included deep dives into the literature in parallel with inquiries entailing direct end-user engagement and the development of frameworks for critical appraisal and speculative prototyping. A structured search through academic knowledge sources concerning ethics across HCI has equipped the work of this thesis with a solid foundation regarding possible ways of thinking, doing and reporting on ethical design in practice. This thesis describes first-hand experiences with diverse yet complementary approaches (both qualitative and quantitative), enabling a rich depiction of that which matters most to data contributors.

This work reveals the extent to which citizens desire to become more actively engaged in learning about and acting upon how their data is collected, shared and used. Data contributors display varied needs for privacy boundaries, as disclosing certain data sources (for example, location, social communication and mental illness diagnosis) are far from being perceived as safe by many. Because of strong concerns regarding the risk of cyber-attacks and the possibility of data being abused by malicious agents, data contributors explicitly request more information and data control. These findings, in turn, serve to increase awareness among those responsible for creating and developing health data technologies about the reasons behind citizens' discomfort.

Furthermore, this thesis offers design recommendations that tap into the potential to transform the relationship between people who collect data and those who consume it. In particular, it is proposed that technology creators consider: communicating more openly about health research requirements, empowering data contributors to learn about clinical research, allowing flexible and customised data sharing options, and providing valuable personal benefits while reducing risks to the most vulnerable. These design suggestions should inspire new initiatives and encourage collective efforts towards more caring health data infrastructures.

Overall, this PhD project has sought to identify, express and outline pillars for a new vision of ethical digital health ecosystem design going forward. In striving to make this a reality, we have supported individual technology creators through research evidence, critical thinking frameworks and educational approaches. The most fundamental contribution aimed for this work is to emphasise the need to take consistent action so that the conception of any technology that directly affects citizens and patients' lives always stands in solidarity with those whom technical advances can harm. Hopefully, the contemporary movement to re-activate the role of ethics for user-centred design finds productive dispositions and welcoming minds, especially within innovation initiatives in the healthcare sector.

Part II

Manuscripts in the Paper Collection

1 Summary of Contributions

A Scoping Review of Ethics Across SIGCHI

Submitted to: *ACM Conference on Designing Interactive Systems*

Motivated by the need for a structured overview of applied knowledge and practical approaches for navigating complex moral dilemmas, this paper contributes a scoping review of ethics as discussed within full-length SIGCHI papers containing the search term ‘ethic*’ in their title, abstract or authors’ keywords from 2010 to 2020. Findings show Value-Sensitive and Critical Design appearing as the most frequently applied orientations, and participatory approaches were found to be more prevalent than those without end-user input. This structured account of SIGCHI’s engagement with ethics topics served as the foundation for the subsequent work of the thesis requiring an understanding of possible pathways to including critical ethical perspectives within user-centred design processes for health data interaction design.

Futures for Health Research Data Platforms From the Participants’ Perspectives

Published in: *ACM Nordic Conference on Human Factors in Computing Systems*

This paper provides an in-depth understanding of health data repositories by reviewing a comprehensive set of existing platforms and then discussing factors impacting willingness to share data with health data platforms. Following this engagement with the literature, findings from a qualitative interview study with 12 young adults living in Denmark bring a contributor-centred perspective to supporting design suggestions for future developments. Based on the evidence gathered, this paper then proposes a conceptual framework structuring critical factors for acceptance (motivation, willingness to share and trust) across the different stages of the data contribution journey (recruitment, data collection and continuous participation).

Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey

Published in: *Journal of Internet Research*

This paper expands and solidifies the qualitative insights of the prior interview study by gathering the perspective of 1600 individuals living in Denmark and Brazil through a quantitative approach (online survey). Data collected included participants’ demographics, level of interest in health topics, past participation in health research studies, awareness of research data repositories, and current attitudes about the idea of shared-access repositories. Data analysis examined the relationships between these variables and participants’ willingness to share different data types, as well as participants’ preferred options for data control, principal reasons for concern, and strongest motivations to contribute. Findings contribute towards future developments with the aim of addressing and engaging with the concerns of those unwilling to participate, and engaging different population segments through means of contribution tailored to their preferences.

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

Published in: *EAI International Conference on Pervasive Computing Technologies for Healthcare*

This paper describes the results of a focus group study complementing the investigations of data contributors' perspectives by providing insights into the work practices and perspectives of those developing, designing and creating digital health technologies. By analysing the qualitative data collected during this focus group, findings reveal technology creators' inputs regarding enablers and barriers for a broader acceptance of systems that allow data to be shared and re-shared for clinical care and research. When combined with findings from the studies conducted with data contributors, this study confirms a need for health data systems to more explicitly support the values of transparency and choice.

A Value-Sensitive Approach for Ethical Health Research Platforms

Presented at: *ACM Conference on Computer-Supported Cooperative Work and Social Computing - Workshop: Beyond Checklist Approaches to Ethics in Design*

This paper applies a Value-sensitive Design approach to designing a prototype for a mobile app to be used as a data collection interface for a shared-access platform for clinical support and health research. The resulting prototype demonstrates how the values of agency and reciprocity can be embedded in user interface features and system functionalities, including through continuous data control settings, personal feedback, clinical support and research study updates. The description of this experience with the value-sensitive design framework illustrates how it is possible to adopt an ethical lens to the process of creating user interfaces to be used by health data contributors.

Is the Automation of Digital Mental Health Ethical? Applying an Ethical Framework to Chatbots for Cognitive Behaviour Therapy

Published in: *Frontiers in Digital Health - Special Issue on Responsible Digital Health*

This paper critically analyses how sensitive data from therapeutic disclosures can be ethically collected, stored and shared in the context of chatbots designed to automate psychotherapy. Possible harmful and positive aspects concerning this technological innovation were raised by applying an AI-ethics framework focused on five principles: (1) beneficence, (2) non-maleficence, (3) autonomy, (4) justice, and (5) explicability. The analysis complements the investigations carried out previously, demonstrating how applying ethical frameworks can offer pointers to possible improvements in future developments.

Teaching User Experience Design Ethics to Engineering Students: Lessons Learned

Submitted to: *Frontiers in Computer Science - Special Issue on Teaching and Learning Human-Computer Interaction*

This paper reports a pedagogical approach to support learning and teaching of User Experience Design ethics applied to the context of digital health. Through a qualitative investigation with engineering students enrolled in an introductory design course, this paper contributes insights concerning how future technology creators apply ethical principles in the task of designing a heart monitoring system. Results shed light on the benefits and

limitations of teaching ethics this way and led to discussion and reflection on the challenges and possible paths forward for teaching and putting ethics into practice.

What Is the Future of Data Sharing for Research?

Published in: *ACM interactions*

This argumentative essay draws a parallel between the acceptance of contact tracing apps for pandemic control and the acceptance of large-scale health data repositories. This discussion had the goal of underlining the severe implications of both blind acceptance and a lack of acceptance for society, and how for this reason, there is a need to be respectful of the needs of people contributing their personal data for the collective good. In particular, this essay questions the justification for building repositories of aggregated data that might mean better healthcare in the future but may also consist of a tool for mass control. Instead of seeking broad acceptance through coercive propaganda and imposed terms, the essay argues in favour of a power shift that would place citizens at the centre of decisions made about their data — as comprises the vision behind this thesis.

2 Papers Included

2.1 A Scoping Review of Ethics Across SIGCHI

Authors:

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Submitted to:

ACM SIGCHI Conference on Designing Interactive Systems (DIS)

A Scoping Review of Ethics Across SIGCHI

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Ethical deliberation has proved a consistent feature of Human-Computer Interaction (HCI) since its earliest years, spanning the ethical involvement of research participants to design choices impacting fairness, freedom and welfare. Despite growing discussions, applied knowledge and practical approaches for navigating complex moral dilemmas remain challenging to grasp. Motivated by the need for a structured overview, this paper contributes a scoping review of ethics as discussed within full-length SIGCHI papers containing the search term ‘ethic*’ in their title, abstract or authors’ keywords over the last ten years. Findings show increasing prioritisation of the topic, particularly within Artificial Intelligence. Value-Sensitive and Critical Design appear as the most frequently applied orientations, and participatory approaches are more prevalent than those without end-user input. Engaging with a spectrum from personal to societal concerns, the SIGCHI literature thus echoes calls for critical perspectives on user-centred processes and the need to establish more sustainable responsibility structures.

CCS Concepts: • **Social and professional topics** → **Codes of ethics**; • **Human-centered computing** → *Interaction design process and methods*; • **General and reference** → Surveys and overviews.

Additional Key Words and Phrases: Ethics; Design Research; Scoping Review.

ACM Reference Format:

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1 Introduction

As digital technologies have expanded their capacity to affect human lives at ever-increasing scales and in ever more intimate ways, the accompanying ethical dilemmas have grown only more prevalent: algorithmic bias, political interference, disinformation and hate online, the misuse of personal data and deceptive interfaces [40, 122]. Researchers, practitioners and professionals working with technology design are increasingly required to have an open and informed engagement with the concept of ethics, as they face complex questions of individual and collective values, power-knowledge asymmetries, and the legal and societal consequences of their choices [13, 52]. Many argue that integrating critical reflection into the daily work of design and research can serve as a productive approach to addressing such issues of ethics [16, 67, 147].

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Manuscript submitted to ACM

Significant efforts have promoted the discussion of ethics within academia as means to support ethical work. Conference panels and workshops on the topic have maintained a regular presence since the very first HCI conferences [116], and ethics remains highlighted as one of the most important concerns of HCI today [155]. The ACM Code of Professional Conduct and the IEEE Code of ethics reflect this broad recognition of the prominent role of ethics through formal sources of guidance, advocating, for instance, that computing professionals should avoid causing harm and ensure that the public good is a central goal [71, 86].

Furthermore, a few authors conducted systematic reviews within specific application contexts, examining, for instance, how different ethical theories have been used to program autonomous machines [164]. Other authors have systematically characterised which ethical issues and arguments have been associated with brain-computer interfaces [26], robots for aged care [173] and assistive technologies for dementia [87]. Van et al. have revised mentions of the keyword ‘ethics’ across the ACM Interaction Design and Children Conference (IDC) [172]. In contrast to these reviews focused on particular technology domains, a much broader systematic review from 2016 has previously analysed Computer Science journals in order to extract insights into how computing ethics has been discussed by this particular section of the literature over the years [154].

While providing essential guidance to practitioners’ and researchers’, these past efforts in the form of systematic reviews have gaps. First, the search query used in the broader review of computing ethics from 2016 has not captured papers published in important HCI venues, such as CHI and DIS [154]. As HCI is at the centre of much ethical reflection concerning technology’s design, use, and implication, this is a critical gap to address. Second, the other past reviews have specifically focused only on certain technology domains (for example, machine learning), which means they do not provide a comprehensive overview of ethical engagement across computing technologies as a whole. A systematic review of ethics across multiple HCI venues, including a diverse set of technology domains, could not only fulfil these gaps but, most importantly, provide general and informed advice on possible routes to action and ways to put ethics into practice.

Motivated by the identified research gaps and the pressing need to support individuals working towards more robust engagement with ethical technology development and design, we conducted a scoping review. For this review, we targeted full-length papers published at conferences sponsored by the ACM Special Interest Group on Computer-Human Interaction (SIGCHI) containing the search term ‘ethics*’ in their title, abstract, or authors’ keyword list. To be clear, instead of aiming to capture all papers within HCI, we sought to coherently, systematically and transparently identify a representative sample of papers discussing ethics in detail as a core focus of their HCI work.

Therefore, the main goal for this review is to provide a rigorous account of the landscape of ethics discussion across SIGCHI in order to support technology creators, designers and researchers looking to fortify orientations towards ethical thinking and doing. We carry out this work from the position of HCI, Software Engineering and Information Science Studies researchers, ranging from all levels of seniority, seeking to learn possible pathways for conceiving technologies that are not only user-friendly but ethically informed. Hence, the following research questions drive the scoping review:

- (1) Which ethical considerations, technologies and user groups have been the subjects of ethical engagements?
- (2) Which approaches, methods and theories have been employed to explore ethical considerations?
- (3) What practical recommendations for putting ethics into action have been reported and discussed?

This paper contributes a systematic and coherent overview of ‘ethics’ as provided by papers published at SIGCHI-sponsored conferences. Next, we describe and motivate our choice for a scoping literature review methodology. Then,

we present the findings gathered through the identified sample of papers, followed by a discussion of the implications and limitation of results, as well as directions for future work.

2 Methodology

Seeking to provide a comprehensive account of HCI publications that could support professionals in their ethical practice, we identified and analysed relevant literature sources about ethics through a scoping review methodology. A *scoping review* is a rigorous literature review procedure that produces a systematic description of previous research about a topic, refraining from judging the quality or weight of evidence provided by individual papers. It is an effective method for identifying knowledge gaps and clarifying concepts across a body of literature and an ideal methodology to initially appraise the field (in contrast to traditional reviews where evidence is critically evaluated) [120]. This review follows the established scoping review procedure of Arksey, and O'Malley [4], and reports the review procedure and its results using best-practice items recommended by the latest version of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews¹ (PRISMA-ScR, 2018) [167].

2.1 Eligibility Criteria

We searched the ACM Digital Library for papers published from January 1st 2010 to December 31st 2020. Using the ACM Digital Library search filter 'sponsored by' SIGCHI (Special Interest Group on Computer-Human Interaction), we then searched for publications containing the keyword 'ethic*' within the title, abstract or authors' keywords. Employing the wild card * means that any word starting with the letters 'ethic' was included in our search results (e.g. ethical, ethics or ethically). Only peer-reviewed, full-length archival publications were eligible for inclusion: a standard literature reviewing practice to ensure the analysis of mature work. These eligibility criteria were driven by the need to produce a rigorous overview of ethics within a transparently delimited, reproducible and manageable scope. See Section 4.4 for more detailed reflections on our rationale.

2.2 Information Sources

The ACM Digital Library was our exclusive information source. We did not contact other authors to identify additional sources. Our most recent search of the ACM Digital Library was conducted on January 27th 2021.

2.3 Search Query

The full query syntax used for the ACM Digital Library search was: *"query": Title:(ethic*) OR Abstract:(ethic*) OR Keyword:(ethic*) "filter": Sponsor: sigchi, Publication Date: (01/01/2010 TO 12/31/2020), ACM Content: DL.*

2.4 Selection of Sources of Evidence

The initial sample produced by the query search was screened to ensure the sole inclusion of peer-reviewed, full-length archival publications. Then, based on the main research questions presented in Section 1, authors agreed upon a concise set of exclusion criteria. Papers that, despite mentioning ethics in title, abstract or authors' keywords, did not engage with the term in the main text would be removed from the sample. Papers using the term ethics to refer to a body of values governing a particular culture or group but not directly addressing technology ethics (e.g., hunting ethics) would also be removed, as would papers only very briefly mentioning the word ethics in order to justify their chosen research

¹The PRISMA-ScR [167] is a standardised guideline for the description of scoping review procedures based on the framework outlined by Arksey and O'Malley [4].

approach without reflecting on ethical considerations to any significant extent within the main text. These criteria were applied to all sources of evidence initially identified, leading to the removal of papers fulfilling any of the above conditions.

2.5 Data Charting Process

The first and second authors discussed and agreed upon a set of predefined data items to be extracted from each paper, based on the overarching research questions listed in Section 1. The first author then charted the data items from the complete set of papers using a spreadsheet, and the third author independently charted 10% of papers in a separate spreadsheet to validate the charting process. There were no substantial disagreements at this stage. Then, the second author independently reviewed the data-charting spreadsheet and iterated upon the results with the first author in order to resolve any disagreements.

2.6 Data Items

Driven by the research questions listed in Section 1, the following predefined data items (variables) were extracted from each paper and organised using a spreadsheet:

- characteristics of sources of evidence:
 - publication year (e.g., 2020)
 - publication venue (e.g., DIS)
- subject matters of ethical considerations:
 - ethical concerns (e.g., privacy invasions)
 - technology types (e.g., public displays)
 - groups of end-users (e.g., children)
- approaches to ethics in design and research:
 - empirical approaches (e.g., focus group)
 - theoretical approaches (e.g., Value-Sensitive Design)
- sample recommendations for putting ethics into action

2.7 Synthesis of Results

For handling and summarising the charted data, we employed a table and two data visualisations to illustrate the distribution of sources of evidence (papers) by publication year and venue. We similarly produced more tables to show the distribution technology types, end-user groups and empirical methods for approaching ethics present within the sample. Next to these tabulated results, a descriptive summary in text-form explained how the results related to the review questions. Findings from other data charting items were reported only in descriptive narrative form.

Results from charting the data items of ethical concerns, technology types, end-user groups and sample recommendations were also classified according to key conceptual categories, as recommended when collating, summarising and reporting scoping review results [4]. These categories were produced by conceptually grouping related findings through an iterative and inductive approach, without employing any particular taxonomies as guides. For example, three broad groups were inductively formed based on conceptual affinity (ethical participation in research, ethics as design choice, and ethics as taking responsibility), and within each group, the recommendations of each paper (or sometimes more than one paper) were depicted in narrative form. After classifying results according to these distinct

conceptual groups, relationships between ethical concerns and different technology types and end-user groups were identified and summarised in descriptive text-form.

3 Findings

Following PRISMA-ScR [167] for the reporting of scoping review results, we first present the process of selecting sources of evidence. We then describe the characteristics of these sources of evidence in terms of publication venue and year. And finally, we present the synthesis of the results organised by research question.

3.1 Selection of Sources of Evidence

The search query employed resulted in an initial sample of 461 papers. The meta-data of this set were then screened to ensure the sole inclusion of peer-reviewed, full-length archival publications. This process led to the removal of 314 manuscripts comprising late-breaking works, workshop calls, works in progress, tutorials, Special Interest Group meetings, keynotes, case studies, courses, doctoral consortia, interactivity publications, research landscapes and awards. Pictorials were not removed as they are considered archived, full-length publications at the annual Designing Interactive Systems (DIS) conference.

The remaining 147 full papers were analysed in relation to the exclusion criteria defined in the previous section (See section 2.4). This resulted in the removal of the following papers: papers that do not engage with the term in the main text (n=5, [76, 78, 111, 148, 187]); papers that use the term ethics only to refer to the values of a group (e.g., the ethics of hunting) rather than the ethics of digital technology research and design (n=4, [62, 101, 157, 165]); and papers that mention the word ethics only very briefly to justify research conduct without further engaging with the topic (n=9, [6, 31, 41, 91, 103, 123, 135, 143, 186]). This process resulted in a final sample of 129 papers relevant to our research questions and constituting the complete source of evidence (See Figure 1).

3.2 Characteristics of Sources of Evidence

As described above, the final review sample includes 129 full-length papers published at SIGCHI-sponsored venues (See Table 1). The majority of papers were published in the last three years: 2018 (17%, n=22), 2019 (20.9%, n=27) and 2020 (28.6%, n=37). The years between 2010 and 2017, in contrast, account for only 33.3% of the sample (n=43). The majority of papers within the sample were published at CHI (59.6%, n=77), with the second-largest group of papers published at DIS (22.1%, n=17)². Figure 2 illustrates the distribution of papers across publication venues and years.

3.3 Subject Matters of Ethical Considerations

Our first research questions was devised to identify the subject matters of ethical considerations concerning specific ethical concerns, technology types and groups of people across this sample in order to discern predominant and under-explored areas of focus. Several ethical concerns were identified, and we classified these concerns in broad groups that even though do not represent a formal taxonomy, provide a valuable depiction of recurrent themes. Examples of autonomy violations include privacy invasions and lack of data sharing choices [1–3, 7, 9, 20, 23, 24, 27, 32, 38, 39, 60, 64, 70, 84, 95, 98, 102, 104, 113, 114, 118, 121, 124, 128, 130, 137, 138, 144, 145, 150, 151, 160, 163, 166, 170, 172, 176, 177, 179, 181, 183, 184]. Hidden persuasion, often found in ‘dark patterns’ (malicious user interface

²The complete list of SIGCHI-sponsored conferences is available at <https://sigchi.org/conferences/>

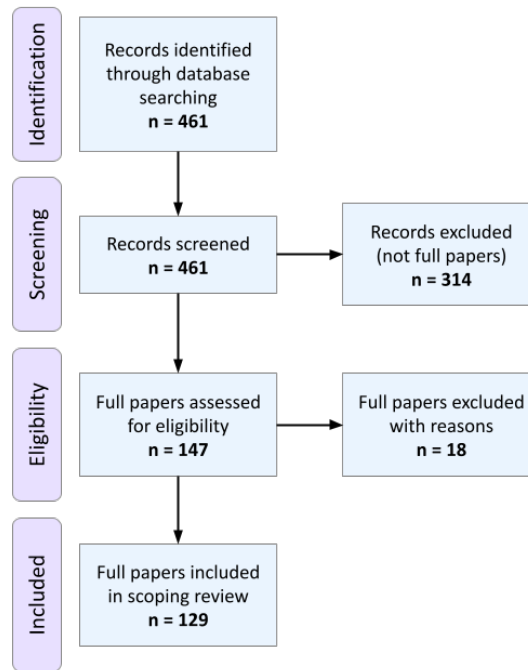


Fig. 1. Selection of sources of evidence (flow diagram)

Year	Instances	Venue and References
2010	0	-
2011	3	CHI [8, 109, 131]
2012	4	CHI [17, 66, 118], DIS [39]
2013	8	CHI [21, 77, 88, 113, 117, 176], ECCE [42], PerDis [98]
2014	9	CHI [53, 77, 79, 180], DIS [38, 158], CSCW [59, 108], CHI PLAY [174]
2015	2	CHI [121], HRI [107]
2016	12	CHI [24, 89, 114, 171, 179, 181], DIS [48, 100], CSCW [177], HRI [33, 85, 142]
2017	5	CHI [12, 75], CSCW [23], HRI [5], MobileHCI [129]
2018	22	CHI [2, 56, 60, 70, 74, 84, 99, 105, 110, 126, 150, 151, 159, 163, 175], DIS [182], HAI [139, 178], RecSys [55], AutomativeUI [112], MobileHCI [104], TVX [137]
2019	27	CHI [1, 10, 14, 29, 32, 34, 36, 72, 83, 96, 115, 130, 134, 136, 138, 160, 185], DIS [9, 64, 184], HRI [90, 92, 95, 97, 140], CHI PLAY [153], CHIIR [18]
2020	37	CHI [3, 7, 30, 35, 44, 57, 63, 81, 94, 106, 119, 124, 125, 128, 142, 145, 146, 156, 169], DIS [20, 73, 82, 141, 144, 152, 166], HRI [47, 183], IDC [27, 46, 93, 170, 172], CHIIR [102, 149], VRST [132], HT [61]

Table 1. Publication year, venue and reference number for each source of evidence included within the sample.

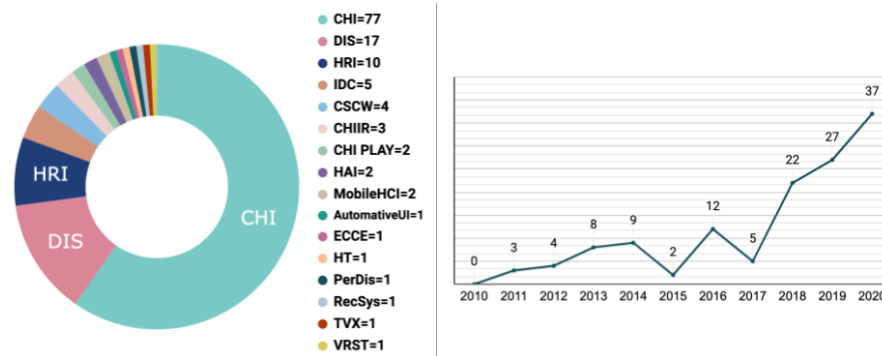


Fig. 2. Sample distribution according to the publication venue (left) and year (right).

patterns), can also be considered disrespectful to autonomy, as these are intentionally employed to engage users in performing actions against their best interests and without their awareness [3, 5, 8, 23, 29, 30, 34–36, 44, 55, 72–74, 85, 90, 95, 97, 100, 129, 131, 137, 139, 140, 146, 170–172, 183]. Harm to integrity and well-being can be identified through evidences of physical and emotional distress [3, 10, 12, 14, 17, 21, 30, 39, 47, 53, 63, 64, 66, 81–84, 88, 92, 93, 95, 96, 99, 100, 104, 105, 108, 109, 117, 121, 131, 134, 138, 141, 142, 149, 151–153, 166, 169, 170, 172, 174, 176, 177, 180–182, 184]. Potential fatal consequences are yet another way individuals can be physically harmed, and their safety is at risk (e.g., accidents with autonomous vehicles) [2, 5, 33, 90, 94, 107, 112, 115, 119, 125, 178, 183]). Issues related to social injustice encompass the negative consequences of exclusion, misrepresentation, stigma, bias and oppression [3, 9, 10, 18, 20, 32, 48, 55, 56, 64, 75, 79, 88, 89, 99, 105, 106, 108, 110, 125, 126, 132, 134, 136, 138, 142, 144, 151, 152, 156, 159, 160, 168, 169, 175–178, 182, 184]. Similarly, instances of unethical monetisation practices, such as the selling of data outside its original context are also related to social (un)fairness [7, 27, 34, 35, 44, 46, 59–61, 72–74, 136, 137, 145, 150, 153, 158, 172, 174, 185]. Most papers explicitly mention and name at least one ethical concern, even though a few papers provide more general discussions that could apply to any type of ethical issue [11, 42, 57, 77].

The first research question also sought to identify which technologies and groups of people have been the targets of ethical considerations. Regarding technology types, this sample includes papers discussing ethics in relation to artificial intelligence (AI) applications, mobile and web applications, social networks and forums, the internet of things (e.g., smart spaces), public installations and displays, wearables and biosensors (e.g., fashion technologies), games, data repositories and broadcast media. AI systems are the most discussed technology type across the sample, with a considerable number of papers focusing on embodied agents (e.g., social robots), although other AI applications (e.g., recommender systems), are also present (See Table 2). Several papers in the sample do not focus on any technology in particular [1, 11, 14, 18, 24, 48, 63, 66, 77, 79, 81, 83, 93, 99, 114, 117, 121, 149, 159, 163, 172, 176, 177]. Very few papers discuss more than one technology type [64, 96, 151].

Papers tend to focus less frequently on specific end-user groups than on technology types. However, this sample did include papers about children/teenagers, independent workers, patients or individuals with health conditions, minorities, women, older adults, rural populations, researchers and non-human end-users (e.g., birds) (See Table 3). The most frequently discussed group of users across this evidence base are children and teenagers, followed by workers. Several papers also targeted intersecting groups such as women with impaired hearing [182] and older adults with dementia [63, 82]. Aside from these papers which discuss ethical considerations in relation to end-users of digital

Technology Types	Instances	References
Artificial Intelligence (AI)	32	social robots [5, 27, 30, 33, 47, 85, 90, 97, 100, 107, 139, 140, 142, 168, 170, 178, 181, 183], autonomous vehicles [112, 115, 151, 185], conversational agents [146, 156], recommender systems [55, 185], facial recognition [184], in general [9, 20, 42, 106, 125]
Mobile and web applications	23	personal health [12, 39, 131, 134, 138, 145, 180], research [23, 113, 118, 129, 152], services [29, 34, 35, 44, 72–74, 105, 136, 151, 171]
Social networks and forums	12	crowd-sourcing [10, 88, 89, 108, 110], social media [3, 32, 56, 60, 104, 150, 151]
Public installations and displays	8	ambient displays [8, 130], installations [17, 29, 53, 94, 98, 179]
Internet of Things (IoT)	7	smart spaces [64, 128, 144, 158], smart TVs [137], educational tools [95], in general [70]
Wearables and biosensors	6	biosensing [38, 64, 84], fashion technologies [166, 182], body integration [119]
Games	6	playful narratives [92], virtual reality [132], intentionally idle [153], with cultural references [174], with sexual content [124], multi-player [96]
Broadcast media	6	video streaming platforms [46, 59, 61, 149], documentaries [75], news media [96]
Data repositories	5	historical archives [102], DNA repositories [7], learning analytics [160], visualisation [36], in general [151]
Others	5	shape-changing interfaces [2], end-of-life technologies [21, 109], drones [57, 151]

Table 2. Technology types as the target of ethics discussions.

technology products, a further group of papers discuss ethics in relation to research participants and researchers [1, 24, 81, 81, 83, 117, 121, 176, 177], UX professionals [34, 35, 72–74], and students learning about technology design [20, 46, 63, 136, 145].

By examining our results, we were able to identify some relationships between ethical concerns and technology types or groups of end-users. Adverse psychological effects and potential harms to individual well-being are in particular surfaced in relation to studies involving women [12, 64, 182], children [27, 47, 104, 170, 174] and the elderly [30, 39, 100, 181]. Papers discussing these concerns are likewise most often focused on technologies for personal health [12, 63, 82, 138, 166] and games [153]. Safety risks, accidents and the possibility of severe physical hazards of technology use are most often associated with social robots and autonomous vehicle interactions [5, 33, 112, 142, 183].

Concerns regarding privacy invasion and security breaches are most often encountered in contexts involving data collection and sharing, such as mobile and wearable sensing [23, 38, 113, 118, 166], Internet of Things (IoT) devices [70, 95, 128, 137, 144], shared-access data repositories [7, 102, 160] and social media networks [3, 104]. Questions of privacy have also been raised however in relation to interactions taking place in public space, as in the case of interactive installations [130, 179]. Many papers also discuss concerns around persuasion and deception in connection to services that aim at increasing profit margins by manipulating end-users' actions [34, 44, 73, 74]. In addition, emotional manipulation is frequently discussed in papers concerning autonomous agents such as social robots [85, 90, 97, 100, 139,

End-Users	Instances	References
Children and teenagers	14	in general [27, 46, 47, 61, 66, 93, 95, 104, 114, 126, 170, 172, 174, 180]
Workers	10	Amazon Mechanical Turk workers [10, 88, 89, 92, 108], musicians [59, 158], Uber drivers [105] and home health aides [169], shipping industry [185].
Patients/with health conditions	9	neurological illnesses [14, 39, 63, 82], mental health diagnosis [134, 141, 152], substance addiction [32], cancer [180]
Minorities	5	gender and sexual [156], people with specific communication [99, 182] and learning needs [18, 149]
Women	4	pregnant [12], with impaired hearing [182], in general [64, 159]
Older adults	4	[1, 30, 63, 82, 100, 181]
Rural populations	3	in Namibia [132], South Africa [21] and Bangladesh [159]
Non-human	1	birds [94]

Table 3. End-users that have raised design questions and considerations of ethics.

140] and chatbots [146]. More rarely, ill-intended persuasion is connected with data visualisations [36] and potentially unethical practices of nudging behaviour [29].

When it comes to broader societal issues, concerns around injustice, unfairness, exclusion, and bias feature most often in relation to AI [55, 106, 156, 168, 175, 178, 185]. Questions of justice are also often raised in studies involving gig workers (e.g., Amazon Mechanical Turk workers) [10, 88, 92, 105, 108, 169]. Ethnographic studies involving rural and indigenous populations also tend to focus on related topics including the digital divide, power asymmetries and digital imperialism [79, 89, 132, 159]. Issues of social stigma and discrimination are similarly often raised in studies involving individuals with mental illnesses [134, 141, 152] and sexual minorities [156].

3.4 Approaches to Ethics in Design Research

The second research question relates to how ethical considerations have been approached, explored and engaged with across the sample. Most papers report empirical studies devised to raise and address ethical issues, often employing user research methods to consult stakeholders directly, although at times also employing design methods without stakeholders' presence such as tools for team discussion. In addition to (or instead of) such empirical explorations however, other papers employ philosophical and theoretical frameworks to inform and support their understanding of ethics. And these diverse approaches to ethics employed across the sample we describe next.

3.4.1 Empirical Approaches Many papers in the sample report on empirical studies conducted to surface ethical considerations (See Table 4). These studies frequently employ user research methods well-known to the HCI community (interviews, questionnaires, focus groups, observations, and co-design workshops), conducted both in the lab and in the field. Participants in these empirical studies include previous or current end-users [3, 7, 10, 59, 88, 92, 110, 114, 118, 144], potential or future end-users [14, 21, 27, 30, 39, 63, 66, 75, 84, 90, 95, 99, 100, 104, 125, 126, 129, 132, 134, 136, 139, 140, 142, 149, 151, 152, 158, 159, 163, 169–171, 174, 178, 180–182, 184], close contacts to end-users [170, 180], technology creators and researchers [2, 9, 33–35, 72, 106, 117, 119, 137, 141, 153, 175, 177, 185], and multiple stakeholders at

once [23, 38, 53, 160]. A small number of papers report on experiments and surveys conducted not with end-users but with paid, crowd-sourced participant samples (e.g., Amazon Mechanical Turk) [90, 107, 139, 146, 168].

The majority of papers report findings from participatory and co-design workshops, followed closely by field and interview studies which are also featured frequently (See Table 4). A small number of field studies additionally propose ‘activist systems’ designed to elevate real-world ethical concerns while striving to realise change. In particular, this sample features examples of a platform for citizen-led governance experiments [110], an immersive theatrical installation designed to raise ethical awareness among the audience [150] and systems targeting fairer conditions for workers crowd-sourced via marketplaces such as Amazon’s Mechanical Turk [10, 88, 92]. In contrast, labs and online experiments are less frequently reported and this sample features a small number of surveys (online questionnaires).

Distinct from empirical approaches entailing the direct involvement of stakeholder at various degrees, some papers promote the use of ‘expert-only methods’. Empathy-building tools, personas, stakeholder matrices and card-based materials have all been used to facilitate self-reflection and collaboration between teams and students [9, 20, 46, 61, 106, 141, 145, 185]. Critical appraisals of design features and speculative scenarios have also been reported [5, 35, 39, 44, 47, 55, 56, 64, 74, 85, 97, 113, 124, 128, 129, 131, 152, 156, 166]. This sample also features content analyses of online forum discussions [60, 73, 105, 108] and presentations of manifestos [70], but these are rare.

Across the sample and diverse methodologies reported, speculation has often been used as a material or stimulus to surface, extrapolate from, and raise awareness of how technologies can become imbued, even invisibly, with values, ideologies and behavioural norms. In particular, speculation has been employed in critical conceptual designs [5, 56, 64, 128, 131, 156, 166, 183], participatory workshops [27, 95, 152, 169, 185] and user inquiry methods [168, 171], often in the form of fictional scenarios and provocative prototypes.

Lastly, several papers take stock of the literature and past projects to review and discuss ethical issues. This includes examples of argumentative essays [11, 18, 24, 48, 77, 81, 109, 115, 176], analyses of case studies, historical and contemporary examples [12, 17, 36, 83, 89, 96, 98, 102, 121] and literature reviews of specific subjects and technology domains [1, 29, 79, 93, 130, 138, 172]. Several of these papers define, propose and argue for theoretical orientations, as described in greater detail in the next section.

3.4.2 Theoretical Approaches Although less frequently encountered than papers presenting empirical methods and findings, various papers contained within this sample also present theories, philosophies and design orientations as means to structure discussions or lend more conceptual framings to empirical explorations. These ‘theoretical approaches’ include engagements with moral philosophy (e.g., Utilitarian and Virtue Ethics), social and political philosophies (e.g., Critical Theory and Social Justice), theories of design (e.g., Value Sensitive Design) and social theories (e.g., Biopolitics). Papers engaging with theory in one form or another make up approximately one third of the sample.

The framework most frequently employed across the sample was Value-Sensitive Design (VSD) [9, 33, 34, 39, 42, 46, 53, 56, 72, 74, 83, 93, 105], which can be considered a theory of design and a formative design framework [80]. The VSD approach seeks to account for ‘human values’ in a principled and systematic manner throughout the design process [69]. Following this approach, human values are conceptualised as an agreed-upon vocabulary defining that which is important to each stakeholder group (e.g., security, transparency, accountability). In our sample, studies employ VSD to identify and engage with human needs, elicit system requirements and prioritise features, in relation to conflicting stakeholder perspectives in particular.

Another theoretical perspective well-represented in this sample is Critical Theory, often taking the form of Critical Design, Design Fictions and Speculative Design [11, 38, 56, 64, 128, 131, 150, 168, 185]. Critical theory is an approach to

Methods	Instances	References
Workshops & Focus Groups	28	[2, 9, 14, 20, 27, 46, 61, 63, 66, 75, 95, 99, 100, 104, 106, 119, 126, 136, 141, 145, 149, 152, 169, 170, 174, 180, 182, 185]
Field Studies	25	[10, 21, 30, 34, 35, 38, 39, 63, 72, 84, 88, 92, 94, 104, 110, 118, 129, 132, 134, 140, 150, 158, 163, 181, 184]
Critical Prototypes & Expert Evaluations	20	[5, 35, 39, 44, 47, 55, 56, 64, 74, 85, 97, 113, 124, 128, 129, 131, 152, 156, 166, 183]
Interview Studies	19	[3, 7, 23, 33, 39, 53, 59, 82, 114, 117, 134, 137, 144, 153, 159, 160, 171, 175, 180]
Experiments	11	[8, 42, 90, 107, 112, 125, 139, 146, 149, 171, 178]
Argumentative Essays	11	[11, 18, 24, 48, 57, 77, 81, 109, 115, 176, 179]
Case Studies	9	[12, 17, 36, 83, 89, 96, 98, 102, 121]
Surveys	8	[7, 93, 114, 142, 144, 151, 168, 177]
Literature Reviews	7	[1, 29, 79, 93, 130, 138, 172]
Content Analysis	6	[32, 60, 70, 73, 105, 108]

Table 4. Papers which have used specific methods to identify, investigate and engage with ethical considerations.

social philosophy that challenges assumptions and conceptions about power relations in society [11]. Critical design brings this perspective to bear on the role product design plays in social and cultural spheres, often to foster debate and increase ethical awareness in lieu of an often-prioritised commercial focus [89]. Moral and technical imaginations are central to such a critical stance, which explains the frequent association of critical theory with design materialisations through speculative concepts and design fiction.

A perspective encountered less frequently across our sample is Care Ethics [83, 136, 145, 153], a philosophical outlook that shifts the moral focus towards embodied, situated and emergent relationships of mutual care [43], and as such a stark contrast to ethical philosophies centred on principles, norms and duties, such as deontology. When applied to design processes, care ethics with its relational and responsive approach foregrounds empathy and reciprocal commitments to each other as fundamental for decision-making [136, 145].

Meanwhile, utilitarian ethical frameworks are also found less frequently [107, 115, 125, 178]. Utilitarianism is a form of consequentialism which holds that an optimal ethical choice produces the greatest good for the greatest number of people by following a sort of ‘moral arithmetic’ in order to calculate the benefits of each outcome [22]. This philosophical perspective is most often encountered in this sample in the context of studies involving AI as a means to inform the programming of autonomous agents [107, 125, 178]. Another paper however notes the common criticism of consequentialism as unhelpful for decision making, given the difficulty (and perhaps impossibility) of weighing all positive and negative outcomes [115].

Other possible theoretical orientations, however, appear even more rarely within this sample. A few papers explicitly engage with Social Justice theory [48, 79, 169], describing Social Justice-Oriented Interaction Design as a framework that can help designers commit to plurality, advocacy, and political considerations [48]. Similarly, Queer and Feminist theories twice appear in regard to issues of inequality in the design of technology for minority groups [124, 156]. Virtue Ethics, which focuses on the cultivation of ethical wisdom through experience, appears in a single paper concerning mobile

technology design to support mental health, resulting in a call for greater scrutiny of the subjective assumptions and hierarchies of expertise underlying design choices [12]. And, Somatic Ethics is explored in a single paper depicting the experience of dancing with drones and positioning ethics as choreographing movements to be experienced somatically (through the body) [57].

Biopolitics is employed in a single instance as an analytical lens to drive reflection on issues of authority in biosensing designs [84]. Similarly, Foucault's theory of 'care of the self' is used to emphasise technology's epistemic dangers as a source of power [96]. And, Thanato-sensitive design is introduced, describing an approach to integrating the inevitability of mortality so that user-centred design can be more sensitive to those in bereavement and decrease harm in that sense [109]. Finally, amidst a predominant emphasis on Western-centric ethical frameworks across the sample, Confucian Ethics is the sole non-Western perspective featured, in a single paper exploring individual roles as the source of ethical obligations and character growth in relation to the design of morally competent artificial agents [183]. Duty-based ethical frameworks (Kantian deontology) are not explicitly applied in any papers within this sample, although studies describing normative rules devised to guide actions could be interpreted as examples of this perspective, such as calls for 'categorised ethical guidelines' [113] and 'checklists' [95].

3.5 Recommendations for Putting Ethics into Action

Our final research question pertains to the compilation of practical recommendations for putting ethics into action. As described in section 2.7, the iterative and inductive analysis of the recommendations identified across the sample resulted in three conceptual groups. The main topics in these groups relate to research participation, design choices and responsibility claims - as described next.

3.5.1 Ethics as Participation in Research This sample offers several practical recommendations for the ethical involvement of people in design research. Some of these suggestions already comprise minimum research ethics standards in some, although not all, jurisdictions [54]. Several papers provide recommendations in relation to ethical procedures for obtaining informed consent from participants prior to data collection, advising that consent forms are written in accessible language [113, 149], participants granted enough time to become familiar with the technology before a study [181] and that consent should be revisited throughout a project [1, 24, 63, 81, 114, 126, 163, 177]. When it comes to making use of publicly available data for research purposes, studies advise reducing the risk of re-identification by reporting results at a low level of detail [1, 32, 113, 177], and if data is shared outside of initial agreements, to inform participants [23, 113]. In the case of public installations, others recommend allowing participants to withdraw at any time [17, 98, 179].

Many papers also advise researchers to prioritise the benefits of participation by, for example, acknowledging participants as co-creators [114] or authors [82], negotiating compensation in line with participants' preferences [83], gifting participants working prototypes [30, 63, 82, 136] or celebrating the conclusion of a project with an event [82]. Authors furthermore advise inviting participants to engage more directly in the configuration of research projects from the very start [14, 75, 83, 99, 110, 176]. Several papers also emphasise the need to identify means to foster, ethically, participant diversity and to become genuinely involved with the communities we study, by, for example, volunteering with organisations [18, 63, 82], yet without falling for the 'design saviour complex' which can ultimately worsen uneven power relations with end-users [89].

On a related note, several papers highlight that participating in and conducting research can prove an emotionally charged experience, and propose appropriately preparing researchers to minimise possible sources of emotional

discomfort to participants and promptly recognise signs of participant distress during the research [63, 81, 99, 109, 149]. Similarly, some papers promote support for researchers' own well-being through counselling, group discussions, and a healthy work-life balance [63, 82, 117, 163]. Authors likewise advise incorporating domain experts and health professionals into teams researching sensitive contexts [66, 81, 109, 121]. A final and inclusive recommendation provided by authors in support of ethical HCI research is to articulate decisions made in support of well-being during published works as means of promoting awareness [63, 117].

3.5.2 Ethics as Design Choice Many papers across the sample frame design choices as means to address ethical concerns, even though they also acknowledge that it is challenging to make detailed recommendations, as each specific context requires an approach tailored to its characteristics. A large number argue that user autonomy can be increased through more transparent communication of both system intentions and technical limitations for example [7, 17, 29, 30, 36, 60, 70, 79, 113, 131, 146]. Several also suggest that privacy concerns can be addressed by providing mechanisms for data control and the collection of less intrusive forms of data [7, 30, 36, 60, 118, 124, 128, 130, 134, 138, 160].

A considerable group of papers draw attention to the potential adverse consequences of technology for users' well-being. Authors in turn advise that designers avoid reinforcing trends towards the over-optimisation of behaviour [3, 29, 36, 84, 131, 134, 138] and consult experts if unfamiliar with how the particularities of a health domain can negatively impact users [14, 21, 53, 66, 94, 109, 138]. When it comes to safety risks, authors advise the careful consideration of the how to mitigate the possibility of physical hazards [112, 115].

Another, slightly smaller, group of papers argue that design can and should serve as a means of accounting for and addressing social justice concerns by involving minorities in the design process and becoming more aware of the role designed products can play in perpetuating systems of oppression [48, 138, 156, 159, 168]. Other papers recommend and deploy 'activist systems' as means to tackle complex social challenges [10, 88]. As many on the other hand highlight however, it is essential to recognise that concepts such as fairness are not easily translated into design features, and authors argue that the complex relationships between technologies and their surrounding socio-economic and political contexts can limit what could be possible to address by means of user interface design [106, 115, 175].

3.5.3 Ethics as Taking Responsibility Many papers additionally encourage professionals to adopt measures against unethical practices by remaining mindful of intentions and reflecting upon the consequences of their choices [36, 56, 77, 81, 96, 98, 118]. Researchers within academic settings have likewise been advised to accept responsibility for ethical conduct beyond what is required and anticipated by institutional ethics procedures [121]. In contrast, however, a small group of papers warn that an individual's capacity to engage in ethical decision-making can be severely constrained by tensions with business goals or roles within enterprise hierarchies [35, 72]. For this reason, authors recommend that more emphasis is placed on the creation of strategies to enhance individuals' capacity to act [72].

Education is often endorsed across the sample as a means of fostering ethical awareness among future generations of HCI and UX professionals [34–36, 72, 74]. Approaches recommended in this regard include the cultivation of an 'ethics of care' among students through the organisation of open-ended projects with small civic organisations [136], collaborative classroom critique of data collection and visualisation practices following first-hand experience [145], and the use of card-based tools to help students reflect on moral dilemmas and build new prototypes in response [20]. Across this subset of papers, authors frequently suggest that classroom activities should be designed to enhance students' awareness of the societal consequences of technology development, and that their effectiveness can be observed by evidence of an increased sensitivity to ethical issues on students' behalf.

A small number of papers also suggest raising end-users' awareness of the risks and social consequences entailed in technology adoption [44]. Attempts to educate the public have been realised in creative ways including an immersive theatre experience designed to engage the public in discussions concerning personal data misuse by third parties [150], a provocative demo employing a bio-metric mirror to entice reactions from passersby [184], and the invitation of school students to discuss the values embedded in a well-known video streaming platform [46]. These papers suggest that strategies devised to invite end-users to reflect on ethical concerns should strive to prove appealing and, if deemed suitable, also provocative, in order to capture end-users' attention and leave behind an impactful, take-home message.

Relatively few papers in contrast invoke responsibility from the higher ranks of organisations or the public sector, by calling, for example, for more robust regulation as means to shape future technological developments or suggesting concrete policy implications [2, 3, 119, 146, 151]. Several papers do criticise current regulations for failing to attend to ethical issues, arguing however that overarching rules are hard to apply if not customised to particular contexts [61, 106]. A single exception praises policies derived from the Responsible Research and Innovation (RRI) agenda [77]. Even though very few papers actively advocate for and discuss ways to increase institutional and national responsibilities beyond the individual, this sample also does not explicitly suggest that higher-level entities are exempt from their share of responsibility.

4 Discussion

This review was motivated by the increasingly urgent need to support researchers, practitioners and professionals working with technology design and user research. By assimilating knowledge of just how to put ethics 'into practice', results shows a plurality of ways of thinking about, approaching and relating to the topic. This review thus demonstrates the potential for ethical thinking to drive, shape and crystallise responsible design and research. This final section revisits the research questions, reflects on the review's findings and discusses how they relate to literature beyond the sample. These reflections further illuminate future directions to commit to the topic more meaningfully, strengthen explorations of ethical requirements, and create more harmonic structures for exercising responsibility.

4.1 Establishing Priorities and Commitments

Our first research question sought to identify the ethical concerns discussed by published research within SIGCHI. Examining these results, it became evident that SIGCHI is concerned with issues ranging from the very personal to the societal; from the emotional work involved in the creation of digital technologies [81] to the consequences of algorithmic bias in aggravating social oppression [48]. This finding is well-aligned with a previous review of ethics in Computer Science journals [154] that also identified similar and diverse ethical discussions across its sample. Increased positioning of social justice as pertinent to technology ethics is likewise much in agreement with the contemporary literature on the politics of artefacts [40], design justice [37] and data feminism [45]. This finding should serve as an encouragement to designers and researchers engaging more actively in contemplation of how technology artefacts can shape the most personal aspects of our experience in connection to historical, cultural and geopolitical contexts - a commitment also brought forth by others within the broader HCI community [19].

The first research question also inquired into which technology types have proved the focus of publications about ethics at SIGCHI - findings revealing the distinctive prevalence of discussions pertaining to artificial intelligence (AI). The capacity of AI to 'think', persuade and influence decisions, sometimes in unfair and unpredictable ways, makes these systems particularly prone to moral dilemmas. The definition of ethical requirements for the AI domain is rendered additionally complex by the general lack of transparency in regard to algorithmic results and performance

metrics [25]. Prior research makes the case that strategies to improve AI ethics demand much more than technical work [15, 175]. The debate about AI ethics extends beyond this sample and HCI, as researchers question just how much power digital systems should have over civic life and if damaging outcomes can ever be avoided [28, 58]. Such reflections only reinforce that critical thinking within this domain is essential to informing the definition and placement of ethical boundaries for autonomous systems [161].

Furthermore, we have examined the groups of people involved in the participatory studies, revealing a surprising gap. Despite demonstrating concern for issues of justice and fairness, the sample seldom features the direct participation of social and ethnic minorities [132]; much research instead engages children, patients, and older adults. Even though this gap might not reflect the HCI literature more broadly [162], it represents an opportunity to emphasise that by not prioritising an ethical engagement with those potentially marginalised, design and research fail to attend to the particularities of groups who are misunderstood, misrepresented and express cultural difference [176]. Discussions on diversity and inclusion are among the most important conversations happening in HCI as of today, and despite challenges in devising and conducting ethical engagements with potentially marginalised populations, it is crucial to elevate this as a high priority in research agendas.

Such gathering of ethical matters at SIGCHI makes evident that technology design should account for users' vulnerabilities and intersections, just as much as it already accounts for the craft of 'appealing' interfaces [149, 181]. Ethical concerns surfaced by the sample illustrate the capacity of technologies of all sorts to disrespect human needs for autonomy, happiness and dignity – in clear contrast with visions of HCI as motivated by the idea of 'sustaining human flourishing' [127]. Ethics is a growing trend at SIGCHI, yet for ethics to become more accepted as a measure of success, we, designers and researchers, might need to reconsider standard assumptions of what 'good' technology design means. The broad range of ethical concerns, technology types and groups identified as subject matters for ethical consideration only confirms that the goal of creating 'useful tools for productive work' and 'delightful experiences' should not to trap user-centred design in a narrow definition of scope that potentially devalues the importance of ethics [49].

4.2 Adding Structure to Explorations of Ethics

The second research question led to the investigation of exactly how ethical considerations have been approached, both theoretically and empirically, at SIGCHI. Our analysis indicates that it is possible to put ethics into practice by adopting methods familiar to the HCI community (e.g., interviews, field studies, lab experiments) and whose procedures, in principle, do not differ substantially from their traditional employment [133]. For instance, across this sample, user studies are often used to critically assess the potential negative impact of technologies, often through qualitative methods to understand subjective, contextual and intricate experiences. Quantitative methods, including surveys and lab experiments, also have their place, providing a somewhat more objective argument for the prevalence of ethical issues. Other approaches have skirted the direct involvement of end-users by yielding tools to facilitate team discussion and proving their value as approaches to conduct a critical appraisal of empirical and secondary data sources to support more informed decisions.

Although there exist examples of papers identifying ethical issues as by-products of their work [2], studies contained within this sample typically engage in research and design processes with the mindset that ethical concerns are in and of themselves primary study objects. This observation constitutes an essential point for individuals seeking to make ethics a more integral aspect of their work: ethics is best enacted if considered a core component of the research design process, and a guiding viewpoint, from the very beginning. The vast spectrum of empirical approaches provides, collectively, a portfolio of various enablers of reflexivity - diverse methods for adoption at stages throughout the design

life-cycle - in contrast with a more transitory, checkbox approach [106], positioning ethical analysis as the core of the design.

In addition to highlighting the possible adoption of well-established user research methods, findings also demonstrate the significance of the so-called ‘speculative approaches’ to envisioning preferable futures and safely surfacing unethical outcomes [51]. Papers contained within the sample often connect speculation to critical design to foreground the intentions of technology creators, illuminate potentially hidden ideologies, and propose under-explored design visions [11, 64, 131, 168]. Beyond speculating about the future, another possibility is to consider evaluating ethical interventions ‘in-the-wild’. This sample offered a few examples of field studies deploying activities and systems designed to drive change in the real world [88], which are a valuable source of inspiration for a type of activism that HCI could strive for [65].

This review surfaces examples of theories, philosophies, and design orientations argued as proper structures for directing engagement with ethics. Different views, of course, conceptualise ethics in considerably different ways. Rather than arguing which yields the definitive perspective on complex moral challenges, learning from this pluralism of perspectives is most likely the most fruitful approach, permitting the deliberation of diverse positions without necessarily falling into a complete relativism. A utilitarian stance, for instance, takes consequences as the dominant aspect to be discussed concerning autonomous agents [107, 125, 178]. Yet, it has been argued that there is value in considering alternative theories to confront automation dilemmas and search for their causes, not only the possible outcomes [115].

Regarding theoretical pluralism, this review also reveals a critical gap previously highlighted as a significant bias in HCI’s engagement with ethics [188]. The vast majority of the sample references ‘Western-centric’ literature, theories, and philosophical orientations, indicating the lack of theoretical diversity across the sample, a finding also remarked by previous AI-ethics reviews [164]. Future work should strive to learn more from other worldviews (e.g., collectivism [183]) as a way to expand theoretical possibilities.

Review findings provide sufficient grounds to argue that it is crucial to continue expanding theoretical knowledge to support the specific ethical challenges of technology design and research. The theoretical and methodological framework most frequently employed across this SIGCHI sample is Value-Sensitive Design, possibly a consequence of its origins in HCI [68]. However, a few papers also introduce theories from other fields, such as Biopolitics [84], which demonstrate how direct engagement with theoretical foundations are advantageous for ethics in practice. Therefore, these findings show that both developing novel theories with HCI roots and building stronger interdisciplinary connections with other fields (e.g., social sciences, philosophy, gender studies) can be highly beneficial to support ethical reasoning applied to the context of digital technologies.

Despite the presence of such references, most of the sample does little to engage with theory actively (See Section 3.4.2), a gap also reported in a previous review of ethics in Computer Science more broadly [154]. While our scope is too narrow to draw conclusions about the field of HCI as a whole, when discussions of ethics are carried out without formal definitions and rely only on ‘intuitive’ understanding of the everyday use of the term, an opportunity is missed to gain value from and add to established sources of knowledge that could function as reference points for more robust analyses. Rather than making ethics a rigid, static and formalised concept, a theoretical foundation can be game-changing for more robust argumentation and decision-making [67].

4.3 Harmonising Roles and Responsibilities

This review has gathered a considerable collection of recommendations for putting ethics into practice. For instance, this SIGCHI sample offers many valuable insights into how to involve stakeholders in research processes and how product design might tackle ethical concerns. Nevertheless, these findings also shed light on the challenges of allocating roles and responsibilities for putting ethics into action.

The recommendations featured across this sample most often imply that the responsibility for ethical decision-making lies with research and design professionals [121]. More rarely featured, although also present, are reflections concerning means of raising users' capacity to question the ethics of the technologies they use and ultimately determine whether to adopt them or not [60]. However, this sample appears to place less emphasis on the need for stronger regulations, external evaluation, and legal accountability as means to protect and guide individuals [113]. For example, institutional ethics committees - which outline standard procedures for the planning and conduct of research - have faced criticism for providing little support when ethical issues do arise in practice [16].

Although there are valid arguments for advocating for individual responsibility - at least as a practice of consciousness-raising [96] - it is not yet fully clear to what extent this is possible given the constraints, demands and formalities of the contexts in which individuals are situated [72]. Despite the original intention of this paper to better equip individuals with this structured literature overview, the limited capacity of individuals to act combined with the complexity entailed in making ethical decisions points to the need to turn to the power of collectives. The formation of communities of practice and a professional culture that encourages critical thinking will probably be vital to supporting the creation of technologies attuned to fairer futures [89, 110, 136]. The influence of sources of funding for research and development should also be more emphatically discussed, as they serve an essential role in enabling individuals to work towards more meaningful and ethical goals [50, 176].

Therefore, there seems to be a significant role for tools and design processes that facilitate 'ethics mediation' [72] between professionals, teams, organisations, and ultimately end-users. Researchers and designers need to be empowered to express the contingencies of ethical decision-making more effectively, especially within the UX industry and in publication venues. Pursuing and promoting an ethics agenda also requires leadership. Further discussions beyond the SIGCHI-community regarding individual, collective and institutional roles should be encouraged in order to gradually establish a framework for organising responsibilities and expectations across entities [52].

4.4 Limitations and Reflections

Despite being motivated by the desire to produce a manageable body of knowledge that would also be sufficient to start answering questions that demand a systematic investigation, this review has limitations. We have deliberately avoided over-generalising findings throughout the text as our contribution is limited to the pre-defined goals and scope. We here reflect and comment on the methodological choices made to acknowledge and discuss the boundaries of our research scope, especially when compared to the vast field of HCI.

Our review focuses only on SIGCHI-sponsored conferences, which means that findings reflect only this specific segment of the broader HCI literature. We justify our choice first by emphasising that our goal was not to provide a definitive account of ethical discourse in HCI but gather a sample of approaches and possible pathways for understanding and applying ethics to technology design research. Future systematic reviews could encompass other HCI venues and different literature sources to add to, and perhaps critically contrast with, the insights extracted through this review of SIGCHI.

Another limitation is that this review includes only archival peer-reviewed full papers. This approach has allowed for a more cohesive analysis by ensuring that each paper included in the sample had a similar structure and underwent a similar submission and acceptance process. However, this choice meant that insights from maturing sources of knowledge such as late-breaking works and workshops were not contemplated. For this reason, we emphasise here that any gaps and trends identified in our sample cannot be interpreted as gaps of SIGCHI papers. Future works could consider reviewing these other papers to understand better how ethics discussions are distributed across specific publication types. The review is also limited by the search strategy focused on title, abstract or keywords. This decision was made for pragmatic reasons to avoid including a large number of papers irrelevant to the research question, such as those that mention only “approval by an ethics committee”. However, this choice meant that those papers that happened to not mention the word ‘ethics’ in these query fields were not identified in our search. Future research conducting a quantitative analysis of how many papers without ethics in their title, abstract and keywords extensively engage with the topic could lead to an insightful discovery.

Finally, a difficult choice in the design of this review strategy concerned whether to include other keywords related to ethics, such as ‘justice’, ‘values’ or ‘rights’ in the search query. Upon careful consideration and discussion, we concluded that any particular set of terms about ethics is at risk of failing to prove exhaustive. We also could not devise unbiased objective criteria to justify the inclusion of specific terms over others, and we deemed it inappropriate to claim a paper is ‘about ethics’ if the authors chose not to use the keyword themselves. We encourage future works to build upon this work and expand the search criteria to gather even more sources of knowledge to guide ethical practice and better characterise the ethics-related landscape in the diverse discipline of HCI.

5 Conclusion

Intending to gain a deeper understanding of how a fundamental philosophical concept applies to the diverse field of HCI, this paper contributes a rigorous scoping review of ‘ethics’ as approached by the SIGCHI literature. Findings highlight a growing interest in the topic through recent years, a trend that only reinforces the importance of ethics for technology design and research. As SIGCHI-sponsored conferences are prominent venues guiding HCI research worldwide, the sources of evidence examined in this paper pave the way for future ethical engagements.

This review reveals a plurality of perspectives and approaches comprising diverse possible paths for recognising and preventing ethical concerns. Learning from this pluralism can allow more robust debates and well-informed argumentation. Similarly, the diverse catalogue of identified methods brings about a vision for ethically-centred design processes in which critical thinking connects user inquiries to design explorations. The opportunity now arises to adopt and develop theoretical and methodological perspectives that support such an applied and reflexive type of ethics. As means to transform insight into positive real-life change, beyond method and theory, it is also essential to consider novel approaches to increase the harmony between individual, collective and institutional responsibilities.

As this sample clearly shows, every unique configuration of context, technology and users has its own requirements and challenges, but ethical thinking often converges in topics of human autonomy, beneficence, welfare and justice. Attending to such core ethical principles will prove beneficial in the conception of technologies more attuned to recurrently prevalent human values. As seen in the review, understanding broader socio-political contexts is just as important as engaging with individual particularities so that ethics can protect those who might be at risk and establish fairer relationships of power.

We commend the pervasive and consistent consideration of ethics evident across this sample. At the same time, we aspire that this work intensifies critical engagement with ethics across the broader HCI community. This sample

offers a vast collection of recommendations regarding opportunities to engage with the often ‘elusive’ concept of ethics, which in aggregate may serve as a valuable resource for a diverse audience of readers, from students and early-stage researchers to seasoned academics and organisational leaders. We hope to see many more future works consulting and building upon these references aggregated through this review.

As a final reflection, some may wonder why we, as researchers, part of the SIGCHI community, should dare to care about ethics in the first place. It can be challenging to cultivate ethical awareness within and across individuals in a knowledge field historically driven by fast and bold technical innovation. Committing to ethical thinking means leaving behind a position of indifference for a path undeniably challenging and rarely permissive of definitive answers. We may find motivation and inspiration, however, in recognising that this is perhaps the only means of pursuing and achieving the human flourishing for which HCI has striven all along. Inhabiting privileged positions as producers and propagators of knowledge, we have a shared responsibility to shape our actions in the world and society. Our choices should serve not only our own goals and desires but the common good, in solidarity with the aspirations and needs of those who comprise our surroundings and, indeed, our planet.

Acknowledgments

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2.2 Futures for Health Research Data Platforms From the Participants' Perspectives

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Futures for Health Research Data Platforms From the Participants' Perspectives

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ABSTRACT

In clinical cohort studies, researchers analyse the life history of population groups to understand the evolution of diseases. Health research data platforms came to facilitate such studies as they allow multiple projects to share access to cohorts' non-identifiable health information. Some latest initiatives are also starting to include mobile-generated data in their research programmes. Although seemingly beneficial, it is not yet clear how potential participants feel about contributing to the new platforms: there is a need to investigate potential factors related to the acceptance in this specific context. In this paper, previous works from related contexts were brought together and, along with a qualitative study, composed a participant-centred perspective of enablers and barriers for contribution. We found that there is an apparent misalignment between current implementations and participants' preferences, leading us to propose design guidelines for future developments which can make participation more ethical and engaging.

CCS CONCEPTS

• **Human-centered computing** → **Empirical studies in HCI**; • **Applied computing** → **Health informatics**.

KEYWORDS

health research; data platforms; personal sensing; acceptance; privacy; ethics.

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1 INTRODUCTION

Clinical cohort studies are used to investigate the natural history of diseases. By analysing demographic, behavioural and health data in chronological order, clinical researchers look for correlations, causes and effects [88]. Some of the challenges of these studies are the recruitment of large samples and the costly collection of longitudinal data [135].

Recently, health research data repositories have emerged to facilitate this process. They consist of large-scale shared-access databases containing different types of information on patients and healthy individuals, allowing multiple researchers to conduct analytical studies without having to recruit new participants [36, 112, 141]. Examples of data stored in such repositories may range from Electronic Health Records (e.g. Danish Civil Registration System [128]) to daily habits and behaviours (e.g. Evidation [44]).

Even though such platforms aim at benefiting society and health-care, previous research in other contexts found that when it comes to sharing behavioural and sensitive data, people have several concerns. In the context of information sharing for health treatments, a benevolent end goal is not enough for patients to agree with disclosing every data type to any receiver [106]. Similarly, in the context of genetic and bio-repositories, individuals feel concerned about their DNA data being misused in the future even though they understand the need for research [96].

Given such evidence from other contexts, individual concerns may represent a risk for the future of the new platforms: lack of acceptance can deter potential participation and compromise cohort diversity [125]. While a large body of research has focused on willingness to share data with bio-repositories [39], genetic testers [70] and clinicians [69], there is a gap in research that focuses on the specific context of the emerging large-scale platforms and research programmes. The latest initiatives differ from bio-repositories because they contemplate the use of continuous behavioural monitoring, which means it is not only DNA being stored but a complete picture of one's daily life.

Therefore, there is a need to investigate how potential participants feel about contributing to shared-access repositories, especially those which include behavioural monitoring. Ethical, legal, and social issues related to the topic have been previously discussed [125], but not much has been considered in terms of the

participants' preferences, concerns and priorities. Data repositories for health research have seen a rise in the last years [33], and since the COVID-19 pandemic, the expectation is that they will become even more predominant worldwide [48]. However, the context in question is underexplored in Human-Computer Interaction (HCI) [70]. It is time to consider how participants want to be engaged in such initiatives [59], as a better understanding of their viewpoint will enable the design of acceptable features aligned with people's concerns and expectations.

The goal of this paper is to investigate the perspectives of those who are not yet participants in these large-scale platforms and inspect their willingness to share different types of data. In order to achieve this goal, an empirical study with young adults was conducted. The motivation to focus on young adults came from the observation that those under 40 years old are often less favourable towards contributing to research repositories [50] and expect more control over how data is used [133], which makes them a more challenging group in terms of acceptance. Through the empirical study, our goal was to tease out their reasons for a potential resistance so that future developments can take these factors into account.

Moreover, this paper also provided a comprehensive compilation of the literature related to acceptance, privacy and motivation, as well as a summary of representative examples of existing platforms. The goal of this extensive narrative review was to put together findings and theories from scattered contexts, and show how they provide the foundation for the understanding of the participation in the new initiatives. Such aggregation is a useful resource to ground future research as well. Finally, we also contribute to design guidelines which are put in contrast with the current platforms to demonstrate what can be done to better align with participants' preferences.

2 LITERATURE REVIEW

The review was conducted in two parts. First, to characterise the spectrum of existing platforms, a set of examples was identified. Some of them had their origin in traditional research, but others came from a commercial or non-profit context, which means they were not listed in academic search engines. Therefore, searches were conducted online, on Google Scholar, via Twitter. Even though not systematic, this was considered as the most appropriate and feasible approach, given the heterogeneous field of search. Platforms were selected and categorised according to their distinctive characteristics to compose a diverse and representative set. Different from other reviews [9], particular emphasis was given to repositories which offered more agency to its participants. Only platforms with details available in English were included, which could mean that some examples, operating locally in their own language, were not detected.

Second, previous works about behavioural monitoring and research participation were identified and reviewed. Google Scholar, ScienceDirect, PubMed and the ACM library were searched for a combination of the keywords: participation in research, open-access repositories, bio-banks, genetic data-banks, motivation, willingness to share, acceptance, trust, privacy, informed consent, behavioural monitoring, self-tracking, research engagement. Papers' reference lists were also consulted (snowballing). We aimed at including a

broad set of reference, in order to illustrate that many how different factors can influence participation, but we were also mindful of the quality of the publication venues. The choice of topics to highlight in the narrative emerged from several rounds of analysis and discussions among authors until the core elements relevant to the context were traced. Particular emphasis was placed on identifying key challenges for acceptance, willingness to share and consent. A summary of these can be seen in Table 1.

2.1 Health research data platforms

A health research data platform is a repository which stores health-related data from population groups, to be used for analytical studies, often by multiple projects [92]. The development of such repositories represents a significant advance on how research can be conducted. Studies using data from existing platforms can provide evidence about the relationship between behaviours and health outcomes in an efficient and less costly way [54]. These repositories have been implemented differently, and the involvement of participants also differs among them.

2.1.1 National initiatives. A well-established example of a national research repository is the Danish Civil Registration System, which holds all medical registers for the entire Danish population [128]. Large-scale cohort studies have been conducted using this data, without much involvement of the patients. Researchers who want to get access to the data need to submit their projects for internal approval. Similar centralised national-level approaches are under development in India [124] and China [80].

Countries that do not have centralised health records have invested in the recruitment of volunteers for bio-banks. The *UK Biobank*, by the Wellcome Trust, collected clinical data from 500,000 patients until 2010 [136]. Their web page shows studies approved and published [89], as well as summaries of the available data [16]. Researchers can request access to this data, but the involvement of patients ended after data collection.

A more recent initiative is the *All of Us Research Programme*, which aims at recruiting one million volunteers and contemplates the collection of mobile-generated data [125]. According to their protocol [107], they want to allow volunteers to use the data to keep track of their health. Access is meant to be provided only to a group of researchers selected by the Programme.

2.1.2 Data portals for researchers. Another type of repository gathers data from previously conducted clinical trials. For instance, the non-profit organisation *Vivli* [25] works as a 'neutral broker' by connecting institutions and companies who are willing to share results from past projects [15]. Each organisation has its own data-sharing policies and access conditions, but *Vivli* run de-identification algorithms to the personal data beforehand. Participants receive the benefits offered by the individual clinical trials but are not involved in the processes at *Vivli*. Other data portals have aggregated information about genes, proteins and published papers, like the European Union's COVID-19 Data Portal [117]. In these platforms, it is up to the researchers to share their data, not the participants.

2.1.3 Opt-in sharing. Individuals may start to collect data for themselves but agree to share it for research afterwards. For instance, *Achievement* [2] is a commercial mobile app for personal health

Acceptance and Trust	People trust some institutions more than others	[34, 39, 118, 132]
	Trust can be hindered by previous experiences	[3, 5, 34]
	Acceptance decreases if data collection is hard	[32, 71]
	Acceptance decreases if the purpose is not useful	[75, 78, 137, 152]
Willingness to share	People worry about data misuse	[78, 95, 96]
	People want to preserve their reputation	[65, 77, 111, 119, 121]
	Some types of data are more sensitive	[14, 47, 61, 86, 123, 146]
	Some people are more concerned than others	[8, 63, 86]
Consent and Ethics	Consent forms are lengthy and complex	[84, 110]
	People cannot understand the risks	[31, 94, 115, 131]
	Lack of flexible sharing options and control	[5, 27, 57, 64, 73, 91, 106]
	Lack of transparency about data use	[39, 99, 142]

Table 1: Challenges identified in the literature, which can represent barriers to participation in health research platforms.

tracking in which users earn points by logging daily behaviours, answering surveys and being passively tracked. They can opt-in to share this data with *Evidation* [44], a platform which uses the information for clinical studies. Before the surge of COVID-19, not many details could be found about the on-going projects of Evidation, besides a publication list, but currently, they post weekly updates for the public. A similar opt-in approach is also used by the DNA genetic testing company *23andMe* [70] and the social network *PatientsLikeMe* [149]. In none of these examples are participants in control of how the data is used once they give their consent to share it for research.

2.1.4 Participant-driven. In some platforms, the initiative to join an initiative and collect data for that comes from the participants themselves. An example is the community-based *Open Humans* [53], in which projects are posted, and members are invited to contribute with their Fitbit, Twitter or symptoms data. Members can also propose projects of their own, and share tools for self-experimentation. With the surge of COVID-19, organisers have been hosting online meetings as a way to open the discussion about pandemic-related projects. A similar example is the recent *Project Baseline*, from Alphabet (parent company of Google) [90]. Their projects range from virtual mood tracking to in-person bio-sample collection. Since the rise of COVID-19, they partnered with local governments to send tests and share results with Departments of Public Health - but so far, this data does not seem to be openly available. Besides such platforms which aggregate calls for several projects, there are also crowd-sourcing projects focused on health, also called 'participatory disease surveillance', in which individuals are invited to self-report symptoms and answer surveys for epidemiological control [103]. The COVID-19 emergency increased the number of such initiatives all over the world [48].

2.2 Behavioural monitoring and research participation

As it can be observed from the above overview, and from previous studies [29, 38, 47, 52, 85], smartphones and wearable data are starting to be considered for health research. Also called 'digital phenotyping', such data sources can provide information about users' environments [38], mental states [52], physical status [29] and daily habits [85]. This data can be collected passively (personal sensing) or manually through self-reports.

When it comes to using this data for health research, individuals are asked to contribute with their personal (and often sensitive) data for a purpose which at first may not directly benefit them - it is meant to help society. In this complex context, there might be a desire to contribute, but privacy concerns might hinder the willingness to share data. Besides, the goal of many of the platforms is to allow data to be reused across multiple projects. Within genetic data repositories, there are several discussions about how consent should be asked in this situation [39]. This section, therefore, reviews factors which are key in the context of data platforms storing health and behavioural information for research beyond the scope of a single project.

2.2.1 Motivation. In the context of participating in research, motivation is the force which drives individuals to contribute and may come from different sources. It is common to reward participants with coupons, lottery tickets and gift cards [76], which are external sources of motivation. Money payments is another potential source of motivation to share personal data [13]. However, individuals might feel more motivated if their behaviours are self-determined: they act because they believe in the inherent value of their action [35]. A common finding in related works about willingness to participate in research is that people are motivated by contributing to science [150], helping patients [49] and seeing the outcomes [39].

In order to enhance motivation, researchers have looked for ways to get participants to be more engaged in the process [21,

40, 46]. It has been discussed that participants should take part in agenda-setting, study design, recruitment, project evaluation [130], as well as decisions about the usage of the data [5]. By being more integrated with the project, they may feel more responsible for the results [7].

Getting test results is a primary motivation of those who send samples for genetic testing, such as 23AndMe [70] and previous works have pointed out to the use of personal data for reflection and behavioural change [45, 68, 82]. In addition to learning from the data collected, people can also feel motivated by comparing themselves to others [87], sharing their goals [30], and receiving feedback on their progress [51, 66]. However, there can also be negative consequences for using these as motivation drivers. When looking at their stats, some may experience anxiety [81, 147], feel guilty for not keeping up [42], lower their self-esteem [28, 100], and make incorrect interpretations [93, 109, 147]. Another issue is that when it comes to self-tracking, motivation may be necessary for keeping adherence to the data collection. It can be challenging for participants to stay consistent after joining a project [122], especially if they have to provide inputs frequently [26, 32].

2.2.2 Privacy. In the same way that motivation is an important enabler to participation in the research, privacy is a major barrier [74]. People worry about the potential for discrimination, undisclosed marketing interests, government surveillance and data used for generating profit [78, 95, 96]. Being constantly monitored can lead to feelings of surveillance [140], paranoia [127], and loss of freedom [24].

Privacy boundaries are often defined to protect internal values of autonomy, social acceptance and impression management [119]. In a study about students' perceptions on disclosing self-tracked data, they mentioned experiencing social pressure, stigma and embarrassment about their data [65]. The fear of a data breach is related to the potential damage to one's reputation and how others may react [111, 121]. By selecting which aspects of their lives to disclose, people can also control the image others have of themselves [77, 113].

However, willingness to share can depend considerably on the context [104], and there is a known mismatch between stated intentions and actual behaviours (privacy paradox) [105]. Therefore, even though privacy concerns may be a barrier to participation, in the context of research, individuals apply a 'usefulness heuristic': they prefer to share information that they know will be useful [83], and that they believe will not increase the risk for personal harm [121]. The Amazon Mechanical Turks were found to base their decision to share personal data for research on pay rate, requester, purpose, and perceived sensitivity of the request. However, they also engage in privacy-protective behaviours, such as abandoning tasks or providing inaccurate data [126].

Some factors can affect the intensity of privacy concerns. Previous research has found that more sensitive data types are disclosed less often [86, 123], such as audio recordings [37], browser history [14], message/phone logs and social media activity [47], camera pictures [121], financial information [146], home address [83], feelings of loneliness [61], sexually transmitted diseases [146], toilet use [12], and any health-related data in general [141]. Privacy is also perceived differently across individuals [22]. Personality traits

of agreeableness, conscientiousness, and openness to experience, can affect privacy perceptions [63]. Privacy fundamentalists are less likely to disclose information [86] as well as anxious individuals [8]. The benefits obtained from information disclosure are also a factor that can modulate the importance people attribute to privacy risks [70].

2.2.3 Acceptance. The decision to share data for research consists of weighing the motivation to contribute against the potential risks [83, 134]. It is clear that in the context of data sharing for research, motivation and privacy are critical components for acceptance. It is only when individuals 'accept' to contribute to a health research platform that their participation begins, but these acceptance should also be considered in the longer term, as it would be undesirable to have people dropping out [101].

The literature has extensively discussed factors for technology acceptance in general - usability and usefulness are known to be key factors for it [71]. In the context of participation in research, acceptance can increase if the burden of data input is low, which can be achieved by high usability [32, 57]. Regarding usefulness, people are more accepting of risks if they see their benefits, which can be for future patients [75], global causes [78, 152], researchers [137] or themselves [70]. However, usefulness can be highly contextual. Individuals may be less willing to participate if they think information is not relevant for the purpose [121, 123, 147]. On the other hand, individuals who are health-motivated [60], familiar with research [96] and who have disabilities [12] can be more accepting, because they understand how data can be useful.

The acceptance of information sharing with research repositories is also closely related to trust, especially on those who will keep and use the data [5, 118]. People may be willing to leave concerns aside when they trust those requesting their information [62, 79]. Scientific institutions are often trusted more than commercial, governmental and insurance institutions holding health information [39]. However, the development of trust is a continuous process, and trust can change over time [34]. Some enablers of trust in digital systems have been listed as fair data access, recommendation by others, customised design features, initial face-to-face contact, stakeholder engagement and improved communication [3].

2.3 Ethics and informed consent

It is well-known that before using any data from research subjects, the ethical approach is to obtain their consent, especially when data is collected through smartphones [55]. Subjects should also be allowed to withdraw from any study effortlessly [31]. The recent European General Data Protection Regulation (GDPR) established that in any data sharing procedure, people need to be at least informed about the information being shared, with whom and for what reasons [144]. However, consent forms are often overly complex [84], lengthy [110] and not efficient in informing participants [19, 58]. Many people do not understand what they are signing up for [145], how much information can be extracted from data [31], what data from sensors can reveal about them [94], how risky it is if someone identifies them [131], and how easily their identities can be revealed [115].

As a consequence, recent works have pointed to a desire for even more transparent and understandable information about data

usage [39, 99, 142]. Participants of genetic repositories have mentioned being interested in receiving more details about the goals of the projects [139], reports on privacy risks [145] and notifications about when data is used [114]. However, it is not trivial to provide an appropriate level of information without confusing users or making it a burden [43, 72]. The literature on how to improve the process of asking for consent is extensive, especially within research [41]. Suggestions have been made to go beyond textual forms and consider face-to-face encounters [4, 114], communication channels (e.g. chats and forum) [129], visual info-graphics [97] and interactive tools [64, 102].

Furthermore, it has been argued that people should be allowed more control over how their data is used [5, 27, 57, 64], such as the level of detail disclosed [91, 106], and how long data is retained [73]. It has been suggested that willingness to share may increase if users can choose what information is shared and to whom [1, 148], and customised settings can enhance trust [114]. User interfaces that allow a selective disclosure of data have been proposed as a way to support automatic sharing rules in order to reduce the burden of continually editing preferences [100].

However, from the review of the existing platforms, it could be observed that most of the large-scale repositories often rely on models of *broad consent* [120], which means that participants provide their consent to any future study using their data for an indeterminate period of time (e.g. All of Us, Evidation). This contrasts with the idea of *narrow consent*, which has been found to be a preferred option over broad consent in some cases [67]. This type of consent consists of consulting participants for each project using the data (e.g. Open Humans), but restricts the re-use across multiple researchers and the combination of data sources. A consent type in between narrow and broad is called the *tiered consent* [20], in which consent is only asked in certain situations, such as if studies vary significantly in nature. None of the platforms seems to follow this type of consent yet - such mid-term appears to be missing in this space.

3 EMPIRICAL STUDY

Our literature review identified enablers and barriers for participation in research and data sharing overall, but it could not identify qualitative works specifically on health research repositories that consider continuous behaviour monitoring. Moreover, the overview of the existing repositories identified different strategies to health data platforms, but it remains unclear if the expectations of participants match the available options. This empirical study is to explore individuals' attitudes and preferences regarding this scenario. The study consisted of semi-structured interviews and a card sorting activity with potential future participants who had not contributed to any research data repository yet.

3.1 Sample

A sample of 12 participants, aged between 19 and 26 (mean=23, std=1.8) was recruited through word-of-mouth. Recruitment stopped when data saturation was reached - no new themes emerged from the last two interviews. Participants were four females and eight males, from France, China, Spain, United States, Hungary, Netherlands, Italy and Scotland. One was a full-time developer, three were

part-time developers, three were doing internships (in wind energy, marine biology and photonics), two were exchange students, and two were finishing their Masters'. They reported being healthy in general, did not mention experiencing data breaches in the past, never been part of a clinical study, and four of them tracked physical activity occasionally. The study was exempt from ethical approval but was conducted according to accepted ethical standards (informed consent, benefit- not harm, confidentiality) and followed the national code of scientific conduct.

3.2 Study design

Semi-structured interviews and card sorting activities were conducted with each of the participants individually. All of the interviews had the same set of questions and cards (within-subjects design).

3.3 Materials

Before the interview, a set of cards was prepared. Each card contained a different 'information item' (see Table 2). The choice of items was based on the analysis of previous works about data sensitivity and willingness to share [12, 14, 37, 47, 61, 83, 86, 121, 123, 141, 146], data collected in the different platforms, and mobile sensing frameworks for behavioural monitoring [23]. Three medical doctors were consulted to confirm that the card set contained only data relevant to health research.

3.4 Procedure

In order to introduce participants about the concept of a health platform, on the day of the interviews, participants were first shown a 1 minute and 55 seconds video about precision medicine, made by the All of Us organisers¹. The short video did not provide any in-depth details about the platform; it was an introduction to the idea of having a data repository for health research. Participants were explained that the video was meant to be just an illustrative example.

Participants were asked to describe their initial opinions about health research platforms. Then, they were asked about potential reasons to contribute to and general concerns. Interview questions deliberately elicited both positive and negative perspectives to try to mitigate the bias of social acquiescence.

After these initial questions, participants were asked to do the card sorting. For each card, they were asked if they would feel comfortable with having the information depicted on the card stored in a repository. They were asked to place the cards in "yes", "no" and "maybe" piles and explain their decision. After the card sorting, they were asked what they would like to happen once their data had been shared and what they expected to hear from the platform. The interview ended with the collection of demographic information. Interviews lasted 45-70 minutes. They were conducted in-person (before the COVID-19 crisis), audio-recorded, and transcribed. The card sorting activity was documented in pictures. Data analysis was conducted using Thematic Analysis [17, 18], with themes being iteratively generated from the data collected (inductive approach). Transcripts were read several times, during which similar quotes

¹<https://www.youtube.com/watch?v=ti50nS7B5vI>

Calls/text content	Calendar	Financial status	Relationship	Address	Blood/urine
Mental illness	Grades	Genetic disorders	Emotional status	Family	Partner health
Toilet habits	Hygiene	Sleep patterns	Places visited	DNA	Contagious illness
Alcohol/ tobacco	Food	Local ambience	On-screen time	Distances	Physical exercises
Physical status	Leisure	Current weather	Physical illness	App	Heart rate

Table 2: List of information items (data types) shown as cards to participants.

were given codes, and groups of related codes were associated with themes.

4 FINDINGS

The interview study had the goal of investigating how young individuals perceive the idea of contributing to a health research repository and how they feel about sharing different data items. The result of the analysis showed that three main themes were recurrently discussed. These were: reasons to contribute to a research repository, characteristics of an ideal platform and the criteria for sharing the different types of information.

4.1 Motivations to contribute

When participants discussed the possibility of contributing to a health research platform in the future, they discussed the potential benefits of this choice. These fell under two categories: public and personal benefits.

4.1.1 Public benefits. Without exception, all of the participants praised the importance of health data repositories for society. Their initial comments often highlighted the usefulness of such idea: *“There could be a lot of good for a lot of people if healthcare providers could have more access to information about people’s lives”* (P3). Such altruistic motivation, of helping researchers and patients, was the first mentioned by the majority of the participants: *“I would share my data with the idea that it can help research and it can help other people to be cured”* (P9).

4.1.2 Personal benefits. Besides altruistic reasons, there was definite interest from the majority of the participants in receiving personal benefits as well, such as using the data for their own health improvement, which was mentioned often: *“If you have all the information about me, you can do more specific tailored care, maybe even like getting life recommendations”* (P3). There was also interest in comparing themselves with others: *“I would like to know how I compare with others. I feel like if I see others are using their phone significantly less time than I do, then I can control myself”* (P7).

On the hand, the prospect of receiving material compensations was rarely mentioned, and when mentioned, participants had opposing opinions. Some believed that their contribution should be rewarded: *“Probably if it takes a lot of time, it should be rewarded, it should be paid”* (P1), but others did not: *“I don’t think I would ask for financial compensation, I think it is more of a volunteering type of work”* (P7).

4.2 Trust in the platform

Throughout the interviews, participants mentioned some key features a platform should offer to be trusted. Two main requirements were recurrent: transparency and choice.

4.2.1 Transparency. In order to verify if a platform presented the desired characteristics, participants mentioned several times the need for more transparency, so that they could make an informed judgement. They would like transparency about:

- *Who will use the data.* Most participants mentioned that they would like to know both who is the organisation behind the platform and who will be provided with access: *“I need to know who are the people behind the programme. Is it the university, is it an external research centre, is it for hospitals? And who is going to check my data?”* (P2).
- *For what purposes.* They also wanted to know precisely for which purposes the data would be used now and in the future: *“It is good not to share anything if we do not know how it can be used in the future”* (P11). The reason for that was because not all purposes were acceptable, as there was an evident objection to allowing data to be used for profit, mentioned by the majority: *“I’m happy to share this for health and public good reasons, but as soon as it starts to be for a private company, I feel like I am being taken advantage of”* (P3). Some of the participants would like to be notified about what was done with the data: *“I would be interested to know if I helped and what conclusions were drawn as a result”* (P8). This interest was not shared by everyone, however: *“I will give you my data, but I will never read the outcomes. For the people more interested, maybe”* (P12).
- *How data is secured and anonymised.* Evidence of cybersecurity measures was regarded as a significant factor for trusting a platform: *“If you feel that data is going to be leaked then I guess you wouldn’t share a lot”* (P5). One participant mentioned feeling reassured by being informed about the protocols used, even without fully understanding them: *“Knowing some technical stuff would make me comfortable even though I don’t understand that type of information”* (P4). The same importance was given for knowing that data is stored anonymously: *“If it is already anonymised in the database, then I would use the platform even if there was some kind of hack in the system because I know that I am just going to be one in the millions”* (P4).

4.2.2 Choice. Besides being thoroughly informed about the aspects above, a topic often mentioned by participants was the desire

to be able to actively keep control of the data during and after it was shared. Participants stated that they would like to choose who can have access and what data is available:

- *Selecting receivers.* Some of the participants would like to allow access to projects on a case-by-case basis: *"If they have new research and want to have access to my data, I want them to ask me if I want to release to the new research or not"* (P7). Not all of the participants agreed with this thought: *"I don't want to give the go-ahead for every researcher. There are probably too many requests, and I don't want to be bothered by this all the time"* (P5). As one of the participants mentioned, it would be interesting to be able to at least block the access for studies they do not agree with: *"I want to choose if I disagree with one of the studies and say: 'with this one I don't want to share' "* (P10).
- *Filtering the data.* Many participants mentioned that it would be good to stop the data collection on some occasions: *"Maybe in some situations is useful to stop recording some data. If you go to some places where you don't want to be followed, for example, you don't want people to know you are there"* (P2); and to be able to see what data is stored and reconsider the decision to give access: *"Once I have given the data, I think it would be nice to have a look at what is in the system, what data you saved and then have the option to maybe delete data points if I think it is not appropriate"* (P5). Additionally, many of them mentioned that they would feel more comfortable if researchers have access only to less detailed information: *"If it just to know what you are going to do in your day, how many hours you are walking, something like that, is fine"* (P10).

4.3 Willingness to share each data type

Participants often diverged opinions about which information they would feel comfortable collecting and sharing. Also, the same data type sometimes led to different types of concerns between participants. An overview of the different criteria for these decisions is listed next.

4.3.1 Relevance for the research. Having a clear understanding how the information is useful for health research was in many cases the reason why a participant would feel comfortable with sharing it: *"I would be happy to share that consumption information. For me, that has a very tangible connection to health"* (P3). On the other hand, not fully understanding the relevance of an item was mentioned by many as a reason to not share: *"I don't think my home address is relevant for the purposes of the research"* (P8). Participants did not always agree on the relevance of the different data items, with some being fine with sharing items that others would not see a reason for it.

4.3.2 Potential for material damage. When participants felt comfortable with sharing a particular data item, it often was because they could not see the potential for any adverse consequences: *"I don't think there is any harm in sharing your sleep patterns"* (P8). On the other hand, when participants said feeling uncomfortable, they mentioned fears related to physical attacks: *"If people want to locate me, it would be really easy. If I am going back home at this time, then someone is just waiting for me at the door and just breaking*

into my room" (P7); cyberattacks: *"Financial situation, no, because people maybe know how much money I have in my bank account and they would see if it is worthy hacking it or not"* (P7); and financial loss: *"If hackers are working for an insurance company, and they sell data to them, it could happen that they [insurance companies] propose different plans"* (P6). Not all of the participants associated these risks of material damage to location and financial situation - participants varied in their opinion about what information would bring each type of risk.

4.3.3 Risks for reputation. Some participants mentioned that there were parts of their life they prefer to keep private, because of the fear of how others perceive this: *"If it is not treatable then maybe it is something you want to keep it for yourself or share with only a limited amount of people"* (P5). Similarly, some mentioned being concerned about the possibility of being discriminated by their employers: *"I am afraid that in a potential data leak, my employer gains access and discriminate me in my employment"* (P11). However, participants often diverged on opinions about which data types they perceived as riskier for their reputation - their decision depended on their judgement of their own habits. Some participants said they would feel ashamed to disclose their drinking habits *"Alcohol, tobacco, I do not want people to know how much I drink because I drink too much"* (P8), but others said they were comfortable with it. Information perceived positively by society was often considered as more comfortable to shared: *"Physical activities, yes, because I feel like is something positive"* (P6).

4.3.4 Invasion of others' privacy. Some participants were not comfortable with sharing data that did not belong to them: *"I think sharing calls and text content overlaps with the privacy of other people"* (P2). Sharing data from others was described as a betrayal by one of the participants: *"I do not want to share their data, it is kind of like going behind their backs"* (P4). They believed they were not in the position to decide: *"When it comes to the condition of my partner, it is tricky because I feel like it is their decision to share the information"* (P3). This concern was not mentioned by all of the participants, however.

4.3.5 The effort of the data collection. Sometimes, the issue was the burden of data collection. Most of the participants mentioned that collecting data can be an inconvenient responsibility: *"I don't want to share data when I'm low on my battery, or when I'm short of data. I wouldn't like this data to interfere with my daily life"* (P2); some also mentioned it can be emotionally difficult: *"If someone is really sad or depressed, I think it is harder to share that"* (P10). Some of the participants did not mention issues with data collection.

5 DESIGN GUIDELINES

Health research data platforms arrived to help science and healthcare to progress [6] and if they stick to this goal, public acceptance should be desirable. The interview study shed light on critical factors involved in young adults decision-making regarding (i) eventually contributing to health research platforms, (ii) and sharing specific types of information. The findings indicate that motivations to contribute (public and personal benefits) and indications that a platform can be trusted (who are the organisers, how data

is secured and used) are significant components for initial acceptance of the platform's terms. Acceptance is, however, not fully achieved before potential participants evaluate their willingness to share the specific data types in question. According to our findings, this decision depends on the relevance for research, the effort to data collection and risks for material and reputation damage. Even though previous works have identified similar factors, our findings are original because of the context under investigation. The literature on participating in research could perhaps enlighten some motivations to join, but it would be insufficient to describe the importance of the willingness to share each data type. Similarly, the literature on data sharing and privacy has not yet considered the case of contributing to a shared-access research platform. This empirical study allowed us to pinpoint the key factors for the acceptance of the emergent platforms for digital phenotyping research, which has not been done before.

In Figure 1, we show the conceptual model we introduce for acceptance in the context of health research data platforms, which includes a summary of our findings and our proposed design guidelines. These guidelines focus not only on the initial acceptance of the platform and its data types but also their *continuous acceptance*. As a recent review on technology acceptance highlights, health initiatives should be aiming for a long-term engagement with its users [101], which is also what we advocate.

5.1 Provide supervised health feedback as a motivation source

As mentioned in the review, the motivation to participate in research can come from many sources. Financial compensation, to start with, has been used in several clinical studies and existing platforms (e.g. All of Us). However, in the interview study, participants rarely mentioned this as a motivation source, which was also the case in previous reviews about bio-banks [96]. Even though it has been found that people might be willing to sell personal data for money [13], another work has questioned whether material incentives lead to increased adherence and data quality [76]. Such types of compensations were found to be more beneficial if combined with other motivations [56].

The reasons to contribute to a research repository mentioned by our participants included both altruistic and more individualistic ones. It is widely known that people are more open to sharing personal data if it is for helping patients [75], science [137] and society [78, 152]. However, it was observed in our study that getting direct benefits from the data was as important, which aligns with studies about sharing genetic information [70]. In the case research repositories which collect health and behavioural data, this direct benefit is related to the possibility of receiving feedback on personal health and well-being indicators. The All of Us Programme seems to offer this, as they state they will provide ways for volunteers to get access to the data they share and some of the results [108]. Allowing people to keep track of their results, could not only motivate people to participate but also stay adherent and see a meaning for the effort of data collection, mentioned in the interview.

However, platforms should be mindful of how they inform users about health management so that they can extract a correct meaning out of their data. There are many studies of digital tools for personal

health monitoring, [45, 68, 81, 87] and social sharing [30, 51, 66], which are useful inspirations on how to integrate personal care with self-tracking. However, an issue with self-administered tools is that there can be negative consequences, such as self-scrutiny [28, 100] and performance anxiety [81], which are particularly applicable to young adults [65]. Furthermore, when it comes to vulnerable patients of any age, self-monitoring is not recommended without the supervision of a specialist [11].

Therefore, research platforms should also consider how to offer proper clinical follow-up. Except for the COVID-19 testing, being offered by Project Baseline, large-scale platforms have not committed to health support. There are several studies about mobile applications which have combined personal health tracking with the close support of healthcare professionals [10, 93, 147]. Using health tracking with supervision and support could be a way to get participants motivated to contribute to research; however, it is also crucial to be mindful of the risks as mentioned above.

5.2 Allow personalised and flexible privacy choices

Our study elicited privacy concerns that could emerge if behavioural data is to be stored in a shared-access repository. Some were connected to the potential for personal harm, which was also found within data sharing for health treatments [106]; others were related to misalignment of personal values, such as data being used for hidden purposes, and a possible invasion to the privacy of others, which have been brought up in studies about genetic repositories [96]. Regarding differences across the different information types, even though quantitative studies could define some data types as more 'sensitive' [14], we observed that the reasons for such sensitivity depended a lot on the meaning people attribute to the different aspects of their lives and the importance they give to the different risks. Also, contrary to another study with young adults mobile sensors and privacy [121], our analysis showed that the same information often led to different types of concerns depending on the person, and no generalisations could be devised.

Such observation has implications for the use of behavioural monitoring for research repositories because if they intend to accommodate this pluralism of experiences, they need to allow participants to choose which data types are to be stored. Currently, consent forms follow an 'all or nothing' approach: participants who join a study are expected to share all the data required [116]; however, it can be difficult for some to disclose some parts of their life [113]. Participants in our interviews would like to stop tracking in some situations and select the level of detail visible to others, suggestions which were mentioned by older people (above 70) as well [106]. A way to achieve could be to provide participants with an overview of their data and allow them to exert some control over it, aligning with the increasing public interest on more flexible privacy options for personal data [1, 64, 74, 151]. User interfaces could be designed to allow interactive forms of selective disclosure [100] through continuous control of the data collected, as well as the possibility to not disclose parts of it. The consent process should also take into account these individual preferences, and volunteers should be given more flexibility about which information they want to share for research.

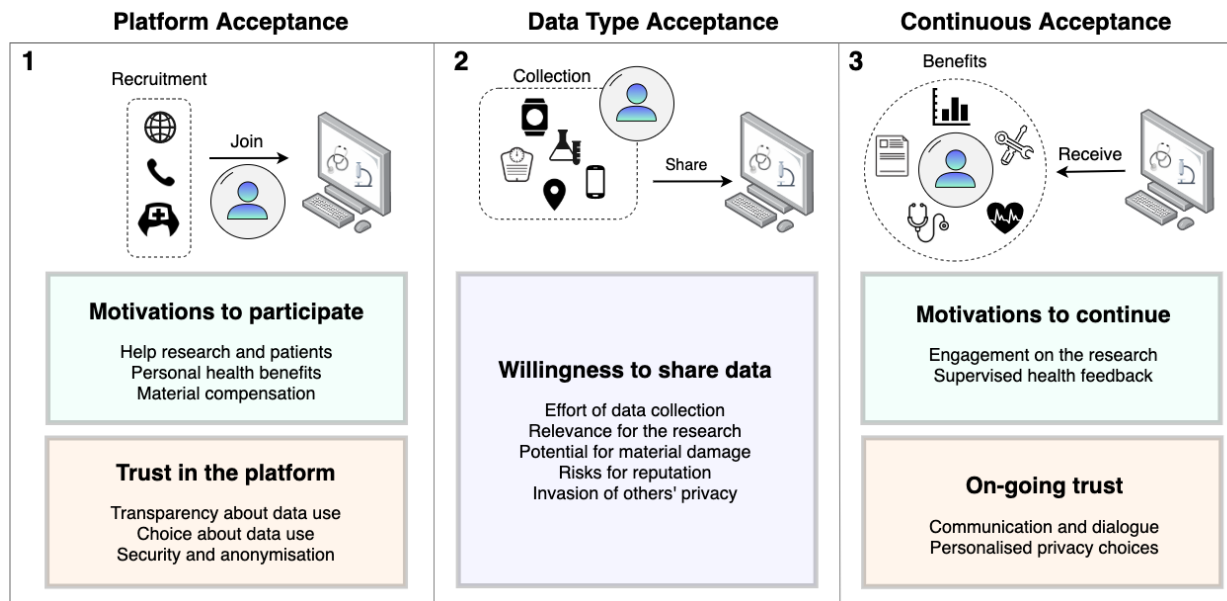


Figure 1: Conceptual model for the acceptance of health research data platforms based on our empirical findings.

Furthermore, our participants demonstrated a desire to have more control over the future of their data. Allowing participants to withdraw from studies is already required in recent regulations [144]; however, each platform has its approach when it comes to how much information and control participants have about the individual studies making use of their data. Participant-driven platforms (e.g. Open Humans) allow users to select precisely to which projects they want to share their data, but this can restrict data usage in the future. On the other hand, more significant initiatives (e.g. All of Us, Evidation) ask for broad consent so that they can use the data for any project they decide, but participants are not asked about anything else afterwards [70]. An attractive mid-term solution is, therefore, to allow participants to set-up rules or conditions under which any studies that fulfil them can access their data (tiered consent [20]). If participants would like to deny access to some receivers, this does not have to imply a complete withdrawal from the repository.

However, setting up privacy rules should not become an overwhelming process, in the way that consent forms became complex and lengthy documents [19, 84, 139]. The idea of moving away from the model of broad consent has been discussed in the context of bio-banks, but it is still an open question if permission should be requested for each new study [96]. Our findings indicate that it should be optional if permission is to be requested each time a new study needs the data - some might consider the obligation to provide consent as a burden while others might prefer to have full control. Providing individuals with more control over their data can be perceived as an indication of respect [98, 143], which can, in turn, become an enabler for trust and acceptance. The negotiation of privacy boundaries can be helped by more communication from the platform side, which is an aspect discussed next.

5.3 Use communication to increase engagement and acceptance

Our participants showed a positive attitude about sharing behavioural data for a research repository, as long as their data is safe, which aligns with the public views about genetic information as well [70, 96]. As discussed in the review, acceptance in this context is connected to the perceived usefulness of the purpose [14, 75]. Therefore, information about this purpose must be efficiently communicated to potential participants [152].

However, even though the repositories are providing a clear overall idea about how contributions can be useful, the ideal platform envisioned by most of our participants would be much more transparent about individual projects. As mentioned in the review of existing platforms, there is a lack of involvement of participants once data is collected. Participation in a repository is not only about the organisation who is behind it. If users want to know more about the on-going projects, they should be provided with complete reports about goals, methods and people involved, so that they know to what they are contributing. However, the communication between contributors and researchers in many cases consists only of 'publication updates' on a website.

For this reason, a continuous dialogue could be a path to fulfil the need for more transparency. Similar to our participants, young individuals in another study were intrigued about how some types of mobile sensors could be health indicators and if their identities could be revealed through them [121]. Platforms could offer more support and information when it comes to explaining how data is being used for research, going beyond public reports, and providing personalised content based on the participants' concerns. Besides, some of our participants were also interested in staying updated

with the research outcomes [39]. Platforms should consider how to keep volunteers updated more frequently about the on-going analysis. Such a continuous form of communication could include chat tools with the scientists, social forums with other participants [129] and open access virtual meetings, similar to what Open Humans has been offering, for example. Another aspect which deserves more attention is the fact that not everyone has the same understanding about the overall risks of sharing data with a repository [31]. Information about how data is secured and kept anonymous to the researchers should be appropriately conveyed [115] and tools for communication could be useful in this process.

Spaces for the active involvement of participants could correspond to the desire expressed by some of the young adults in our interviews. Active engagement may involve suggesting new research questions, providing feedback and voting on decisions [21, 46, 130], which in turn can make people feel rewarded when the initiatives are successful [7]. Learning materials could be provided for participants interested in understanding the methods behind the investigations [150]. By considering and providing such options, the platforms of the future could move forward from the traditional relationship between ‘study subjects’ and ‘scientists’ [138].

From the review of the existing platforms, it could be observed that since the surge of the virus, there have been efforts to promote more participant-centred features, such as open community calls (Open Humans) and weekly reports (Evidation). However, none of these examples has fully considered the directions presented in this section. The COVID-19 pandemic brought urgency to data sharing for research, which represents an excellent opportunity to reflect on how we should be building acceptance and trust. Our vision is that by bringing participants closer to the research process, their participation can become more engaging and respectful. Instead of imposing terms and conditions from the top, these could be negotiated and established based on participants’ input of how they would like the future of research repositories to be.

5.4 Limitations and future work

This paper presents a limited empirical study in terms of sample demographics, which could compromise broader generalisations. Besides, as the study happened before the COVID-19 pandemic, any possible changes in attitudes because of that are not represented. Future follow-up studies could investigate the perspective of other age groups, as well as the effect of the pandemic on their opinions. Quantitative approaches could also be used in the future to identify patterns across larger samples. It could also be interesting to expand this comprehension and consider how the emerging platforms are being conceived and perceived across the globe. Finally, further studies could investigate the impact of our design guidelines in-the-wild.

6 CONCLUSION

This paper provided an overview of health research data repositories from a participant-centred perspective. It reviewed the landscape of current platforms and brought together scattered literature to conceptualise the experience of participating in them. The acceptance to participate was found to depend on the trust in the

platform, individual motivations, and the willingness to share different data types. Based on the review and the empirical results, we formulated guidelines on how to enhance identified enablers and dissipate barriers for participation in an ethical way.

We argue that participants should not be considered passive study subjects, but rather be invited to get actively involved in the studies and control the shared data. Some existing initiatives have started moving towards this direction, but there are still several opportunities to design features to reshape relationships of power between data contributors and platform organisers. After all, the future of health research data platforms should be guided by the participants’ perspectives, because they are the ones putting themselves in a vulnerable position for the common good.

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2.3 Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey

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Original Paper

Public Attitudes to Digital Health Research Repositories: Cross-sectional International Survey

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Abstract

Background: Digital health research repositories propose sharing longitudinal streams of health records and personal sensing data between multiple projects and researchers. Motivated by the prospect of personalizing patient care (precision medicine), these initiatives demand broad public acceptance and large numbers of data contributors, both of which are challenging.

Objective: This study investigates public attitudes toward possibly contributing to digital health research repositories to identify factors for their acceptance and to inform future developments.

Methods: A cross-sectional online survey was conducted from March 2020 to December 2020. Because of the funded project scope and a multicenter collaboration, study recruitment targeted young adults in Denmark and Brazil, allowing an analysis of the differences between 2 very contrasting national contexts. Through closed-ended questions, the survey examined participants' willingness to share different data types, data access preferences, reasons for concern, and motivations to contribute. The survey also collected information about participants' demographics, level of interest in health topics, previous participation in health research, awareness of examples of existing research data repositories, and current attitudes about digital health research repositories. Data analysis consisted of descriptive frequency measures and statistical inferences (bivariate associations and logistic regressions).

Results: The sample comprises 1017 respondents living in Brazil (1017/1600, 63.56%) and 583 in Denmark (583/1600, 36.44%). The demographics do not differ substantially between participants of these countries. The majority is aged between 18 and 27 years (933/1600, 58.31%), is highly educated (992/1600, 62.00%), uses smartphones (1562/1600, 97.63%), and is in good health (1407/1600, 87.94%). The analysis shows a vast majority were very motivated by helping future patients (1366/1600, 85.38%) and researchers (1253/1600, 78.31%), yet very concerned about unethical projects (1219/1600, 76.19%), profit making without consent (1096/1600, 68.50%), and cyberattacks (1055/1600, 65.94%). Participants' willingness to share data is lower when sharing personal sensing data, such as the content of calls and texts (1206/1600, 75.38%), in contrast to more traditional health research information. Only 13.44% (215/1600) find it desirable to grant data access to private companies, and most would like to stay informed about which projects use their data (1334/1600, 83.38%) and control future data access (1181/1600, 73.81%). Findings indicate that favorable attitudes toward digital health research repositories are related to a personal interest in health topics (odds ratio [OR] 1.49, 95% CI 1.10-2.02; $P=.01$), previous participation in health research studies (OR 1.70, 95% CI 1.24-2.35; $P=.001$), and awareness of examples of research repositories (OR 2.78, 95% CI 1.83-4.38; $P<.001$).

Conclusions: This study reveals essential factors for acceptance and willingness to share personal data with digital health research repositories. Implications include the importance of being more transparent about the goals and beneficiaries of research projects using and re-using data from repositories, providing participants with greater autonomy for choosing who gets access to which parts of their data, and raising public awareness of the benefits of data sharing for research. In addition, future developments should engage with and reduce risks for those unwilling to participate.

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KEYWORDS

digital medicine; health informatics; health data repositories; personal sensing; technology acceptance; willingness to share data; human-centered computing; ethics

Introduction

Background

Health research is increasingly adopting digital technologies to accelerate scientific discovery, as digital data sources increase scalability and predictive power for algorithmic inferences [1-3]. Novel data collection techniques include wearables and smartphone sensors to extract participants' behavioral features passively [4]. Records of calls and texts can flag social activity fluctuations; location tracking can reveal mobility patterns; heart rate measures can indicate sleep quality [5-7]. Ecological momentary assessments further complement such passive indicators by sampling individuals' health status in real time through questionnaires [8,9]. The motivation for considering pervasive and digital sources of health and behavioral information is related to the possibility of closely observing research patients' daily lives [10,11].

Intending to personalize future patient care, researchers search for scientific evidence by analyzing longitudinal streams of personal sensing data from large segments of the population [12,13]. Because of this expansion of personal sensing in the health domain, digital health research repositories are gaining momentum. An ambitious concept similar to biobanks [14], a digital health research repository allows multiple projects and researchers to share access to personal data streams beyond DNA and biosamples [15-17]. Although still in their initial steps, initiatives with this goal in mind include nationwide programs [18,19], university-led projects [20,21], and community-driven data platforms [22-24].

Despite promising benefits, barriers to public acceptance can hinder the successful implementation of digital health research repositories [25,26]. Without a diverse range of participants agreeing to contribute with their personal health data, repositories cannot accomplish their ambitious goal of providing reliable evidence for personalized medicine to the broad population [27]. Furthermore, a potential lack of acceptance is aggravated by ethical debates questioning which rights individuals should have following contribution of their data [28-30], especially if data are shared beyond a specific project's scope. Given such challenges, previous research has emphasized that in contrast to most current initiatives, which mainly cater to researchers' needs, health data repositories should attend more to participants' preferences to identify enablers for participation [31,32].

Previous Studies

Previous studies have investigated public attitudes toward biobanks [33-36] and digital health data [37,38] separately. Other past studies have examined motivations to contribute [39], privacy concerns [40], and access control preferences [41] for data sharing within health research in general, yet these studies consider only a few variables simultaneously and rarely inquire about the magnitude of specific attitudes [42,43]. To

the best of our knowledge, published quantitative studies have not thoroughly examined how different factors can affect attitude and willingness to share in digital health research repositories' timely and emerging context. Thus, it remains unclear how the public perceives the risks and benefits of shared access of multiple sources of behavioral and health indicators, including digital sensing, for research repositories.

Study Goal

Given this research gap, an online cross-sectional survey was conducted examining public attitudes to research repositories storing health information, biosamples, personal sensing, and behavioral data. This survey study aims to identify implications for future developments by consulting those whose personal data are to be shared for research. The study took place in Denmark, where the project is funded, and the principal investigators are based. Furthermore, with the goal of investigating the potential contrast between 2 very different historical, social, and cultural contexts, we contacted a research group in Brazil to establish a partnership and conduct the study with a sample of Brazilian residents. This decision allowed a cross-country analysis that illuminated similarities and divergences between 2 very disparate contexts. The results contribute to substantial empirical evidence about enablers and barriers for participants' acceptance and discussions on how community engagement, technology design, and policymaking can lead to a stronger participant-centric development in this field.

Methods

Population, Sample, and Recruitment

Denmark and Brazil are very different in terms of population, geography, economy, and culture. Denmark is a small country in area and population (5.8 million inhabitants), with a robust economy and a strong focus on social welfare, which is evident given the country's investments in education, research, and health care. By contrast, Brazil, the fifth largest country globally (208 million inhabitants), has a diversified economy, rich biodiversity, and industrial potential but at the same is characterized by an unequal society. Most of the population still lacks access to high-quality education and health services given the vast disparities of wealth distribution across the country. These differences make the population of these 2 countries very contrasting.

This survey study was part of an academic consortium project, publicly funded, to develop a digital health research repository for youth mental health, in turn defining our main target population (young adults), but without excluding the possibility of collecting data from other, older groups, if those participants would be interested in the study. As the project investigators are in Denmark, participants were first recruited among young Danish residents. Later, to enable the comparison of findings with a divergent historical, cultural, and social context, we

sought to form a partnership with clinical researchers at a university in Northeast Brazil, the Universidade Federal do Rio Grande do Norte (UFRN). Therefore, recruitment efforts were also made to collect data from a sample of young adults in Brazil, but without being restrictive over the age groups that could respond. The online survey was deployed using LimeSurvey and hosted on a server at the Technical University of Denmark (DTU). The survey link was distributed across several channels in an extensive recruitment process that started on March 9, 2020, and ended on December 9, 2020. The link was made available in forums and newsletters at university portals, emailing lists, social networking groups, online chat platforms, and unpaid posts on Twitter. Recruitment in person happened once during an event hosted at DTU (prior to the surge of COVID-19). Participants were compensated with a cup of coffee at this event. Besides this one-time event, no other compensation was given to respondents to avoid providing incentives for repeated participation. Given the distribution of the survey in multiple channels without access restriction, a considerable number of responses came from participants beyond the target population (older than 27 years old). The research team decided not to exclude data from these respondents belonging to age groups above 27 years from analysis; instead, the data collected enabled another dimension for comparison (age). The sample, therefore, includes participants from all age groups residing in Brazil and Denmark.

Ethical and Legal Compliance

Following local jurisdictions, this survey study received ethical approval from the Institutional Review Board of the partner university in Northeast Brazil and was exempt from ethical approval in Denmark. As established by the European General Data Protection Regulation (GDPR), the first page of the survey included information about the study's purpose, which data were collected, measures to anonymity and confidentiality, and data handling processes. Participants were asked to provide their consent after reading this information and confirming that they were older than 18 years. Besides the consent question, none of the questions were mandatory, following standard ethical conduct principles for online research. In addition, the survey was anonymous (IP address and identifiable information were not collected).

Questionnaire Design

Overview

The instrument development was based on (1) several previous surveys and focus groups about public acceptance of biobanks, electronic health records, and clinical trial repositories [43-53]; (2) a previous qualitative study about enablers and barriers for participation in digital health research repositories [32]; and (3) the input from the research team, clinicians, statisticians, and participants of the target population (young adults). The instrument went through several iterations until the final version, which is the one available in [Multimedia Appendix 1](#). First, questions were designed in English and this version was used to ask for the initial rounds of feedback from both experts and targeted participants. After each round of feedback, the questionnaire was incrementally modified. Once a final English version was agreed upon by the research team, the questionnaire

was professionally translated to the official language of each country (Portuguese and Danish). The translations were then verified by native speakers from the research team (GV and JB) to ensure content validity. Using the translated versions and the original in English, pilot tests were conducted by the research team with small convenient samples of 5 young adults in Denmark (in person) and in Brazil (remotely). These pilot tests consisted of asking participants to fill the survey and provide feedback on the readability of the questions, comprehension of the vocabulary used for the answer options, navigation of the interface, and time taken to complete all questions. Participants unanimously expressed that the instrument was easy to use and understand and completion time was reasonable. All members of the research team then approved the distribution of the final versions of the questionnaire (in Portuguese, English, and Danish). The complete questionnaire is available in [Multimedia Appendix 1](#). A summary of the survey questions and their rationale are described next. This study is the first to combine such a set of diverse factors to the best of our knowledge.

Demographics and Socioeconomics Questions

This first group of questions inquired about participant age group, gender, education level, country of residence, and usage and ownership of digital devices (computers, smartphones, smartwatches, smart home assistants, and tablets). Some individuals may have a gender that is neither male nor female. They may identify as both male and female at one time, different genders at different times, no gender at all, or dispute the very idea of only 2 genders. Therefore, the term "nonbinary" in this study refers to gender identities outside of the gender binary (male or female). The survey conducted in Brazil also contained 2 additional questions: race and household income (based on minimum salary). Minimum salary has been defined as the minimum amount of remuneration that an employer is required to pay for the work performed during a given period (usually per month), which cannot be reduced by collective agreement or an individual contract. In Brazil, at the time of the study, the minimum salary per month was 1040 Brazilian Reais (approximately US \$188.45). Following recommendations by local Brazilian investigators, these questions were added to examine whether the sample reflected the Brazilian population's diversity, which, by contrast, was not considered a usual requirement by local investigators in Denmark.

Factors Related to Technology Acceptance

This group of questions asked participants about factors highlighted by previous research as essential for technology acceptance in data-sharing contexts: self-assessed health status [54], personal interest in health topics [34], previous participation in health research [33], and awareness of examples of data repositories [55]. This group of questions also asked participants about their current attitude toward digital health research repositories (positive, negative, or indifferent) [43,56] after being provided with the following short description of the concept: A research data repository is an online database containing data collected during research studies. In such repositories, deidentified data is to be re-used in the future by other research studies.

Motivations to Participate and Reasons for Concern

These questions asked participants how motivated they would feel by the following reasons to contribute to a research data repository: helping future patients, helping researchers, receiving results about themselves, knowing the research outcomes, getting financial compensation, and proposing questions to be investigated in future studies. Participants were also asked how concerned they would feel about the following risks if their data were stored in a health research repository: having their data used for profit without their knowledge, having data used for projects that they perceive as unethical, agreeing with terms and conditions that they do not fully understand, being socially discriminated against because of the information shared, becoming vulnerable to cyberattacks and blackmail, and being asked to provide more data in the future. Such questions about motivations and concerns were based on findings of a qualitative interview study [32] and previous research on motivations to contribute to research [57] and concerns related to data sharing in general [58,59]. The order of the answer options was randomized for each respondent to avoid order bias.

Access Control Preferences

This group of questions asked participants how desirable or undesirable different access control choices would be once they shared their data with a research platform (answers were not mutually exclusive). The listed answers were: to never be contacted after data are shared, to receive information about who is using the data, to decide who has access to which parts of the data, to have the repository managers decide who has access, to grant data access to public or academic institutions, and to give data access to private laboratories and companies. These questions were based on previous research about informed consent options in biobanks and health data-sharing contexts [48,51,58,60]. The order of the answer options was randomized for each respondent to avoid order bias.

Willingness to Share Data

Questions in this group concerned how comfortable or uncomfortable participants would feel about sharing different deidentified data sources for a research repository, as previous studies have shown that willingness to share personal health data varies according to the data source [61-63]. Data sources were grouped as (1) biospecimen samples and input data provided through health questionnaires (online or in-person); and (2) passive data collected through smartphone or wearable devices, without end user input. The first questions inquired about participants' willingness to share the following: clinical diagnosis (physical), clinical diagnosis (mental), family health status, DNA samples, food consumption, alcohol consumption, sleep patterns, and blood samples. These data types were based on previous studies of willingness to share clinical and health data for research [64]. The second group of questions inquired about participants' willingness to share frequency of social communication (calls/texts), the content of social communication (calls/texts), distances traveled per day, places visited, physical activity levels (heart rate), stress/emotional levels (heart rate), screen time, and apps used. The choice of data types to include in this second group was based on digital

data sources previously identified as objective behavioral features for health research [5]. Based on previous studies that showed that different granularities might affect willingness to share, the options in this second group were purposely varied in terms of levels of detail provided by the sensor data (eg, frequency of calls/texts versus the content of calls/texts) [65]. The order of the answer options was randomized for each respondent to avoid order bias.

Statistical Analysis

Data were analyzed and visualized using the R Project for Statistical Computing (software environment for statistical computing and graphics). First, frequency distributions were used to characterize responses for each variable, and bivariate associations (odds ratio [OR]) examined relationships between variables. Following previously established reference values, an OR below 1.5 was considered weak and above 5.0 strong [66]. For a 95% CI, results were considered significant if $P < .05$. Then, a binary logistic regression was conducted to examine directional relationships between explanatory variables and participants' current attitudes toward digital health research repositories. Similarly, another binary logistic regression was conducted to examine directional relationships between explanatory variables and participants' willingness to share data types. Missing values from "prefer not to say" responses were removed before conducting these regression analyses and assumptions were verified beforehand.

Results

Survey Participants

A total of 2299 participants started answering the survey, of whom 1963 completed all questions (1963/2299, 85.38%). This paper includes only responses from participants living in Denmark (583/1600, 36.44%) and Brazil (1017/1600, 63.56%), thus excluding participants residing in other countries from the data analysis for this study (336/1963, 17.12%). The majority of the sample is aged between 18 and 27 years (933/1600, 58.31%); the second largest age group is between 28 and 37 years (459/1600, 28.69%). Only 12.56% (201/1600) were aged above 37 years. There are slightly more individuals who identify as females (891/1600, 55.69%) than males (682/1600, 42.63%). A majority of participants are educated, having at least a university degree (992/1600, 62.00%), own and use smartphones (1562/1600, 97.63%) and computers (1537/1600, 96.06%), but only 36.75% (588/1600) own and use more than 2 types of digital devices. The vast majority is currently in good, very good, or excellent health (1407/1600, 87.94%), while most are moderately, very, or extremely interested in health topics (1088/1600, 68.00%). Around half of the Brazilian participants (555/1017, 54.57%) are White and 43.17% (439/1017) are Black or Brown; most of the respondents living in Brazil have a monthly household income between 1 (1040 Brazilian Reals or US \$190) and 5 (5200 Brazilian Reals or US \$950) minimum salaries (739/1017, 72.66%). As explained in the previous section, information about race and income was not collected in the Danish survey. Further details on the sample characteristics are presented in [Table 1](#).

Table 1. Participants' characteristics, awareness, past experiences, and attitudes.

Variables	All participants (N=1600), n (%)	Participants in Brazil (n=1017), n (%)	Participants in Denmark (n=583), n (%)
Age (years)			
18-27	933 (58.31)	613 (60.28)	320 (54.89)
28-37	459 (28.69)	273 (26.84)	186 (31.90)
38-47	105 (6.56)	80 (7.87)	25 (4.29)
48-57	64 (4.00)	38 (3.74)	26 (4.46)
>57	32 (2.00)	9 (0.88)	23 (3.95)
Prefer not to say	7 (0.44)	4 (0.39)	3 (0.51)
Gender			
Female	891 (55.69)	606 (59.59)	285 (48.89)
Male	682 (42.63)	399 (39.23)	283 (48.54)
Nonbinary	9 (0.56)	5 (0.49)	4 (0.69)
Prefer not to say	18 (1.13)	7 (0.69)	11 (1.89)
Self-reported race			
White	— ^a	555 (54.57)	—
Black or Brown	—	439 (43.17)	—
Yellow	—	3 (0.29)	—
Indigenous	—	2 (0.20)	—
Prefer not to say	—	18 (1.77)	—
Household income (monthly)^b			
Less or equal to 1 minimum salary	—	114 (11.21)	—
Between 1 and 3 minimum salaries	—	340 (33.43)	—
Between 3 and 5 minimum salaries	—	399 (39.23)	—
Higher or equal to 5 minimum salaries	—	113 (11.11)	—
Prefer not to say	—	51 (5.01)	—
Education			
Less than secondary education	1 (0.06)	1 (0.10)	0 (0)
Currently on higher education	595 (37.19)	479 (47.10)	116 (19.90)
Higher education degree completed	992 (62.00)	527 (51.82)	465 (79.76)
Prefer not to say	12 (0.75)	10 (0.98)	2 (0.34)
Digital devices owned			
Smartphone(s)	1562 (97.63)	994 (97.74)	568 (97.43)
Computer(s)	1537 (96.06)	962 (94.59)	575 (98.63)
Tablet(s)	399 (24.94)	194 (19.08)	205 (35.16)
Smartwatch(es)	267 (16.69)	145 (14.26)	122 (20.93)
Smart home assistant(s)	132 (8.25)	59 (5.80)	73 (12.52)
Number of digital device types owned			
0	5 (0.31)	5 (0.49)	0 (0)
1	64 (4.00)	50 (4.92)	14 (2.40)
2	943 (58.94)	666 (65.49)	277 (47.51)
3	437 (27.31)	227 (22.32)	210 (36.02)
4	119 (7.44)	54 (5.31)	65 (11.15)

Variables	All participants (N=1600), n (%)	Participants in Brazil (n=1017), n (%)	Participants in Denmark (n=583), n (%)
5 or more	32 (2.00)	15 (1.47)	17 (2.92)
Current health status			
Poor	30 (1.88)	16 (1.57)	14 (2.40)
Fair	157 (9.81)	119 (11.70)	38 (6.52)
Good	513 (32.06)	355 (34.91)	158 (27.10)
Very good	666 (41.63)	406 (39.92)	260 (44.60)
Excellent	228 (14.25)	117 (11.50)	111 (19.04)
Prefer not to say	6 (0.38)	4 (0.39)	2 (0.34)
Interest in health topics			
Not interested	39 (2.44)	21 (2.06)	18 (3.09)
Slightly interested	471 (29.44)	247 (24.29)	224 (38.42)
Moderately interested	124 (7.75)	72 (7.08)	52 (8.92)
Very interested	559 (34.94)	340 (33.43)	219 (37.56)
Extremely interested	405 (25.31)	336 (33.04)	69 (11.84)
Prefer not to say	2 (0.13)	1 (0.10)	1 (0.17)
Previous participation in a health research study			
No	815 (50.94)	440 (43.26)	375 (64.32)
Yes	763 (47.69)	567 (55.75)	196 (33.62)
Prefer not to say	22 (1.38)	10 (0.98)	12 (2.06)
Awareness of examples of research data repositories			
No	884 (55.25)	528 (51.92)	356 (61.06)
Yes	459 (28.69)	330 (32.45)	129 (22.13)
Not sure	245 (15.31)	152 (14.95)	93 (15.95)
Prefer not to say	12 (0.75)	7 (0.69)	5 (0.86)
Perception of digital health data repositories			
Positive	1339 (83.69)	927 (91.15)	412 (70.67)
Indifferent	188 (11.75)	53 (5.21)	135 (23.16)
Negative	45 (2.81)	19 (1.87)	26 (4.46)
Prefer not to say	28 (1.75)	18 (1.77)	10 (1.72)

^aData not collected.

^bRanges between 1 (1040 Brazilian Reais or US \$190) and 5 (5200 Brazilian Reais or US \$950).

Previous Participation, Awareness of Examples, and Current Attitude

Around half of the respondents participated in a health research study before (763/1600, 47.69%), and those who participated are more likely to have a moderate to high interest in health topics (OR 2.35, 95% CI 1.88-2.93; $P < .001$). By contrast, only a minority are aware of research data repository examples (459/1600, 28.69%). Those aware of examples are more likely to have a moderate to high interest in health topics (OR 3.02, 95% CI 2.30-3.96; $P < .001$) and to have been participants in previous health studies (OR 3.36, 95% CI 2.66-4.23; $P < .001$). In addition, most participants have a positive perception of

health research data repositories (1339/1600, 83.69%), and those who have a positive perception are more likely to be aware of examples of research data repositories (OR 3.26, 95% CI 2.17-4.90; $P < .001$). Further details on the frequency distribution for these variables are shown in [Table 1](#).

Results from a binary logistic regression show that interest in health topics (OR 1.49, 95% CI 1.10-2.02; $P = .01$), previous participation in health research studies (OR 1.70, 95% CI 1.24-2.35; $P = .001$), and awareness of examples of existing repositories (OR 2.78, 95% CI 1.83-4.38; $P < .001$) are significant factors influencing participants' current perception of digital health research repositories. See the results of the binary logistic regression in [Table 2](#).

Table 2. Binary logistic regression model for the current perception of digital health data repositories (base: not positive perception).

Factors for current perception digital health data repositories (base: not positive perception)	Estimate (B)	Standard error B	P value	Odds ratio (95% CI)
Age (base: above 27)				
Below 27 years	0.10	0.17	.56	1.11 (0.79-1.55)
Gender (base: not female)				
Female	-0.05	0.15	.73	0.95 (0.70-1.28)
Education (base: no university degree)				
With university degree	-0.29	0.17	.10	0.75 (0.52-1.06)
Device ownership (base: less than 2 device types)				
Owns more than 2 types	-0.26	0.15	.07	0.76 (0.56-1.04)
Health status (base: poor or fair health)				
Good, very good, or excellent health	0.06	0.23	.79	0.94 (0.57-1.74)
Interest in health (base: none or slight interest)				
Moderate to extreme interest	0.39	0.15	.01	1.49 (1.10-2.02)
Participation in health study (base: no past participation)				
Participated in a health study	0.53	0.16	.001	1.70 (1.24-2.35)
Awareness of an example (base: no awareness or not sure)				
Aware of an example of repository	1.02	0.22	<.001	2.78 (1.83-4.38)

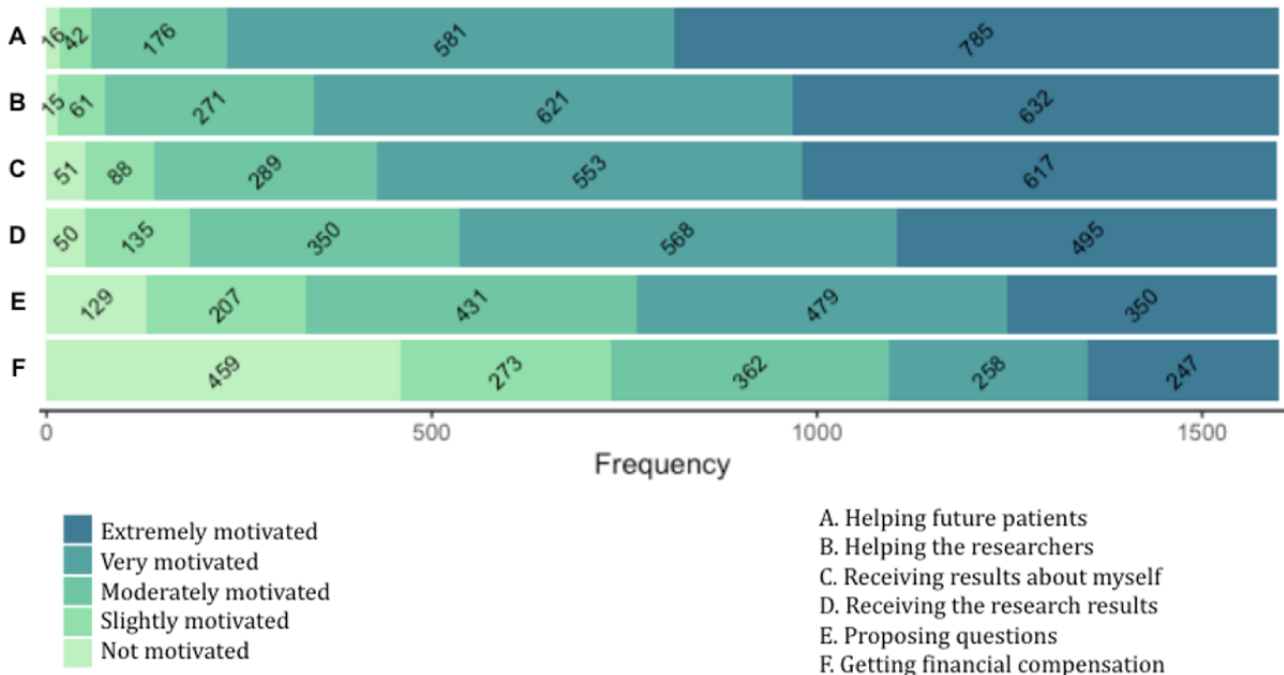
Motivations to Participate

The majority of participants feel very or extremely motivated by helping future patients (1366/1600, 85.38%), helping researchers (1253/1600, 78.31%), receiving results about themselves (1170/1600, 73.13%), and receiving the results of the research (1063/1600, 66.44%). In addition, being provided with the possibility of suggesting research questions to be investigated is very or extremely motivating for more respondents (829/1600, 51.81%) than receiving financial compensation (505/1600, 31.56%), which is not motivating for 28.69% (459/1600). [Multimedia Appendix 2](#) shows the entire distribution of responses, and [Figure 1](#) displays this information as stacked bar charts.

Those who have a positive perception about health data repositories are more likely to be moderately, very, or extremely

motivated by 5 out of 6 motivation sources: helping future patients (OR 9.44, 95% CI 5.43-16.40; $P<.001$), helping researchers (OR 5.74, 95% CI 3.56-9.25; $P<.001$), receiving results about themselves (OR 4.12, 95% CI 2.82-6.03; $P<.001$), receiving results of the research (OR 4.15, 95% CI 2.94-5.85; $P<.001$), and proposing questions to be investigated (OR 3.46, 95% CI 2.57-4.66; $P<.001$). Those moderately, very, or extremely interested in health topics are more likely to be moderately, very, or extremely motivated by receiving results of the research (OR 2.25, 95% CI 1.65-3.06; $P<.001$) and proposing questions to be investigated (OR 2.53, 95% CI 1.97-3.24; $P<.001$). The youngest segment (18-27 years old) is more likely to feel moderately, very, or extremely motivated to receive financial compensation (OR 1.92, 95% CI 1.57-2.35; $P<.001$).

Figure 1. Bar chart displaying the distribution of answers for each motivation source.

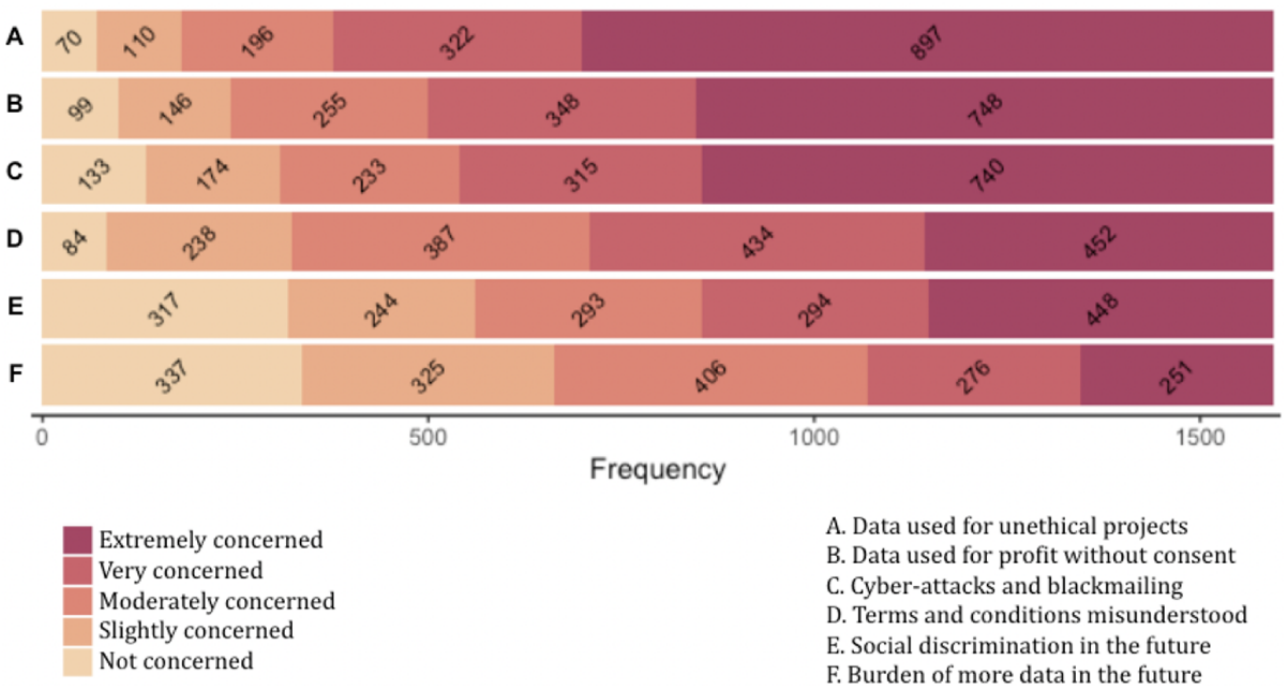


Reasons for Concern

The vast majority of participants feel very or extremely concerned about having their data used for unethical projects (1219/1600, 76.19%) and profit making without their consent (1096/1600, 68.50%). In addition, the risk of becoming vulnerable to cyberattacks and blackmail is very or extremely concerning for 65.94% (1055/1600); the possibility of not

understanding terms and conditions for 55.38% (886/1600); and the fear of being socially discriminated for 46.38% (742/1600). By contrast, not as many participants feel very or extremely concerned about the burden of being asked to share more data in the future (527/1600, 32.94%). [Multimedia Appendix 3](#) shows the entire distribution of responses, and [Figure 2](#) displays this information in the form of a stacked bar chart.

Figure 2. Bar chart displaying the distribution of answers for each reason for concern.



Willingness to Share Different Types of Data

Regarding the willingness to share specific data items, most participants feel uncomfortable or very uncomfortable sharing

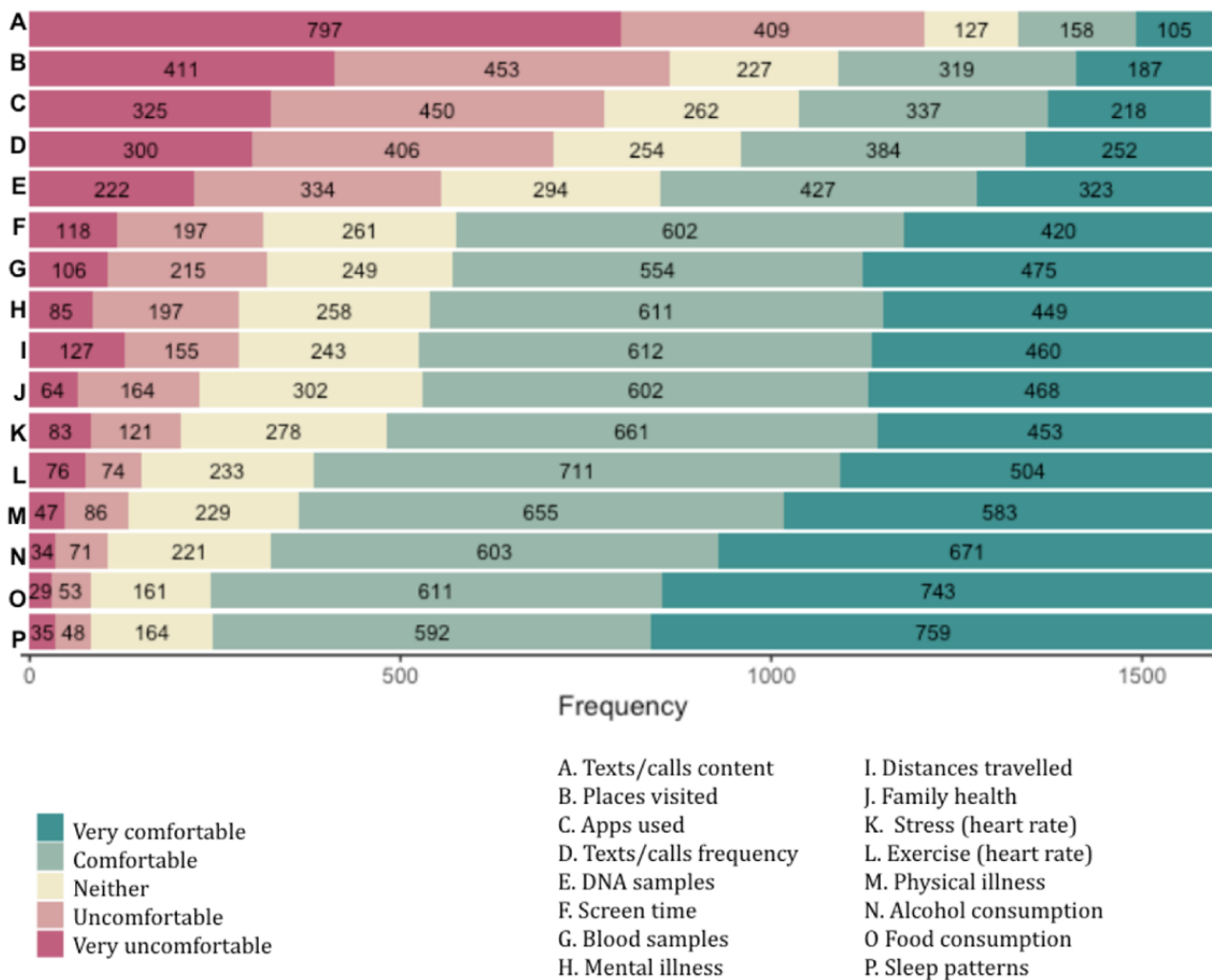
the content of texts and calls (1206/1600, 75.38%), while fewer participants feel uncomfortable or very uncomfortable sharing the frequency of texts and calls (706/1600, 44.13%). Places visited (864/1600, 54.00%) and apps used (775/1600, 48.44%)

are perceived as uncomfortable or very uncomfortable data to share by many.

By contrast, most participants feel comfortable or very comfortable sharing sleeping patterns (1351/1600, 84.44%), food consumption (1354/1600, 84.63%), alcohol consumption (1274/1600, 79.63%), physical illness diagnosis (1238/1600, 77.38%), physical activity levels (1215/1600, 75.94%), stress

levels (1114/1600, 69.63%), family health history (1070/1600, 66.88%), distances traveled (1072/1600, 67.00%), mental illness diagnosis (1060/1600, 66.25%), blood samples (1029/1600, 64.31%), DNA samples (750/1600, 46.88%), and screen time (1022/1600, 63.88%). Multimedia Appendices 4 and 5 show the full distribution of responses, and Figure 3 displays this information as stacked bar charts.

Figure 3. Bar chart displaying the distribution of willingness to share across different data types.



Those who have a positive perception about health research repositories are more likely to feel comfortable or very comfortable sharing 15 out of 16 data items: physical illness diagnosis (OR 3.84, 95% CI 2.87-5.15; $P < .001$), mental illness diagnosis (OR 3.44, 95% CI 2.59-4.59; $P < .001$), family health history (OR 3.45, 95% CI 2.59-4.59; $P < .001$), DNA samples (OR 2.51, 95% CI 1.85-3.41; $P < .001$), blood samples (OR 2.31, 95% CI 1.74-3.06; $P < .001$), food consumption (OR 4.15, 95% CI 3.01-5.70; $P < .001$), alcohol consumption (OR 3.25, 95% CI 2.41-4.40; $P < .001$), sleep (OR 3.85, 95% CI 2.80-5.30; $P < .001$), screen time (OR 3.17, 95% CI 2.38-4.22; $P < .001$), apps used (OR 2.09, 95% CI 1.50-2.91; $P < .001$), frequency of calls or texts (OR 2.07, 95% CI 1.51-2.83; $P < .001$), distances traveled per day (OR 3.34, 95% CI 2.51-4.45; $P < .001$), places visited (OR 2.77, 95% CI 1.91-4.00; $P < .001$), physical activity levels (OR 3.43, 95% CI 2.56-4.59; $P < .001$), and stress levels (OR 3.60, 95% CI 2.70-4.79; $P < .001$). However, no significant

association was found between having a positive perception of digital health research repositories and feeling comfortable with sharing the content of calls and texts ($P = .03$).

Those moderately, very, or extremely concerned about being discriminated against are more likely to feel uncomfortable or very uncomfortable sharing data about mental illness diagnosis (OR 2.26, 95% CI 1.66-3.07; $P < .001$). Those uncomfortable or very uncomfortable sharing information about app usage are more likely to be moderately, very, or extremely concerned about data being used for profit (OR 2.57, 95% CI 1.91-3.46; $P < .001$) and not understanding terms and conditions (OR 2.22, 95% CI 1.71-2.87; $P < .001$). Those not motivated or only slightly motivated by receiving results about themselves are more likely to feel uncomfortable or very uncomfortable with sharing information about alcohol consumption (OR 5.76, 95% CI 3.63-9.13; $P < .001$), distances traveled per day (OR 3.31, 95% CI 2.29-4.80; $P < .001$), stress levels (OR 6.46, 95% CI 4.43-9.44;

$P < .001$), and physical activity levels (OR 6.78, 95% CI 4.52-10.17; $P < .001$).

A small number of participants feel uncomfortable or very uncomfortable sharing any of the data items (94/1600, 5.88%). Those who feel uncomfortable or very uncomfortable sharing any data items are more likely to have a negative or indifferent perception about health research repositories (OR 3.91, 95%

CI 2.49-6.14; $P < .001$). A binary logistic regression shows that age (OR 2.16, 95% CI 1.28-3.70; $P = .004$), digital device ownership (OR 1.90, 95% CI 1.14-3.26; $P = .01$), health status (OR 2.28, 95% CI 1.24-3.98; $P = .01$), and current attitude regarding digital health research repositories (OR 3.77, 95% CI 2.24-6.26; $P < .001$) are significant factors affecting participants' willingness to share data with a health research repository. [Table 3](#) shows the results of the binary logistic regression.

Table 3. Binary logistic regression model for willingness to share data with repositories for health research (base: unwilling to share any data).

Factors for willingness to share data (base: unwilling to share any)	Estimate (B)	Standard error B	P value	Odds ratio (95% CI)
Age (base: above 27)				
Below 27 years	0.76	0.27	.004	2.16 (1.28-3.70)
Gender (base: not female)				
Female	0.06	0.23	.78	1.06 (0.66-1.70)
Education (base: no university degree)				
With university degree	0.21	0.28	.45	1.24 (0.70-2.16)
Device ownership (base: less than 2 device types)				
Owens more than 2 devices	0.64	0.26	.01	1.90 (1.14-3.26)
Health status (base: poor or fair health)				
Good, very good, or excellent health	-0.82	0.29	.005	2.28 (1.24-3.98)
Interest in health (base: no or slight interest)				
Moderate to extreme interest	-0.01	0.25	.95	0.99 (0.59-1.62)
Participation in health study (base: no past participation)				
Participated in a health study	0.14	0.24	.55	1.16 (0.71-1.90)
Awareness of an example (base: no awareness)				
Aware of an example of repository	-0.12	0.28	.65	0.88 (0.51-1.56)
Current perception (base: negative or indifferent)				
Positive current perception	1.32	0.26	<.001	3.77 (2.24-6.26)

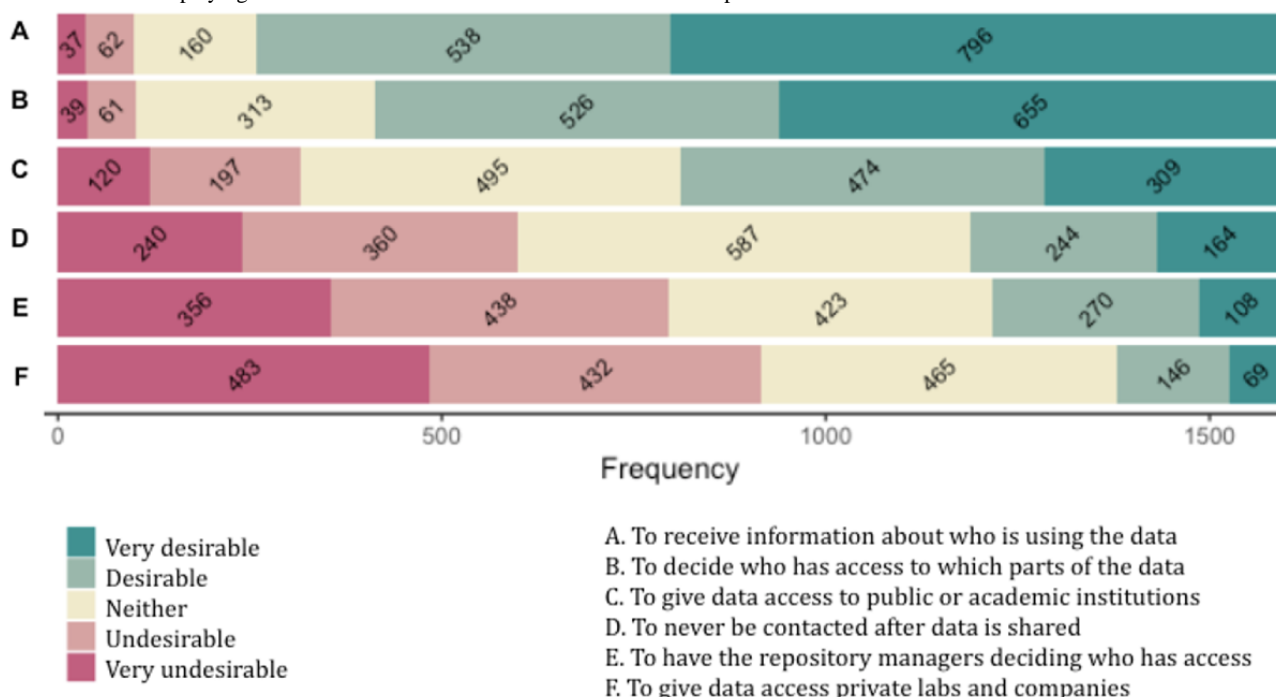
Preferred Access Control Options

After collecting and sharing their data with a research platform, most participants find it desirable or very desirable to receive information about which projects access their data in the future (1334/1600, 83.38%). The majority also find it desirable or very desirable to decide who gets access to which parts of their data (1181/1600, 73.81%). By contrast, not being contacted is desirable or very desirable to only 25.50% of participants (408/1600), and the option to allow the owners of the repositories to decide who can access the data is desirable or very desirable only to 23.63% (378/1600). Finally, allowing public or academic institutions to access the data is desirable or very desirable for 48.94% (783/1600), while allowing private laboratories and companies to obtain access is desirable or very

desirable to only 13.44% (215/1600). [Multimedia Appendix 6](#) shows the entire distribution of responses, and [Figure 4](#) displays this information as stacked bar charts.

Those who find it is desirable or very desirable to be informed about who is using their data are more likely to have a positive perception of health data repositories (OR 2.45, 95% CI 1.77-3.39; $P < .001$). Those moderately, very, or extremely concerned about data being used for unethical projects are more likely to find it desirable or very desirable to have control over how their data are used (OR 2.45, 95% CI 1.80-3.42; $P < .001$) and to be informed about it (OR 3.09, 95% CI 2.18-4.37; $P < .001$). Those moderately, very, or extremely concerned about data being used for profit are more likely to find it undesirable or very undesirable to have private laboratories and companies access their data (OR 2.24, 95% CI 1.69-2.96; $P < .001$).

Figure 4. Bar chart displaying the distribution of answers for each access control option.



Cross-country Analysis

The sample comprises 1017 respondents living in Brazil (1017/1600, 63.56%) and 583 living in Denmark (583/1600, 36.44%). The demographics of the participants residing in these 2 countries do not differ substantially, except for a higher percentage of female respondents and a lower percentage of respondents who completed a higher education degree within the Brazilian sample (Table 1). The Brazilian sample also has a higher percentage of extremely interested individuals in health topics than the Danish sample (Table 1).

Around half of the participants in Brazil participated in health research previously (567/1017, 55.75%), in contrast to a minority of the participants in Denmark (196/583, 33.62%). Similarly, the vast majority of participants from the Brazilian sample have a positive initial impression of health data repositories (927/1017, 91.15%), in contrast to a smaller majority of participants in Denmark (412/583, 70.67%). See Table 1 for complete information regarding these differences.

The majority of participants from both countries are highly motivated and concerned by similar sources of motivation and concerns; however, there are differences in the magnitude of the motivation and concern levels reported by those residing in Brazil and Denmark. The Brazilian sample is more likely to rate themselves as moderately, very, or extremely motivated by receiving results about themselves (OR 6.35, 95% CI 4.25-9.50; $P < .001$), proposing questions to be investigated (OR 6.08, 95% CI 4.67-7.91; $P < .001$), receiving results of the research (OR 4.13, 95% CI 2.98-5.72; $P < .001$), and helping the researchers (OR 3.36, 95% CI 2.07-5.44; $P < .001$). The Brazilian sample is also more likely to rate levels of concerns as moderately, very, or extremely concerning for all of the options listed: having data used for unethical projects (OR 5.44, 95% CI 3.86-7.66; $P < .001$), becoming vulnerable to cyberattacks and blackmail (OR 3.88, 95% CI 2.99-5.04; $P < .001$), having data used for

profit without consent (OR 3.68, 95% CI 2.77-4.89; $P < .001$), being asked to provide more data (OR 3.28, 95% CI 2.65-4.06; $P < .001$), agreeing to terms without understanding them (OR 2.29, 95% CI 1.79-2.94; $P < .001$), and being socially discriminated against (OR 2.10, 95% CI 1.70-2.60; $P < .001$). Multimedia Appendices 2 and 3 show the frequency distribution of answers regarding motivations and concerns according to country of residence.

When it comes to access preferences, important differences arise between the 2 countries. The Brazilian sample is more likely to find it desirable or very desirable to receive information about who is using the data (OR 5.51, 95% CI 4.12-7.37; $P < .001$). By contrast, the Danish sample is more likely to find it desirable or very desirable never to be contacted (OR 3.63, 95% CI 2.87-4.60; $P < .001$), to have the repository managers decide who can obtain access (OR 2.84, 95% CI 2.24-3.60; $P < .001$), and to allow private organizations (OR 3.73, 95% CI 2.77-5.04; $P < .001$) and public institutions access the data (OR 4.51, 95% CI 3.61-5.63; $P < .001$). Multimedia Appendices 4-6 show the frequency distribution of answers regarding access control preferences and willingness to share according to country of residence.

In summary, the vast majority of the participants residing in Brazil have a positive attitude regarding the idea of health data repositories. These findings are further endorsed by the Brazilian sample reporting higher motivation to help the researchers and willingness to share several data types. However, those residing in Brazil are also more likely to be strongly concerned about all of the potential negative consequences. The Brazilian sample is also more likely to find it desirable to keep the control and be informed about the use of the shared data, rather than never being contacted, delegating control to repository owners, or allowing both private companies and public institutions to get access.

Discussion

Enablers for Acceptance

Our survey contributes novel empirical insights regarding an extensive set of factors contributing to the acceptance of repositories storing biosamples, health records, and digital data sources for observational research. Previous research suggests that individuals may view some loss of privacy as worthwhile to advance medical research and benefit future generations [4,33], with altruism being a strong incentive for participation in clinical studies [50,67]. Aligned with such previous research, we found that helping future patients and researchers is indeed a powerful source of motivation across our sample, with most participants also feeling very motivated by the prospect of being updated about research outcomes. Furthermore, our findings show that those who do not feel motivated by helping future patients and researchers are more likely to be unwilling to share data, highlighting the critical role of altruism in this context.

Participants are also motivated by learning about their health through the data they provide, aligning with past research [68]. By contrast, our findings indicate that financial compensation may not be a more decisive factor than other sources of motivation. For instance, being invited to suggest research questions for a project strongly motivates more participants than financial compensation. However, consistent with previous studies [41,50], the youngest participants in our sample are more likely to be motivated to share health data in exchange for financial benefits. Such observations reinforce the importance of providing both societal and individual benefits to accommodate different preferences.

Another essential enabler for acceptance is individuals' current perception of the idea of health research data repositories. In our survey, a positive perception appears to be associated with higher levels of motivation to help patients and researchers, and those who have a positive perception are also more likely to feel comfortable sharing 15 out of 16 data items. These results confirm past research highlighting that a positive opinion about biomedical research can predict willingness to participate [33], and attitudes about health care interventions can predict patient acceptance [56]. We also extend previous findings from other contexts [34,43,55] by providing evidence about key factors that can affect individuals' perceptions of digital health research repositories, emphasizing the critical role that positive past experiences and personal interests have in enabling favorable attitudes.

Regarding cross-country differences, the vast majority of our participants residing in Brazil have a positive perception of the idea of health data repositories, further demonstrated by their reported higher motivation to participate and higher willingness to share several data types. It could be speculated that such enthusiasm stems from the prospect of significantly improving an imperfect yet ubiquitous public health care system, which may become an essential enabler for acceptance as digital health emerges in Brazil [67]. By contrast, Denmark has a long history of using clinical databases and electronic health records for population-level clinical research [44]. This observation could explain why our sample residing in Denmark is more likely to

find it desirable to allow repository owners to make decisions regarding access control, an arrangement already familiar to them, as the Danish public health authorities manage data use. These differences illustrate that acceptance depends not only on individual predispositions but also on broader sociocultural contexts [36].

Barriers for Acceptance

In contrast to such enablers, our findings show that even though participation in research repositories might occur under the promise of sharing deidentified data, participants still report concerns. Our sample's most substantial concern is the fear that their data will eventually be used for unethical research goals or profit without consent, which is a fear also reported by several previous studies [37,38,42]. Further aligned to previous research, the fear of cyberattacks or blackmail is considered very or extremely concerning to most of our participants [69-72]. Surprisingly, however, the fear of social discrimination is not as prevalent, contrasting a previous study's claim that this might be a core reason behind privacy concerns [58]. It is also surprising that the fear of not fully understanding terms and conditions was a more significant concern for participants than the burden of providing more data, which contradicts previous findings from another study [4].

The predominant concern of data misuse may explain the preference for more restrictive access control options. Many of our participants report feeling comfortable sharing their data if the purpose is to protect the common good, but the same does not apply to the prospect of supporting others' profit making, in alignment with previous research [36,44,73]. Related to this, the large majority of our sample want to receive information about the different projects using their data, and most also want to be deciding who can ultimately obtain access to their data, a finding which has been highlighted in other past studies [38,55,73-75]. By contrast, leaving this responsibility to repository owners is often not our participant's preferred option, especially within the Brazilian sample. Furthermore, approaches such as notification-only and opt-out options have been considered less acceptable than re-consent [73,76], showing the importance of reconsidering usual consent practices.

Another barrier to participation is that willingness to share data depends strongly on the data type [32,47,67], even though there are divergent findings in the literature about which data types people feel most uncomfortable sharing [37,38,42,61-65]. For example, previous studies with young adults have observed a high willingness to donate DNA samples [33,34], but 2 extensive worldwide surveys have observed the opposite [36,44]. Our analysis indicates that when compared with behavioral indicators such as food consumption and sleeping patterns, DNA and blood samples are among the data types most uncomfortable to be shared.

However, even more so than DNA, participants in our study feel uncomfortable sharing passive mobile and wearable sensing data. Interestingly, these are data with the less obvious connection to health in a traditional sense. While the relationship between health and food consumption or sleep might be apparent to many people, the relevance of app use or social communication data may be less noticeable. Such observation

is particularly relevant for behavioral health research contemplating passive data sources as a strategy to reduce the data collection burden for participants. Our results also add a more nuanced understanding of participants' willingness to share data. We empirically demonstrate that participants feel uncomfortable sharing more detailed and revealing data sources, such as apps used, frequency of texts and calls, and places visited, compared with broader and less granular information such as screen time, the content of texts and calls, and distances traveled. These findings have important implications for health research studies that consider collecting high granularity information, especially when it comes to location and social communication.

Furthermore, sociodemographic factors have been emphasized by several past studies as possible barriers to the willingness to share data [35,36,39,43,45,54,74]. Our analysis shows that participants' willingness to share data can be related to age, health status, and digital device ownership. However, contrary to previous studies, which observed that members of American ethnic groups other than White have higher odds of being unwilling to donate their DNA data [43,45], our study does not find a significant association between race and unwillingness to share. We also do not find significant associations between race and fear of discrimination [43,45] or desire to control data access [35]. However, our sample is in its vast majority young and educated, in contrast to these previous studies.

Research Implications

The empirical findings discussed above provide the basis for a series of implications for community engagement, technology design, and policymaking. First, we found evidence that a lack of knowledge about health research may be a challenge for public acceptance, which points to the importance of broadening public awareness. For instance, education and familiarity-increasing programs can be possible community engagement approaches and strengthened relationships between potential participants, clinicians, and health research experts may be helpful during recruitment and beyond [40]. Regardless of the medium, participant information could include explanations about the collaborative nature of contemporary health research and why digital data sources extracted passively may be necessary for answering specific research questions. Given the factors found to motivate and demotivate data sharing, it may be necessary to explain the benefits of sharing data types where the direct connection to health is not immediately visible. Additionally, appropriate communication may help to emphasize the importance of data collection compliance to participants, especially when it comes to experience sampling and the provision of frequent self-reports [77].

Personal health informatics could also be considered to increase the appeal of and the motivation for participating. Given that data collection may require interactions with mobile and wearable devices, it is a natural step to also provide participants with personalized data visualizations and, potentially, digital health interventions. However, digital tools for personal health must consider how existing health care practices complement (or hinder) novel approaches [78-80]. Interface design should focus on suitably informing patients about how their data relate

to their health to facilitate rather than replace efficient clinician-patient relationships. Above all, risks to individual well-being should be avoided, as an intense "datafication" of personal health standards might prove to be more harmful than beneficial [81]. For instance, our analysis shows that those uncomfortable with sharing alcohol consumption, levels of stress, and physical exercise are less likely to feel motivated by receiving results about themselves. Thus, any consideration of adding personal health informatics features to health research systems should be mindful of the preferences of each individual.

Furthermore, our analysis makes it clear that broader acceptance will be challenging to achieve if contributing to health research repositories demands that participants share every digital source of data [38]. Health research projects might need to acknowledge that certain personal information is associated with social stigma [82], which may compromise willingness to participate in research as a whole. For instance, we observe a strong association between fear of discrimination and unwillingness to share mental illness diagnoses. For this reason, health research should consider personal boundaries by allowing participants to opt-out from specific data collection types and decide which level of details are to be shared. Even if individuals do not exercise this right to choose, the option to safely do that without negative consequences may still enhance trust [83].

When it comes to access control options, our results show that participants would like to be informed about the different projects which may access their data and customize their consent. Even though granular data control options may reduce privacy concerns [84], broad consent models are still the most used approach in current health research platforms [32], which means that once participants provide their consent, they are usually not consulted about data reuse in the future. The conception of digital systems for continuous communication with participants could transform consent practices. For instance, research participants could be consulted about whether they would like to receive a request each time a new project wants to use their data. Access requests could include details about who benefits from the research outcomes and how organizations use any profit. The possibility of opting out from data sharing could also be provided. Beyond allowing participants to make choices about data access, participants could further contribute with questions to a research project, which is an interest identified in our survey and explored in other research platforms [22]. Nondigital approaches could also be considered (eg, phone calls, letters) for those who prefer or do not have access to digital devices. However, a challenge is how to help participants stay informed and control their data without making them overwhelmed [42].

As pervasive sensing technologies become more refined and widespread in health research, those proposing shared-access repositories for collecting, sharing, and using such sensing data will need to take responsibility for identifying risks and be accountable for consequences against participants' best interests. Proactive legal and ethical guidelines are necessary, as current regulatory frameworks for digital health data sharing are relatively weak in some jurisdictions [44]. Likewise, regulatory board members and grant reviewers could evaluate how managers of digital health research repositories demonstrate

awareness of ethical considerations and strategies to mitigate possible negative consequences of participation. For instance, being transparent about the trustworthiness of the technical infrastructures and governance arrangements of the platforms hosting the data is essential, even if it means acknowledging challenges [50]. Clear and understandable evidence of compliance with regulations may help diminish individuals' reticence to share health data and increase public acceptance.

Finally, future developments should not ignore that without a diverse cohort providing data, research outcomes and benefits will be unevenly distributed [42,85]. Even though our sample, composed mainly of educated young individuals, does not show significant associations between race, income, and unwillingness to share data, other past studies have shown that these factors can be significant [43,45]. For this reason, communication efforts, interface design, and data sharing policies should be made accessible and inclusive by being mindful of language choices, cultural requirements, access costs, and participation demands (eg, owning and using smartphones and smartwatches). After all, strategies to increase acceptance should be motivated by research repository owners' genuine desire to make data sharing fairer and more ethical.

Limitations and Future Work

Based on our team experience, we suggest that similar surveys in the future should strive to focus recruitment efforts on racial, ethnic, gender, and disability minorities to achieve a higher representation from these groups. We also suggest that quantitative findings should be complemented with parallel qualitative investigations, to provide richer and subjective insight into justifications and reasonings behind responses. Another suggestion is to consider depicting data usage scenarios with illustrations, infographics, and narrative forms instead of purely descriptive texts.

In terms of methodological limitations, sampling bias is a common challenge of voluntary response samples, given that those who take the time to respond to online survey requests tend to have strong opinions compared with the rest of the population. Despite our efforts to use a diverse range of digital channels for recruitment, our sample is biased in terms of age and education level, partially due to the scope of the overarching project (mental health for young adults) and partially because the higher response rate stemmed from posts on university web portals. A constrained focus on specific population segments can be considered a strength, given that it allows the investigation of particular perspectives at a time; however, future

work must seek to consider the perspectives of many other groups of individuals, especially underrepresented minorities.

Another methodological limitation is that, as an exploratory cross-sectional study, our results can only capture attitudes about hypothetical future participation. Thus, future work must consider evaluating participants' perspectives while taking part in an actual digital health research repository initiative. In addition, factors such as the burden of continuous data collection might be better examined throughout actual participation.

Finally, it could be speculated that public attitudes may shift following the global experience of a public health emergency (COVID-19 pandemic). Given that this survey was conducted during the first waves of the pandemic, future work is still needed to evaluate further consequences of this unprecedented crisis in the long term. In particular, the impact of contact tracing apps and vaccination passports may prove significant when it comes to the acceptance of digital health data storage on a population level.

Conclusion

This survey study reveals essential factors for potential acceptance and willingness to share personal data with a digital health research repository. In summary, most participants feel very motivated about helping future patients, helping researchers, and receiving results about their health; most also feel comfortable sharing data sources usually associated with health research, except DNA data. However, most respondents feel very concerned about the risk of cyberattacks, the possibility of data being used for unethical research goals or for-profit without consent, and the prospect of sharing personal sensing data, especially social communication and location. The majority of participants find it desirable to receive information about which projects access their data and would like to be able to decide who gets access to which parts of their data.

The analysis of such a large spectrum of variables and their relationships provides a strong foundation for suggesting implications for future developments. The implications discussed include to disseminate knowledge about health research; to value the role of transparency for trust development; to engage participants with the research process and their health management; to allow flexible and customizable data sharing; and to align policies and regulations with ethical considerations. Providing valuable benefits for individuals and reducing the risks involved in participation are essential requirements in this context, and by recognizing differences between groups, it is possible to better understand and respond to individual views and expectations.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire applied to participants (survey questions).

[\[PDF File \(Adobe PDF File\), 447 KB-Multimedia Appendix 1\]](#)

Multimedia Appendix 2

Distribution of answers for the question: “How motivated do you feel by the following?”.

[\[PDF File \(Adobe PDF File\), 43 KB-Multimedia Appendix 2\]](#)

Multimedia Appendix 3

Distribution of answers for the question: “How concerned are you about the following?”.

[\[PDF File \(Adobe PDF File\), 43 KB-Multimedia Appendix 3\]](#)

Multimedia Appendix 4

Distribution of answers for the question: “How comfortable do you feel about sharing the following data items (collected through questionnaires and surveys)?”.

[\[PDF File \(Adobe PDF File\), 53 KB-Multimedia Appendix 4\]](#)

Multimedia Appendix 5

Distribution of answers for the question: “How comfortable do you feel about sharing the following data items (collected through mobile and wearable sensing)?”.

[\[PDF File \(Adobe PDF File\), 53 KB-Multimedia Appendix 5\]](#)

Multimedia Appendix 6

Distribution of answers for the question: “How desirable are the following options?”.

[\[PDF File \(Adobe PDF File\), 46 KB-Multimedia Appendix 6\]](#)

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Abbreviations

DTU: Technical University of Denmark

GDPR: General Data Protection Regulation

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Please answer our survey and express your opinion about data sharing for health research. We want to hear from you to understand your boundaries and preferences.

Questions should take 10 minutes only. We hope you can help!

Section A: Informed Consent

We are a group of researchers from the Copenhagen Center for Health Technology (CACHET). Before we start collecting data, we need to be sure you read, understand and agree with the following:

What is the purpose of this survey? To understand people's opinions about health research for a university/academic project.

Which data will be collected? Voluntary demographics (e.g., age, gender), opinions about research and preferences about data sharing.

Will this data be linked to me personally? No, this survey is anonymous: no personally identifiable data is collected (e.g., name, e-mail, IP address, geo-location).

How will data be processed? Statistical analysis will be conducted by the principal researcher for scientific reports, which will only contain aggregate results.

How will data be stored? The anonymous answers will be stored at a secured repository hosted at the university until the end of the project (October 2021).

How can I delete my data? You can click on [Exit and clear survey](#) on the top right of the page or contact us with a unique ID code which you will create.

How to contact us? - Responsible researcher: PhD candidate, Giovanna Vilaza: gnyi@dtu.dk - Director of the CACHET Research Centre: Prof Dr Jakob Bardram: jakba@dtu.dk - Data protection officer at DTU, Ane Sandager: anesa@dtu.dk

A1. Do you confirm that:
- you are more than 18 years old;
- you have read and understood the information above; - and you
voluntarily agree to participate in this survey?

Yes

No



Section B: Demographics

B1. What is your age group?

- 18-27
- 28-37
- 38-47
- 48-57
- Above 57
- Prefer not to say

B2. What is your gender?

- Female
- Male
- Non-binary
- Prefer not to say
- Prefer to self-describe

Prefer to self-describe

B3. What is your education level?

- Less than High School/Secondary School
- Completed High School/Secondary School
- Completed a Bachelor's degree/Undergraduate
- Completed a Master's degree/Graduate
- Completed a PhD degree or above
- Prefer not to say
- Other

Other



B4. Which of these digital devices do you have and use?

Computer (desktop, laptop)

Tablet (iPad)

Smartphone (Samsung, iPhone)

Wrist wearables (Apple Watch, Garmin, Fitbit, Polar)

Smart home devices (Alexa, Google Home, Hive, Philips Hue)

Other

Other

B5. In which country do you currently live?

Afghanistan

Albania

Algeria

Andorra

Angola

Antigua and Barbuda

Argentina

Armenia

Australia

Austria

Azerbaijan

Bahamas

Bahrain

Bangladesh

Barbados

Belarus

Belgium

Belize





- Benin
- Bhutan
- Bolivia (Plurinational State of)
- Bosnia and Herzegovina
- Botswana
- Brazil
- Brunei Darussalam
- Bulgaria
- Burkina Faso
- Burundi
- Cabo Verde
- Cambodia
- Cameroon
- Canada
- Central African Republic
- Chad
- Chile
- China
- Colombia
- Comoros
- Congo
- Cook Islands
- Costa Rica
- Côte d'Ivoire
- Croatia
- Cuba
- Cyprus
- Czech Republic
- Democratic People's Republic of Korea





- Congo
- Denmark
- Djibouti
- Dominica
- Dominican Republic
- Ecuador
- Egypt
- El Salvador
- Equatorial Guinea
- Eritrea
- Estonia
- Ethiopia
- Fiji
- Finland
- France
- Gabon
- Gambia
- Georgia
- Germany
- Ghana
- Greece
- Grenada
- Guatemala
- Guinea
- Guinea-Bissau
- Guyana
- Haiti
- Honduras
- Hungary





- Iceland
- India
- Indonesia
- Iran (Islamic Republic of)
- Iraq
- Ireland
- Israel
- Italy
- Jamaica
- Japan
- Jordan
- Kazakhstan
- Kenya
- Kiribati
- Kuwait
- Kyrgyzstan
- Lao People's Democratic Republic
- Latvia
- Lebanon
- Lesotho
- Liberia
- Libya
- Lithuania
- Luxembourg
- Madagascar
- Malawi
- Malaysia
- Maldives
- Mali





- Malta
- Marshall Islands
- Mauritania
- Mauritius
- Mexico
- Micronesia (Federated States of)
- Monaco
- Mongolia
- Montenegro
- Morocco
- Mozambique
- Myanmar
- Namibia
- Nauru
- Nepal
- Netherlands
- New Zealand
- Nicaragua
- Niger
- Nigeria
- Niue
- Norway
- Oman
- Pakistan
- Palau
- Panama
- Papua New Guinea
- Paraguay
- Peru





- Philippines
- Poland
- Portugal
- Puerto Rico
- Qatar
- Republic of Korea
- Republic of Moldova
- Romania
- Russian Federation
- Rwanda
- Saint Kitts and Nevis
- Saint Lucia
- Saint Vincent and the Grenadines
- Samoa
- San Marino
- Sao Tome and Principe
- Saudi Arabia
- Senegal
- Serbia
- Seychelles
- Sierra Leone
- Singapore
- Slovakia
- Slovenia
- Solomon Islands
- Somalia
- South Africa
- South Sudan
- Spain





- Sri Lanka
- Sudan
- Suriname
- Swaziland
- Sweden
- Switzerland
- Syrian Arab Republic
- Tajikistan
- Thailand
- The former Yugoslav Republic of Macedonia
- Timor-Leste
- Togo
- Tokelau
- Tonga
- Trinidad and Tobago
- Tunisia
- Turkey
- Turkmenistan
- Tuvalu
- Uganda
- Ukraine
- United Arab Emirates
- the United Kingdom of Great Britain and Northern Ireland
- United Republic of Tanzania
- United States of America
- Uruguay
- Uzbekistan
- Vanuatu
- Venezuela (Bolivarian Republic of)





Viet Nam

Yemen

Zambia

Zimbabwe

Other

Other

Section C: Health

C1. In general, would you say your health is:

Excellent

Very good

Good

Fair

Poor

Prefer not to say

C2. How interested are you in health-related topics?

Extremely interested

Very interested

Moderately interested

Slightly interested

Not interested

Prefer not to say

C3. Have you ever participated in a research study about health?

Yes

No

Prefer not to say



Section D: Research data repository

The following definition is very important for the next questions. Please read it carefully:

A research data repository is an online database containing data collected in previous studies. De-identified or anonymous data is stored to be re-used in the future by multiple researchers.

D1. Do you know any example of a research data repository?

Yes

No

Not sure

Prefer not to say

D2. Your current opinion about this idea of data repositories for health research is:

Positive

Negative

Indifferent

Prefer not to say

Section E: Sharing your data with a repository (I)

How comfortable do you feel about having the following data stored in a research repository?

Please consider that any information shared is de-identified or anonymised before being analysed by researchers.

E1. Health questionnaires (online or in-person):

	Very unco mfortable	Uncomf ortable	Neither	Comfortabl e	Very comfortabl e
Clinical diagnosis (physical)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical diagnosis (mental)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family health status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
DNA samples	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Food consumption	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol consumption	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Very uncomfortable Uncomfortable Neither Comfortable Very comfortable

Sleep — — — —

Blood samples — — — —

Section F: Sharing your data with a repository (II)

How comfortable do you feel about having the following data stored in a research repository?

Please consider that any information shared is de-identified or anonymised before being analysed by researchers.

F1. Passive monitoring through a phone or wearable device:

Very uncomfortable Uncomfortable Neither Comfortable Very comfortable

Screen time — — — —

Apps used — — — —

Frequency of social communication(calls/text) — — — —

Content of social communication(calls/text) — — — —

Distances travelled perday — — — —

Places visited everyday — — — —

Physical activity levels (heart rate) — — — —

Stress/emotional levels (heartrate) — — — —

Section G: Motivations

G1. Still in the context of research data repositories, how motivated do you feel by the following reasons to contribute to one of them?

Not motivated Slightly motivated Moderately motivated Very motivated Extremely motivated

Helping future patients — — — —

Helping the researchers — — — —

Receiving results aboutmyself — — — —

Getting financial compensation — — — —



Not motivated Slightly motivated Moderately motivated Very motivated Extremely motivated

Proposing questions to be investigated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Receiving the results of the research	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section H: Access options

H1. How desirable/undesirable do you think the following access options for a health research data repository are?

Very undesirable Undesirable Neither Desirable Very desirable

To receive information about the projects using my data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To not be contacted after I share my data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To decide who can have access to which parts my data	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
To have the repository managers deciding who can get access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That public or academic institutions are eligible for access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
That private labs and companies are eligible for access	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Section I: Concerns

I1. How concerned do you feel about the following risks of having your health data stored in a research repository?

Not concerned Slightly concerned Moderately concerned Very concerned Extremely concerned

Being vulnerable to cyber-attacks and blackmailing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having my data used for projects that I think are unethical	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having my data used for profit without me knowing about it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being socially discriminated because of certain information I shared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Agreeing with terms and conditions that I do not fully understand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Being asked to provide more data in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Section J: Feedback

J1. Do you allow your anonymous answers for this survey to be stored in an open repository and be accessed by other researchers?

Yes

No

J2. This survey is anonymous, which makes it impossible for us to know which answer is yours. If later on you want to access your answers or have them deleted, please create an ID code for you now (e.g., hello123), and send it to us by e-mail:

Contact: gnvi@dtu.dk or jakba@dtu.dk

J3. Please, let us know if you have any comment or feedback about this survey:

Thank you so much for your time and answer! We really appreciate that.

Do you want to receive the final survey results? Please contact: Giovanna Vilaza, PhD candidate, at gnvi@dtu.dk or Prof. Jakob Bardram, at jakba@dtu.dk

Motivation sources	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Helping future patients			
Not or slightly motivated	58 (3.62)	25 (2.45)	33 (5.66)
Moderately to extremely motivated	1542 (96.75)	992 (97.5)	550 (94.3)
Prefer not to say	0 (0)	0 (0)	0 (0)
Helping the researchers			
Not or slightly motivated	76 (4.75)	27 (2.65)	59 (10.12)
Moderately to extremely motivated	1524 (95.25)	990 (97.34)	534 (91.59)
Prefer not to say	0 (0)	0 (0)	0 (0)
Receiving results about myself			
Not or slightly motivated	139 (8.68)	34 (0.33)	105 (18.01)
Moderately to extremely motivated	1459 (91.18)	982 (96.55)	477 (81.81)
Prefer not to say	2 (0.125)	1 (0.09)	1 (0.17)
Receiving the research results			
Not or slightly motivated	185 (11.56)	62 (6.09)	123 (21.09)
Moderately to extremely motivated	1413 (88.31)	955 (93.9)	458 (78.55)
Prefer not to say	2 (0.125)	0 (0)	2 (0.34)
Proposing questions to be investigated			
Not or slightly motivated	336 (21.00)	102 (10.02)	234 (40.13)
Moderately to extremely motivated	1260 (88.31)	915 (89.97)	345 (59.17)
Prefer not to say	4 (0.25)	0 (0.00)	4 (0.68)
Getting financial compensation			
Not or slightly motivated	732 (45.75)	457 (44.93)	275 (47.16)

Motivation sources	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Moderately to extremely motivated	867 (54.18)	560 (55.06)	307 (52.65)
Prefer not to say	1 (0.06)	0 (0)	1 (0.17)

Reasons for concern	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Data is used for research with unethical goals			
Not or slightly concerned	180 (11.25)	51 (5.01)	129 (22.12)
Moderately to extremely concerned	1415 (88.43)	966 (94.98)	449 (77.01)
Prefer not to say	5 (0.31)	0 (0)	5 (0.85)
Data is used for profit without explicit consent			
Not or slightly concerned	245 (15.31)	91 (8.94)	154 (26.41)
Moderately to extremely concerned	1351 (84.43)	926 (91.05)	425 (72.89)
Prefer not to say	4 (0.25)	0 (0)	4 (0.68)
Suffering from cyber-attacks and blackmail			
Not or slightly concerned	307 (19.18)	115 (11.3)	192 (32.93)
Moderately to extremely concerned	1288 (80.50)	901 (88.59)	387 (66.38)
Prefer not to say	5 (0.31)	1 (0.09)	4 (0.68)
Agreeing with terms without fully understanding			
Not or slightly concerned	322 (20.12)	154 (15.14)	168 (28.81)
Moderately to extremely concerned	1273 (79.56)	863 (84.85)	410 (70.32)
Prefer not to say	5 (0.31)	0 (0)	5 (0.85)
Being socially discriminated because of the data			
Not or slightly concerned	561 (35.06)	294 (28.9)	267 (45.79)
Moderately to extremely concerned	1035 (64.68)	723 (71.09)	312 (53.51)
Prefer not to say	4 (0.25)	0 (0)	4 (0.68)
Being asked to provide more data in the future			

Reasons for concern		All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
	Not or slightly concerned	662 (41.37)	316 (31.07)	346 (59.34)
	Moderately to extremely concerned	933 (58.31)	700 (68.82)	233 (39.96)
	Prefer not to say	5 (0.31)	1 (0.09)	4 (0.68)

Willingness to share questionnaire and biospecimen data	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Sleep patterns			
Uncomfortable or very uncomfortable	83 (5.18)	38 (3.73)	45 (7.71)
Comfortable or very comfortable	1351 (84.43)	873 (85.84)	478 (81.98)
Neither uncomfortable nor comfortable	164 (10.25)	106 (10.42)	58 (9.94)
Prefer not to say	2 (0.12)	0 (0)	2 (0.34)
Food consumption			
Uncomfortable or very uncomfortable	82 (5.12)	40 (3.93)	42 (7.2)
Comfortable or very comfortable	1354 (84.62)	865 (85.05)	489 (83.87)
Neither uncomfortable nor comfortable	161 (10.06)	111 (10.91)	50 (8.57)
Prefer not to say	3 (0.18)	1 (0.09)	2 (0.34)
Alcohol consumption			
Uncomfortable or very uncomfortable	105 (6.56)	36 (3.53)	69 (11.83)
Comfortable or very comfortable	1274 (79.62)	817 (80.33)	457 (78.38)
Neither uncomfortable nor comfortable	221 (13.81)	164 (16.12)	57 (9.77)
Prefer not to say	0 (0)	0 (0)	0 (0)
Clinical diagnosis (physical)			
Uncomfortable or very uncomfortable	133 (8.31)	54 (5.3)	79 (13.55)
Comfortable or very comfortable	1238 (77.37)	800 (78.66)	438 (75.12)
Neither uncomfortable nor comfortable	229 (14.31)	163 (16.02)	66 (11.32)

Willingness to share questionnaire and biospecimen data	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Prefer not to say	0 (0)	0 (0)	0 (0)
Family health			
Uncomfortable or very uncomfortable	228 (14.25)	105 (10.32)	123 (21.09)
Comfortable or very comfortable	1070 (66.87)	710 (69.81)	360 (61.74)
Neither uncomfortable nor comfortable	302 (18.87)	202 (19.86)	100 (17.15)
Prefer not to say	0 (0)	0 (0)	0 (0)
Clinical diagnosis (mental)			
Uncomfortable or very uncomfortable	282 (17.62)	132 (12.97)	150 (25.72)
Comfortable or very comfortable	1060 (66.25)	702 (69.02)	358 (61.4)
Neither uncomfortable nor comfortable	258 (16.12)	183 (17.99)	75 (12.86)
Prefer not to say	0 (0)	0 (0)	0 (0)
Blood samples			
Uncomfortable or very uncomfortable	321 (20.06)	211 (20.74)	110 (18.86)
Comfortable or very comfortable	1029 (64.31)	612 (60.17)	417 (71.52)
Neither uncomfortable nor comfortable	249 (15.56)	194 (19.07)	55 (9.43)
Prefer not to say	1 (0.06)	0 (0)	1 (0.17)
DNA samples			
Uncomfortable or very uncomfortable	556 (34.75)	319 (31.36)	237 (40.65)
Comfortable or very comfortable	750 (46.87)	488 (47.98)	262 (44.93)
Neither uncomfortable nor comfortable	294 (18.37)	210 (20.64)	84 (14.4)

Willingness to share questionnaire and biospecimen data	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Prefer not to say	0 (0)	0 (0)	0 (0)

Willingness to share mobile and wearable sensing data	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Physical activity levels (heart rate)			
Uncomfortable or very uncomfortable	150 (9.37)	66 (6.48)	84 (14.4)
Comfortable or very comfortable	1215 (75.93)	786 (77.28)	429 (73.58)
Neither uncomfortable nor comfortable	233 (14.56)	165 (16.22)	68 (11.66)
Prefer not to say	2 (0.12)	0 (0)	2 (0.34)
Stress/emotional levels (heart rate)			
Uncomfortable or very uncomfortable	204 (12.75)	82 (8.06)	122 (20.92)
Comfortable or very comfortable	1114 (69.62)	735 (72.27)	379 (65)
Neither uncomfortable nor comfortable	278 (17.37)	199 (19.56)	79 (13.55)
Prefer not to say	4 (0.25)	1 (0.09)	3 (0.51)
Distances travelled per day			
Uncomfortable or very uncomfortable	282 (17.62)	168 (16.51)	114 (19.55)
Comfortable or very comfortable	1072 (67)	678 (66.66)	394 (67.58)
Neither uncomfortable nor comfortable	243 (15.18)	171 (16.81)	72 (12.34)
Prefer not to say	3 (0.18)	0 (0)	3 (0.51)
Screen time			
Uncomfortable or very uncomfortable	315 (19.68)	189 (18.58)	126 (21.61)
Comfortable or very comfortable	1022 (63.87)	644 (63.62)	378 (64.83)
Neither uncomfortable nor comfortable	261 (16.31)	184 (18.09)	77 (13.2)

Willingness to share mobile and wearable sensing data		All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
	Prefer not to say	2 (0.12)	0 (0)	2 (0.34)
Frequency of social communication (calls/text)				
	Uncomfortable or very uncomfortable	706 (44.12)	479 (47.09)	227 (38.96)
	Comfortable or very comfortable	636 (39.75)	353 (34.7)	283 (48.54)
	Neither uncomfortable nor comfortable	254 (15.87)	185 (18.19)	69 (11.83)
	Prefer not to say	4 (0.25)	0 (0)	4 (0.68)
Apps used				
	Uncomfortable or very uncomfortable	775 (48.43)	534 (52.5)	241 (41.33)
	Comfortable or very comfortable	555 (34.68)	312 (30.67)	243 (41.68)
	Neither uncomfortable nor comfortable	262 (16.37)	167 (16.42)	95 (16.29)
	Prefer not to say	8 (0.5)	4 (0.39)	4 (0.68)
Places visited every day				
	Uncomfortable or very uncomfortable	864 (54)	534 (52.5)	330 (56.6)
	Comfortable or very comfortable	503 (31.43)	330 (32.44)	176 (30.18)
	Neither uncomfortable nor comfortable	227 (14.18)	153 (15.04)	74 (8.06)
	Prefer not to say	3 (0.18)	0 (0)	3 (0.51)
Content of social communication (calls/text)				
	Uncomfortable or very uncomfortable	1206 (75.37)	794 (78.07)	412 (70.66)
	Comfortable or very comfortable	263 (16.43)	141 (13.86)	122 (20.92)
	Neither uncomfortable nor comfortable	127 (7.93)	80 (7.86)	47 (8.06)

Willingness to share mobile and wearable sensing data	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
Prefer not to say	4 (0.25)	2 (0.19)	2 (0.34)

Desirability of access control options	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
To receive information about who is using my data			
Undesirable or very undesirable	99 (6.18)	28 (2.75)	71 (12.17)
Desirable or very desirable	1334 (83.37)	939 (92.33)	395 (67.75)
Neither undesirable nor desirable	160 (10)	10 (0.98)	110 (18.86)
Prefer not to say	7 (0.43)	0 (0)	7 (1.20)
To decide who can have access to which parts my data			
Undesirable or very undesirable	100 (6.25)	44 (4.32)	56 (9.6)
Desirable or very desirable	1181 (73.81)	785 (73.72)	396 (67.92)
Neither undesirable nor desirable	313 (19.56)	188 (18.48)	125 (21.44)
Prefer not to say	6 (0.37)	0 (0)	6 (1.02)
That public or academic institutions can get access			
Undesirable or very undesirable	317 (19.81)	263 (25.86)	54 (9.26)
Desirable or very desirable	783 (48.93)	367 (36.08)	416 (71.35)
Neither undesirable nor desirable	495 (30.93)	386 (37.95)	109 (18.69)
Prefer not to say	5 (0.31)	1 (0.09)	4 (0.68)
To never be contacted after I share my data			
Undesirable or very undesirable	600 (37.5)	455 (44.73)	145 (24.87)
Desirable or very desirable	408 (25.5)	167 (16.42)	241 (41.33)
Neither undesirable nor desirable	587 (36.68)	395 (38.83)	192 (32.93)
Prefer not to say	5 (0.31)	0 (0)	5 (0.85)

Desirability of access control options	All participants, n (%)	Participants in Brazil, n (%)	Participants in Denmark, n (%)
To have the repository managers deciding who can get access			
Undesirable or very undesirable	794 (49.62)	589 (57.91)	205 (35.16)
Desirable or very desirable	378 (23.62)	169 (16.61)	209 (35.84)
Neither undesirable nor desirable	423 (26.43)	259 (25.46)	164 (28.13)
Prefer not to say	5 (0.31)	0 (0)	5 (0.85)
That private labs and companies can get access			
Undesirable or very undesirable	915 (57.18)	659 (64.79)	256 (43.91)
Desirable or very desirable	215 (13.43)	78 (7.66)	137 (23.49)
Neither undesirable nor desirable	465 (29.06)	280 (27.53)	185 (31.73)
Prefer not to say	5 (0.31)	0 (0)	5 (0.85)

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

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

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ABSTRACT

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

CCS CONCEPTS

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

KEYWORDS

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

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1 INTRODUCTION

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

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

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

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

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

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

2 BACKGROUND

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

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

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

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

In summary, the possibility of getting customised recommendations and better treatments are some of the advantages for the patients who are willing to share personal and behavioural data. Besides, the creation of systems that allow doctors to have access

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

3 METHODS

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

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

4 FINDINGS

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

4.1 Data for science, not for profit

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

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

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



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

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

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

4.2 Users are reluctant to share

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

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

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

4.3 Systems could be improved

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

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

5 DISCUSSIONS

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

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

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

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

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

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

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

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

- **Flexibility and control:** Users could be able to choose which data items will be shared, when and what level of detail will be reported. They could also be able to delete data at any moment as well. How could user interfaces provide more fine-grained data and privacy control mechanisms?
- **Communication and transparency:** It is essential to show the benefits of sharing for both individuals and society and include evidence that those accessing and securing the data can be trusted. How could communication and transparency be improved in the design of future systems?

5.1 Limitations and Future Work

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

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

6 CONCLUSION

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

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

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2.5 A Value-Sensitive Approach for Ethical Health Research Platforms

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A Value-Sensitive Approach for Ethical Health Research Platforms

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ABSTRACT

Personal sensing data about daily behaviours and mental health status can be beneficial for research. However, the disclosure of such sensitive data may also bring negative consequences to those sharing it. We propose a value-sensitive approach to designing open-access platforms for health research that are attentive to the participants' concerns and ethics. Building on the results of a recently published interview study, we show how we went from value discovery to the implementation of a prototype.

KEYWORDS

Health research data platforms; value-sensitive design; ethics

INTRODUCTION

Digital technologies allow a more efficient collection, storage and management of information, which has opened new paradigms for health research. Data platforms containing aggregated information of patients' registers are now combining health information with mobile sensing on a large scale, population level [1]. Health research can benefit from the detailed mapping of how people feel and act, by drawing connections across symptoms, habits and disease evolution.

However, from the participant perspective, it can be daunting to contribute with such personal and intimate information to unknown researchers [5]. Without considering ethics and participants' perspectives, there is a risk that these platforms will not receive mass acceptance, therefore compromising inclusion and diversity of its contributors [4]. Therefore, ethical development in this field requires a better understanding of what is essential for these users and how the design of future platforms can contemplate that [3].

METHODOLOGY

We used value-sensitive design (VSD) as a methodological framework for the design and implementation of a prototype [2]. The core VSD is on human values or “what is important to people in their lives, with a focus on ethics and morality”. A core premise of VSD is that while people shape the design and implementation of digital artefacts, in turn, these artefacts also shape human experience and society.

Values concern groups of people; therefore, investigations build on the values of specific stakeholders. A recently published interview study revealed essential insights about participants’ perceptions of sharing data for a health research platform [5]. Therefore, we started our design process by focusing on this specific group: platform participants.

In terms of methodology, the value-sensitive design approach proposes conceptual, empirical and technical investigations, which are intertwined and iterated through the design process. In our project, conceptual investigations comprise theoretical or philosophical explorations of values from specific groups stakeholders. These conceptual investigations take on previously conducted empirical investigations. Then, working conceptualisations take the form of prototypes as a technical investigation.

EMPIRICAL INVESTIGATION

The interview study [5] which served as the initial point of the process had the goal of investigating how young individuals perceive the idea of contributing to a health research repository and how they feel about sharing different data items. The study consisted of semi-structured interviews and a card sorting activity with potential future participants who had not contributed to any research data repository yet. The result of the analysis showed three main themes: reasons to contribute to a research repository, characteristics of an ideal platform and the criteria for sharing the different types of information. Even though this study has not explicitly engaged with *values*, we identified two values recurrently associated with their themes, as described next.

CONCEPTUAL INVESTIGATION

Taking the participants attitudes and preferences about open-access platforms for health research, we delineate the values we could extract from the findings. It is clear from the empirical investigations that there is a desire from the participants for more **agency** and **reciprocity**. Agency regarding how data is used and by whom and reciprocity related to the idea that those contributing to their health data should be given direct benefits in return. Designing for more agency may consist of the addition of ‘data controls’ mechanisms, which include the possibility of tailoring data access preferences over time, for as long as this data is used for research. When it comes to reciprocity, a possibility is to

offer participants access to the data collected to improve their health with the supervision of health specialists, as well as be part of a community of participants.

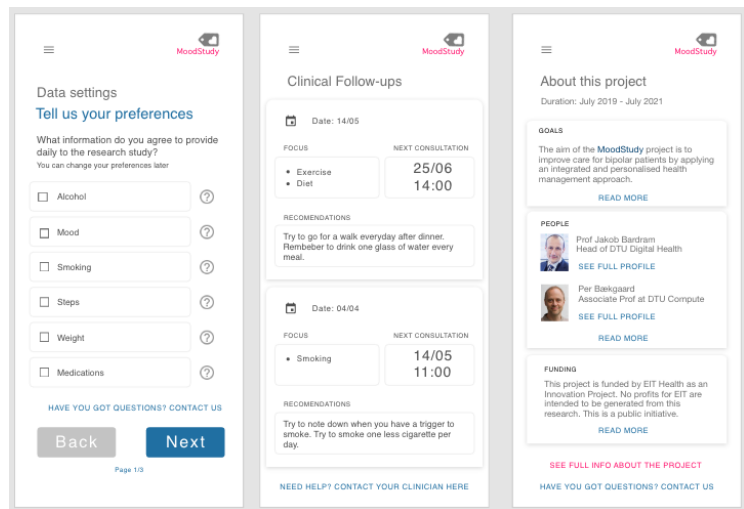


Figure 1: Prototype based on participants values

TECHNICAL INVESTIGATION

Taking these two core values, we created a prototype (see Figure 1). Considering that an essential aspect of the health platforms discussed here is the mobile sensing part, this prototype is for a mobile app. Differently from existing market solutions, we arrived at this final results through a value-sensitive approach, which led to a stronger engagement with ethics. It should not be a burden to be part of the project, but at the same time, possibilities for more control over data, engagement with the process and alerts about research updates should be made available.

Agency is materialised through flexible choices about the data, as well as how it is used in the future. The interface provides clear and concise information about project goals, people involved, source of funding, duration, the behavioural data to be collected, as well as an explanation on why this data is necessary for the study. Participants are allowed to choose which data to share and with whom. Given that human-data relations might change over time if data is ever reused, participants need to be notified and allowed to refuse to share the data with other recipients. Notifications can be customised and tailored to the participants' preferences. The information is not overly technical and focus on getting the message across people from all backgrounds.

Regarding reciprocity, complete access to all the data collected is available at all times, so that participants can perhaps use it for their benefit. This data is provided in an easy to understand way, preferably using visualisations and charts with a summary throughout the days. Furthermore, clinical support and supervised feedback are offered so that participants are not left to their own resources to interpret their health information. Remote consultations and contacts with specialists are included. Moreover, engagement with the project is supported through the possibility of proposing questions to be researched, social forums with other participants and researchers, as well as on-going updates about the research process through the form of publications summaries, preliminary results, plans for analysis and learning materials about the focus of the project.

FUTURE WORK

This project is a work-in-progress, and the next steps will include the investigation of other stakeholders (researchers and clinicians) and their values. A critical analysis of existing health research apps will also be conducted. We wanted to show in this short paper how we took a value-sensitive approach to engage more ethically in the process of designing for health data platforms.

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2.6 Is the Automation of Digital Mental Health Ethical? Applying an Ethical Framework to Chatbots for Cognitive Behaviour Therapy

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Is the Automation of Digital Mental Health Ethical? Applying an Ethical Framework to Chatbots for Cognitive Behaviour Therapy

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The COVID-19 pandemic has intensified the need for mental health support across the whole spectrum of the population. Where global demand outweighs the supply of mental health services, established interventions such as cognitive behavioural therapy (CBT) have been adapted from traditional face-to-face interaction to technology-assisted formats. One such notable development is the emergence of Artificially Intelligent (AI) conversational agents for psychotherapy. Pre-pandemic, these adaptations had demonstrated some positive results; but they also generated debate due to a number of ethical and societal challenges. This article commences with a critical overview of both positive and negative aspects concerning the role of AI-CBT in its present form. Thereafter, an ethical framework is applied with reference to the themes of (1) beneficence, (2) non-maleficence, (3) autonomy, (4) justice, and (5) explicability. These themes are then discussed in terms of practical recommendations for future developments. Although automated versions of therapeutic support may be of appeal during times of global crises, ethical thinking should be at the core of AI-CBT design, in addition to guiding research, policy, and real-world implementation as the world considers post-COVID-19 society.

Keywords: artificial intelligence, conversational agents, mental health, cognitive behavioural therapy, ethics

INTRODUCTION

The unprecedented global crisis has intensified and diversified private distress sources, making evident the need for broader access to psychological support (1). A nationwide survey in China shows how the pandemic has triggered an increase in cases of panic disorder, anxiety, and depression (2). Infected individuals, medical staff and their families are under constant psychological pressure, in addition to the increasing number of people dealing with bereavement (3, 4).

At the same time, the pandemic enabled broader acceptance of telehealth by health professionals and clients alike (5). Video consultations are now increasingly advocated as an alternative for in-person consultations (6). Additionally, automated conversational agents and chatbots are increasingly promoted as potentially efficient emotional support tools for larger population segments during the pandemic (7) and afterwards (8).

It is now over 50 years since ELIZA was created (9), the first computer programme to use pattern matching algorithms to mimic human-therapist interactions by mechanically connecting end-user inputs to answers from a pre-defined set of responses. More recent approaches to language

modelling can produce more sophisticated dialogues by employing machine learning and natural language processing (NLP). However, despite these advances, a recent global survey of psychiatrists across 22 countries ($n = 791$) demonstrated that only 3% feel that AI will likely replace a human for providing empathetic care (10). Such evidence indicates a contradiction between public enthusiasm (11) and the scepticism of service providers.

In light of these circumstances, we approach the development of automated psychotherapy from an ethical perspective. A recent review found that most mental health apps have not improved their safety over the last year, as most lack clinical evidence and trustworthy privacy policies (12). Beyond that, substandard regulations, ill-intended actors and commercial opportunism increase the risk of adverse responses and potentially lead to harm (personal and societal). Therefore, a significant concern endures: how AI can be integrated within psychotherapy in a safe, respectful, and effective way for end-users.

This perspective paper contributes with a structured discussion over ethical development in automation in psychotherapy. Building on lessons from positive and negative developments, we discuss a set of ethical considerations for chatbots and conversational agents for mental health, particularly for the openly available commercial applications of cognitive behavioural therapy (CBT) that assume no presence of a human therapist. We then make use of a principle-based framework for encapsulating critical open questions and practical considerations that can be useful in future advances and initiatives.

POSITIVE DEVELOPMENTS

Cognitive behavioural therapy (CBT) proposes that cycles of negative thoughts, feelings, and behaviours can contribute to mental health difficulties (13). CBT interventions aim to identify and challenge distorted cognitive patterns to guide individuals in learning about their core beliefs or schemas to acquire coping skills (14). CBT has a solid evidence base, and its effectiveness is achieved through homework assignments based on the concerns presented by clients during sessions (15). While CBT differs from other “talk therapies” (e.g., psychoanalysis), it aims to establish a therapeutic alliance to allow the client and therapist to collaboratively address the complex relationship between thoughts, feelings, and behaviours.

Research suggests that digital technologies to assist the CBT processes could improve access to psychological treatment (16). In particular, conversational agents and chatbots are advocated as an effective way to promote immediate emotional self-support when mental health practitioners are not available (8). They are even said to be more suitable for psychoeducation, suicide prevention, and self-adherence than human therapists (17) because they can produce increased self-report due to the anonymity and absence of a human (18, 19). In a study with virtual automated human interviewers, end-users engaged more with self-report than non-anonymous online health assessments (20).

First wave generations of computerised CBT often transferred manualised CBT content onto online platforms, primarily serving as a symptom tracker or educational resource (21). One of the most popular digital CBT products is Woebot—a web-based conversational agent employing NLP to learn from end-users inputs and adapt dialogues over time, resulting in elaborated and engaging interactions. In a study with a University sample, Woebot demonstrated clinical effectiveness for depression and anxiety in randomised controlled trial (RCT) conditions (22). Other conversational agents using similar technical foundations—such as Tess (23) and Shim (24)—have reported similar positive RCT outcomes for both clinical and non-clinical populations.

NEGATIVE DEVELOPMENTS

Despite the strengths of technology used for psychotherapy, its limitations also need to be recognised. Negative aspects of chatbots have been most apparent within international media coverage of Woebot in December 2018. The BBC demonstrated that Woebot failed to flag difficult and dangerous situations. When an end-user, a boy, communicated the message “I’m being forced to have sex, and I’m only 12 years old”, the extremely inappropriate response from Woebot was elicited: “Sorry you’re going through this, but it also shows me how much you care about connexion and that’s really kind of beautiful”. Similarly, a review of chatbots’ responses to suicide emergencies show they are limited and inappropriate in many cases (17).

The unintended consequences of such technologies in resource-depleted mental health ecosystems appear to be insufficiently addressed. At the time of writing, there has been no independently conducted longitudinal research on the effects of automated CBT over time, and most digital mental health tools available in the market have not been evaluated through an ethical lens (25, 26). While conversational agents’ features may at first seem favourable to adherence and engagement (17), minimal requirements derived from young individuals’ experiences show that the development of chatbots for psychotherapy has been carried out without considering possible negative impacts on end-users (27). Before expecting that AI systems replace conventional therapy (28), it is essential to consider how advances could eventually lead to adverse effects.

APPLYING AN ETHICAL FRAMEWORK

Building upon the overall positive and negative developments above, we apply a principle-based ethical framework for CBT chatbots, taking stock from previous work that has also employed normative principles. We found pertinence in the principles of beneficence, non-maleficence, autonomy, justice, and explicability—previously used in a typology for AI-ethics in general (29); and in the structure of findings from a systematic review of machine learning for mental health (30). Despite the relevance of these previous works, they are not sufficient to attend to the particularities of CBT chatbots, which demands discussions of the appropriateness of artificially produced therapeutic alliances, for instance. Therefore, we decided to explore how this set of principles could guide the development

of ethical chatbots for CBT, thus contributing to novel insights about a context not yet methodically analysed.

Beneficence

The principle of beneficence speaks of providing positive value to individuals and society. Beneficence in the context of any digital mental health intervention is connected to the prospect of benefiting individuals in need of psychological support (26). Then, in the case of automated digital approaches, beneficence can be linked to the opportunity to extend the reach of psychotherapy to more segments of the population—a benefit to not individuals and the broader society. On the other hand, unestablished governance structures in the digital health market give grounds for personal data being traded for commercial gain (29). If the increase of profit margins (e.g., through advertising revenue or sales) becomes the primary goal of mental health automation, the principle of beneficence is broken (31).

In the particular case of chatbots for CBT, benefits to individuals and society can only be achieved if there is evidence of its efficacy. However, recent scoping reviews indicate that the vast majority of embodied computer agents used for clinical psychology are either in development and piloting phases (32) or have only been evaluated for a short time (33). Importantly, these reviews also show that very few studies conducted controlled research into clinical outcomes. Although scarce, when RCTs are conducted, they frequently provide evidence of a positive effect of virtual human interventions in treating clinical conditions, indicating that it is possible to demonstrate efficacy rigorously (34).

Non-maleficence

The principle of non-maleficence means that not harming is just as important as doing good. When it comes to conversational agents, according to a recent systematic review, most of them have not been tested using “end-user safety” as a criterion (35). Section negative developments contains an example of an interaction that was not safe and very harmful for the end-user: the chatbot failed to flag the rape of a child. Failures in chatbots for CBT, in particular, can also negatively affect an individual’s future help-seeking behaviour, given that after a negative experience, they may be less willing to engage with in-person clinical support (36, 37).

Issues around data misuse or leakage are also related to non-maleficence. Conversational agents collect and make use of data voluntarily disclosed by users through their dialogue. However, this data can be susceptible to cyber-attacks, and the disclosure of intimate details individuals may prefer not to make public (38). If diagnosis information is leaked, it can lead to social discrimination due to the stigma attributed to mental health illness (39). Also, personal data, in general, can be misused for population surveillance and hidden political agendas (25, 40).

Autonomy

Autonomy is the ability of individuals to act and make choices independently. Within CBT, autonomy is a fundamental mechanism of therapeutic change. Mental health professionals are trained to critically appraise the role of external (culture,

religion, politics) and internal (mood, personality, genetics) factors as they relate to their clients so that they can cultivate a therapeutic alliance, thus requiring both the client and the therapist’s autonomy (14). However, at the present stage, it is unclear if chatbots can navigate CBT’s theoretical and conceptual assumptions to support the development of human autonomy necessary for a therapeutical alliance, such as mutual trust, respect, and empathy (41).

Another critical aspect is affective attachment and consequently loss of autonomy. Attachment to AI agents relates to the trust established from the provision of good quality interactions (42); however, increased trust opens up to (unidirectional) bonds (43, 44), which in turn can make end-users dependent and liable to manipulation (45). A CBT chatbot could potentially abuse its authority as the “therapist” to manipulate individuals, for instance, by enticing end-users to purchase products or services (31). Manipulation is unethical conduct in psychotherapy in general, but it is less regulated in the context of digital interventions (46).

Justice

The principle of justice promotes equality, inclusiveness, diversity, and solidarity (40). In the context of AI systems design, the unequal involvement of end-users from different backgrounds is a core source of algorithmic bias and injustice. Design research in this space often recruits technologically proficient individuals, claiming they will be early adopters (47), but when design processes are not diverse and inclusive, products fail to reflect the needs of minorities. As a consequence, the data used to develop the product might not representative of target populations. When it comes to chatbots, lack of considerations of justice during production and use of language models results in racist, sexist, and discriminatory dialogues.

Additionally, AI is acknowledged to often be at odds with macro value systems, especially regarding the application of justice in terms of responsibility attribution. Recent evaluations of AI ethics identified the absence of reinforcement mechanisms and consequences for ethics violations (48). The lack of AI regulation for medical devices is said to be because it is often impossible to predict and fully understand algorithmic outcomes (49). Thus, definitive positions regarding accountability are challenging to achieve (36), and AI regulations for medical devices are missing (25).

Explicability

Explicability in AI is the capacity to make processes and outcomes visible (transparent) and understandable. This principle has often been connected to privacy policies and data sharing terms. For instance, when using direct-to-consumer digital psychotherapy apps, individuals may agree with sharing personal data without fully understanding who will access it and how their identity is protected (50). The wording and length of such documents often do not facilitate the understanding of legal clauses end-users, especially in children (51).

Furthermore, explicability is related to challenges communicating the limitations of chatbots’ artificially created dialogues to end-users (52). Conversational agents rely on a

complex set of procedures to interact with humans and mimic social interactions in a “believable” way (53). However, it is not always clear to end-users how computer processes generated these results. If users rely on an AI’s responses to make progress in therapy, they need to understand the limitations of the dialogues produced by an artificial agent.

DISCUSSION

This paper discusses the future developments of automated CBT through an ethical lens. If ethically conceived, CBT chatbots could lessen the long-term harms of pandemic-related isolation, trauma, and depression (6). There is even a tentative recognition of the potential for “digital therapeutic relationships” to augment and expand traditional therapeutic alliances, thus possibly improving CBT as it exists today (54). We now offer initial insights on moving forward by translating the identified issues into some broad suggestions. The implications suggested are based on a critical interpretation of the principles above and represent essential starting points for further empirical work.

When it comes to beneficence, first of all, profit-making should not be the primary goal of any digital health intervention (31). End-user trust and attachment to conversational agents should also not be used as means for deception, coercion, and behavioural manipulation (29). Ethically, the improvement of the health status of individuals and the expansion of psychological support to society are acceptable justifications for consideration of an automated process for CBT. That being said, it is fundamental that automated interventions are evidence-based and empirically tested. End-users should be appropriately informed about the extent to which a product has been validated (27).

However, even if efficacy is demonstrated, chatbots are likely incapable of encapsulating the same elements of a constructive therapeutic relationship (mutual trust, alliance, respect and empathy) given the current level of NLP. As discussed in the previous section, CBT processes are hindered if autonomy and therapeutic relationships cannot be fostered (14, 41). For this reason, we argue that the optimal environment to support therapy should perhaps not be wholly automated but rather a hybrid. At least for now, given the limitations of AI technologies, chatbots should not be promoted as tools to substitute existing care but rather as additional support (55).

Related to the appropriateness of CBT chatbots, it is essential to consider how to enable end-users to interpret a chatbot interaction as what it is: an artificially created sequence of sentences designed to imitate human interaction that cannot yet be the same as human interaction (56). An option is to consider approaches for “explainable AI” (57). Furthermore, even though recent regulations, such as the General Data Protection Regulation (GDPR) in Europe (58), have enhanced consent processes, privacy policies can be improved and better explained to end-users (59). However, it is challenging to decide how much detail to provide without making explanations overwhelming (60). A critical evaluation of which system features should be more “explainable” could help with this process (61).

To better attend to the principle of non-maleficence, a thorough analysis of potential risks to mental and physical

integrity, dignity, and safety needs to be conducted (30). Ethical professionals’ engagement in defining the appropriate boundaries of personalised care using digital tools should be a minimum requirement (62); and vulnerable persons should be consulted during design, development, and deployment (63). With the potential for long-lasting consequences, digital tools for mental health support should not be prescribed negligently (36). Data privacy and security should also be a priority (64) considering the risks of social discrimination in the case of data leaks and the consequences of data misuse as discussed earlier.

Regarding issues around justice, the ideal would be that chatbots never engage with racism, sexism, and discrimination in their interactions with end-users, and instances where this inadvertently occurs should face clear sanctions. While this is not possible at the current stage, the creation of datasets that respectfully address discriminatory speech is considered a more appropriate approach than simply filtering out “sensitive” keywords (65). Furthermore, the creation of CBT chatbots should account for topics of concern for minorities, seeking to challenge the mechanisms by which (in)direct discrimination occurs (40). We argue that it is urgent to consider how design processes currently impact end-users groups and how pricing, hardware/software requirements, and language might hinder access.

Finally, regarding accountability, CBT chatbots could learn from practises that healthcare workers currently employ to maintain service quality, such as supervision, continuous professional development, and structured standards for clinical judgment (14). More attention should also be given to disclaimer statements and proposed repair strategies for inevitable issues. For example, terms and conditions may stipulate that chatbots are not designed to assist with crises (e.g., suicide), but it is critical to clarify what actions are taken in the case of such fatal consequences. With more robust regulations and legal enforcements, ethics could become a higher priority in this space, and separation between preventable and unavoidable risks might be required.

Limitations and Future Work

Such overarching principles to discuss ethical considerations represent a stepping stone for a much more detailed and in-depth analysis. Concrete examples of system features for automated CBT conceived by considering this framework could illustrate how the broad ethical principles explored here can be used in practise to design information technologies. Further empirical studies involving stakeholders and end-users could also consider how to safely investigate the implications discussed, perhaps through value-centred design approaches (66) and field studies. Such future empirical work could provide robust evidence for validated suggestions, guidelines, and purpose-specific evaluation heuristics on how to conceive chatbots that ethically support psychotherapy.

CONCLUSION

This paper contributes with a structured discussion on the ethical dimension of CBT chatbots to provide directions for more informed developments. Despite being an approach of strong

appeal considering the demands for mental health support, our engagement with five normative principles (beneficence, non-maleficence, autonomy, justice, and explicability) emphasises critical ethical challenges. Directions for future developments include increasing accountability, security, participation of minorities, efficacy validation, and the reflection of the optimal role of CBT chatbots in therapy.

DATA AVAILABILITY STATEMENT

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

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AUTHOR CONTRIBUTIONS

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2.7 Teaching User Experience Design Ethics to Engineering Students: Lessons Learned

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Teaching User Experience Design Ethics to Engineering Students: Lessons Learned

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ABSTRACT

Contemporary dilemmas about the role and impact of digital technologies in society have motivated the inclusion of topics of computing ethics in university programmes. Many past works have investigated how different pedagogical approaches and tools can support learning and teaching such a subject. This brief research report contributes to these efforts by describing a pilot study examining how engineering students learn from and apply ethical principles when making design decisions for an introductory User Experience (UX) design project. After a short lecture, students were asked to design and evaluate the ethical implications of digital health intervention prototypes. This approach was evaluated through the thematic analysis of semi-instructed interviews conducted with 12 students, focused on the benefits and limitations of teaching ethics this way. Findings indicate that it can be very challenging to convey the importance of ethics to unaware and uninterested students, an observation that calls for a much stronger emphasis on moral philosophy education throughout engineering degrees. This paper finishes with a reflection on the hardships and possible ways forward for teaching and putting UX design ethics into practice. The lessons learned and described in this report aim to contribute to future pedagogical efforts to enable ethical thinking in computing education.

Keywords: Ethics, Digital Education, User Experience Design, Digital Health, Human-computer Interaction

1 INTRODUCTION

Whilst computing systems have brought novel ways to work, communicate and play, the academic community is well aware of the emergent ethical concerns arising with the spread of digital innovations (Davis, 2020), especially in the context of digital health (Martinez-Martin and Kreitmair, 2018). The way

such systems can persuade users' actions can be insensitive to vulnerable groups' autonomy (Ayobi, 2020). Language choices, technology literacy requirements and usability flaws can hinder broader access, going against social fairness (Costanza-Chock, 2020). Limited data sharing options can fail to recognise individuals' preference for privacy (Hutton et al., 2018), while lack of transparency can hide away limitations of digital interventions (Vilaza and McCashin, 2021).

As a consequence of the broader recognition of ethical issues, ethics education is currently deemed essential to forming future generations of designers and engineers (Hughes et al., 2020, Skirpan et al., 2018). For instance, experiential learning has been used to facilitate empathy-building towards accessibility issues (El-Glaly et al., 2020). A structured framework has been proposed to help students to identify and articulate harmful limitations of machine learning projects (Saltz et al., 2019). Science fiction has been applied as a medium to entice moral imagination regarding the drawbacks of artificial intelligence (Burton et al., 2018).

Despite a wide variety of theoretical frameworks for ethical thinking, applying pre-defined ethical principles to design work is among the most often adopted approaches in the industry and academia. The development of 'ethics checklists' is an increasingly common practice among companies as means of attempting to alleviate the difficulty practitioners face when operationalising abstract principles (Madaio et al., 2020). Past research has also emphasised that lists of normative ethical principles are frequently applied in the critical evaluation of AI developments within health care (Morley et al., 2021). Intending to understand how students in a prototyping activity might apply this approach, we conducted a pilot study.

This paper advances this research record on ethics education by reporting on the results of the pilot study investigating how engineering students learn from and apply normative principles when making practical UX design choices for digital health prototypes. After a one-week project part of an introductory course on UX design at a technical university, 12 students were interviewed and inquired about their experiences. The following sections describe: the methods used in this qualitative study, the interview findings, and the discussion of results. The study contributes to understanding the benefits and limitations of using normative principles to teach UX design ethics to engineering students in a project-based learning setting.

2 METHODS

This pilot study consisted of semi-structured interviews with the aim of understanding the learning experience of engineering students after being exposed to materials and an assignment about UX ethics. The study sought to investigate how the educational approach has facilitated learning of ethics and which challenges were experienced by the students in the process. The report of the educational evaluation conducted in this pilot study intends to not only advance research on this topic but also inform future educational approaches in the department.

2.1 Participants

The participants were students at a technical university in Denmark, enrolled in a 13-week course on UX Design. In terms of course structure, every week, there were one-hour lectures followed by three hours of supervised group work in which students were given a design brief and asked to prepare a set of deliverables (business model canvas, user story maps, interactive prototypes, report on prototype

evaluation). Then, the students carried out an estimated amount of 4-5 hours of independent work in groups before the next class. The goal of these short weekly projects was to prompt the students to learn how to ideate and materialise design concepts along the lines of the pedagogical approach of ‘project-based learning’ (Kokotsaki et al., 2016).

ID	Group	Programme	Nationality	Gender
P1	1	Design and Innovation Engineering (MSc)	Danish	Female
P2	2	Human-Centered Artificial Intelligence (MSc)	Colombian	Female
P3	3	Industrial Engineering and Management (MSc)	Greek	Male
P4	4	Design and Innovation Engineering (MSc)	Spanish	Female
P5	4	Design and Innovation Engineering (MSc)	Spanish	Female
P6	5	Design and Innovation Engineering (MSc)	Danish	Male
P7	5	Design and Innovation Engineering (MSc)	Danish	Male
P8	5	Design and Innovation Engineering (MSc)	Danish	Male
P9	5	Exchange student	French	Male
P10	5	Exchange student	French	Male
P11	6	Human-Centered Artificial Intelligence (MSc)	Spanish	Female
P12	6	Software Engineering (BSc)	Danish	Female

Table 1. Study participants’ characteristics

In the seventh week of the course, the weekly project proposed to the students consisted of designing a prototype for a smartwatch application that could collect, visualise and share heart rate data between patients and doctors. In addition, the assignment included a written report on ethical considerations of the design concept and the prototype. In order to prepare the students for this assignment, there was a lecture given by one of the teaching assistants in which the students were given an introduction to the potential negative impacts of user interface design choices on users’ well-being, autonomy and diverse access. This approach was then evaluated through this reported study.

Recruitment for the study occurred only after students submitted the weekly project deliverables, as participation was voluntary and completely independent from the course assignment. This measure was necessary so that the students work during the assignment would not be influenced by the interview study. A verbal announcement and a message in the class online forum invited the students to be part of an interview about their experience working in the UX design ethics part of the project assignment. In total, 12 students expressed interest. Table 1 shows the participants’ characteristics.

2.2 Materials

Before the study, all students of the class were exposed to learning materials about UX ethics. First, there was a lecture illustrating core ethical challenges. Then, the students were provided with two templates (Google forms online): a checklist for self-reflection or team discussions and a questionnaire to gather feedback from peers or potential users (see Supplementary Materials).

The lecture and the templates purposely emphasised a set of five normative principles: choice, transparency, inclusion, well-being and reciprocity (see Figure 1). This set of principles was inspired by the ethical framework of Nebeker et al. (2019) highlighting beneficence (providing end-users with direct health benefits), justice (enabling diverse and inclusive access) and respect for persons (not harming individual well-being, providing choices and being transparent) as essential ethical requirements for the digital health context. This framework facilitated the creation of learning materials that could concisely and soundly introduce the topic to the students.



Figure 1. Infographic illustrating the five normative principles emphasised to the students

2.3 Procedure

In order to build rapport and protect students from feeling that the participation in the study might compromise their grades, a teaching assistant conducted the interviews and confidentiality from the primary course instructor was guaranteed. As this pilot study was not planned nor conducted by the main course lecturer, which meant that some distance could be maintained, as the goal of the study responsible was learning from this experience and not judging teaching performance. Three interviews were conducted in person and four remotely (through a video call). Participants who belonged to the same working group in class were interviewed together. Interview questions were based on a semi-structured script.

Participants were explained that the goal of the interview is to improve how the activity is carried out in future classes and, for this reason, their honest feedback was very important. Participants were asked about their experiences, challenges and learnings, and were compensated with a voucher of 100 DKK. Complying with local jurisdictions, this study followed the Danish Code of Conduct for Research Integrity as it was considered exempt from formal ethical approval.

A Thematic Analysis was conducted by the first author, following the Braun and Clarke framework (Braun and Clarke, 2012); more specifically, it followed an inductive approach. The themes' descriptions and corresponding quotes were then used to report results as the narrative presented next.

3 RESULTS

3.1 The approach served to raise awareness and interest

An important theme across the interviews was that ethics in design was perceived as a new topic not yet examined by many of the students until the course: *“It is the first time I hear about ethics in design”* (P2). Despite being a novelty, the educational materials were effective in bringing the topic to the students’ attention: *“The lecture you gave raised some awareness. Since that lecture, ethics has been part of our work in the group”* (P1). Bringing this topic to class also changed some of the students’ perspectives about technology design: *“We thought about ethics, but maybe not in a good way. We did the opposite with the previous courses. We thought: how can we be as evil as possible with this? How can we gather as much data? How can we blackmail the user the most? Now we think the opposite”* (P6). Despite being a novelty, most students were clearly interested in the topic: *“I have not thought about it, but as soon as I read it, I was like, okay, this is important, it is something that I really want to address because ethics is something that I care about”* (P11). Some also expressed an interest in learning more: *“I would like to see more about it because I am interested as a person”* (P3). Overall, these findings indicate that the educational approach was efficient in raising the students’ awareness of the topic.

3.2 The principles helped to identify ethical concerns

The interviews show that students understood how their prototypes could be designed to consider ethical aspects. In particular, issues of transparency and choice were often mentioned by the students as elements they have re-considered: *“We tried to add more things to the smartwatch regarding transparency and freedom of choice”* (P4). One of the students also mentioned adding more privacy settings to the design proposal: *“We were thinking that being able to know what you are showing and what you are not and having more settings, because, in the first app that we made, we did not have settings”* (P11). Harm to well-being was another concern tackled often by the students in their design process: *“The whole point is trying to make the users not feel bad if they have not done something they should have done. The notification could like tell them to go out for a walk without trying to make them feel bad and just try to stay positive”* (P10). In addition, when asked how they approached the evaluation of their prototypes, students reported that they used the templates as a guidance: *“Going through the checklists. It was quite informative, it made it quite clear the things we should be looking for”* (P1) and *“What we did was to use the templates, and that is how we learned how to do it. Without the templates we would not be able to know what to change”* (P5). The use of normative principles, therefore, appear helpful in helping to identify specific ethical issues.

3.3 Ethical design was a new topic to many students

A lack of previous knowledge on ethics was raised by the students as a source of insecurity when making decisions: *“I feel hesitant, doubtful, concerned because I have never heard of the topic before. Of course, it is something important, but I never thought about it”* (P2). Missing specialised domain knowledge that could help to make ethical findings actionable was also an issue for some: *“We felt a lack of knowledge*

because in this particular case, we need a doctor to say what is more important. Maybe it could be nice to have more health information because we know it is something we should take into consideration but as we do not know the potential damage” (P4). Similarly, one of the students felt unsure about how to attend to disabled users’ needs: “How to include the handicap? I think it is important, but I have no idea how. You must be the blind person to understand the blind person” (P2). Another student did not know how blind users could use mobile apps: “One of the comments that we kept getting when we were reviewing each other’s solutions was that blind people would not be able to use this but are blind users even able to use apps?” (P1). Such findings indicate that despite the ethics lecture, they may still need more info in the course to grasp the concepts.

3.4 Ethics was perceived as an antagonist for success for some students

In contrast with previous themes, a few students were not entirely convinced that ethics should be a priority to design: “I think it was a good add on to the course, but I do not consider it being a high priority” (P1). These students believed that ethical ideals could conflict with business growth: “I think it is rather unrealistic to incorporate ethics in such a corporate area. How would you ask big corporations or developing companies to be more aware of ethics if it is clear that their primary concern is money?” (P2). In particular, a student remarked how ethics could be a barrier to profit: “Data is money, and all I ever wanted is to make money. So we need all the data even if you do not want to share it, that was our app’s logic: money” (P7). Aligned with this finding, a student stated that getting a high grade was, in fact, the primary motivation to engage with the subject: “In the end, we were caring about a good grade, so I am not going to lie this was the reason behind” (P3). Such negative views of ethics illustrate the resistance of a few students to consider the importance of the topic.

3.5 Group members had conflicting views at times

As the students were working in a group, social dynamics played a role in how discussions were held, with many students stating it was sometimes difficult to reach agreements: “We have been able to agree on many things, but we are a group of people who do not know each other very well so we do not always turn out super compatible. It is hard to say: ‘I think you should change all the work you just did’ ” (P12). Some also reported that their group members did not consider the topic important, leading to a conflict of interest: “We were more interested in it than the others. It is not that they were against it, they just did not care” (P12). As an attempt to handle disparate views, one of the students mentioned that when conflict arises regarding the ethical implications of a certain UX design choice, the group decides to ask for feedback from end-users or peers: “The moment one has a question and asks the group, but we cannot agree in a few minutes, we decide to validate the concept with others” (P5). This lack of alignment within teams is another challenge to teaching and learning ethics in design projects.

3.6 Time pressure was a source of frustration

The fast pace of the course and the requirement for weekly deliverables, where time on purpose becomes a scarce resource and thus forces the student to prioritise hard, were nevertheless barriers to deeper discussions: “At that point, we were too busy and concerned with the next hand-in. We were just going to leave it because we did not have much time. We were not making great philosophical discussions about

everything, but if we had a longer time frame, we could do it” (P2). In order to be more efficient within the time frame, one of the students suggested that seeing more examples could help making faster decisions: *“Maybe we could see some examples of how to implement it more quickly” (P3).* Besides lack of time, some students wished they had started considering ethical aspects at the beginning of the project, not as an after-thought: *“It felt stressful and frustrating because it was late in the process, and I feel like that is something that should have come earlier” (P11).* Therefore, time management was a significant factor in deciding whether to engage in ethical reflections during the course.

4 DISCUSSION

The educational approach evaluated in this paper was effective in raising students’ awareness, which is in itself a very favourable outcome for classroom activities about ethics (Skirpan et al., 2018; Saltz et al., 2019). Results show that the selected set of normative principles was a helpful structure for analysis, as the principles functioned as reference points guiding the students’ creative process. A previous study evaluating a similar framework of ethical questions for machine learning also found that a list of ethical questions acted as a catalyst to students’ debate (Saltz et al., 2019).

Findings also provide evidence that the students can make some ethical design decisions once instructed. Such reports of applying ethical thinking to the design of prototypes are not usual in the literature on ethics. An exception is perhaps a previous study that observed how students re-shaped their design concepts after experiencing the vulnerabilities of data collection and visualisation firsthand (Shapiro et al., 2020). As the goal of ethics education in computing is to provoke change in future technological developments, ethical insights should lead to observable outcomes in the design process (Barry et al., 2020; Bauer et al., 2017).

Despite such supportive indicators, the study makes evident that students faced challenges. Even though disparate views can support debate and reflexivity, students could not perceive the group conflicts in such a positive light. Previous works have discussed that methods for ‘ethical mediation’ are critical in decision-making so that arguments from conflicting views can be taken into account during team discussions (Gray et al., 2019), and our findings support the need to include that in the classroom. Past research has also highlighted that putting ethics in action is a demanding task, requiring an empathetic mindset, attentive to situational complexities (Frauenberger et al., 2017; Munteanu et al., 2015). Such a deep type of reflection can take time, and our observations indicate that it can be challenging to achieve more ethical design if time is too limited of a resource. Obstacles with group dynamics and time prioritisation should still be used as pedagogical tools to prepare students for situations that may appear in their workplace, but course structures should consider including more concrete examples and tools to help students navigate the constraints of a design process more productively.

Findings also confirm previously discussed shortcomings of pre-defined checklist items and the limitation of atomistic normative frameworks. As previous research with employees working with artificial intelligence has argued, co-designing checklist items as a team is a more effective approach than providing professionals with pre-made broad guidelines (Madaio et al., 2020). However, checklists and normative principles may as well do not function as tools enabling more comprehensive ethical thinking,

rather becoming manual tasks to be completed without genuine reflection. For this reason, if an approach based on lists of ethical principles is chosen, it is important to consider how to complement the method with other design inquiry methods, such as active stakeholder involvement and speculative prototyping (Friedman and Hendry, 2019).

Furthermore, results indicate that a one-time lecture and a prototyping assignment may not be sufficient to fill existing knowledge gaps. In fact, it has been argued that ethics education would greatly benefit from acknowledging the need to expose students to a diverse range of disciplines, skills and methodologies related to the topic throughout their studies (Raji et al., 2021). Aligned with such perspective, previous studies have proposed empathy-building tools and role-playing as ways to increase sensitivity to issues that are beyond a designers' lived experience, thus adding to their capacity to relate to their users (Sas et al., 2020; Honary et al., 2018; Matthews et al., 2014). The importance of empathy development is particularly relevant in the case of students who believe that technology should be "as evil as possible" (P6), as they might not have realised that, in the future, they might be victims of malicious technologies they built by refusing to act in solidarity with their users in the present.

Moreover, the analytical stance deployed by the students in this particular study is not the only way to engage with ethics. Active involvement of different stakeholders through participatory and emancipatory research methods are other options that can be used in UX education. An example is a study reporting on how the collaboration with communities and non-profit organisations was very effective in teaching students how to propose caring design concepts, more attuned to users' needs (Sabie and Parikh, 2019). Still, even though consulting others may be a way for students to seek different perspectives, it can also become a shortcut for making decisions without genuine reflection, which should not be the goal.

Regardless of the educational approach chosen, findings suggest that some misconceptions need to be addressed first if students are expected to produce concrete ethical designs in class. It is not easy to know exactly why some students seem to care less about ethics than others. However, a previous study on ethics education has found that students usually do not see themselves as political agents responsible for ethical work (Petelka et al., 2022). Previous works have brought to attention that engineering students may never come across topics of ethics during their education, which further complicates this problem (Saltz et al., 2019). The combination of standalone modules and the insertion of activities about the topic in multiple technical courses across secondary education programmes might prove to be the most effective approach in the long term, as advocated by previous research (Garrett et al., 2020). It is also fundamental to keep probing strategies for the challenging quest of turning indifferent students into caring ethical agents in their future careers.

4.1 Limitations and Future Work

This pilot study has methodological limitations. The fact that only students who volunteered to participate were recruited means that findings may not reflect the perspective of the whole class (sample bias). In addition, the empirical data comes from the students' reports of their experiences in retrospect, which can result in recall bias. Another limitation is that students had to share their views to one of the

class tutors, which might have blocked the disclosure of opposing opinions despite our efforts to stay open to their feedback (acquiescence bias).

In order to complement and build upon the observations reported in this study, future work could consider the direct observation of students as they work on their projects and the discussion of the produced artefacts as additional empirical sources, as a way to evaluate the impact of the course based on the changes students bring into their processes. Further studies could also examine the preferences of students regarding different ethical frameworks, such as ethics of care. Finally, future research could consider more objective measures for the evaluation of pedagogical efforts, such as questionnaires and examinations.

5 CONCLUSION

This pilot study had the goal of learning from the experience of introducing students from a technical university to the concept of ethical UX design. Results were very insightful as they showed in practice the limitations and benefits of our approach. With the lessons learned through this study, we contribute to future pedagogical efforts to teaching ethics for UX design as the explicit statements from the students are powerful indicators of the challenges of teaching HCI ethics.

In summary, even though the educational materials could effectively raise awareness and guide some ethical decisions in the project-based learning setting, challenges remained. Some students seemed sceptical about the applicability of ethics in technology, and lack of interest was a significant barrier to a genuine engagement. Gaps in engineering education also became apparent as students reported feeling insecure with their knowledge on the topic. Students also claimed time pressure and group dynamics as obstacles to more profound reflections that could lead to user interface designs that respect human autonomy, promote well-being and broader access to digital innovation.

Such findings emphasise the need to expose students more often to a more diverse range of teaching methodologies, design skills and ethical philosophies throughout their engineering education. With the broader recognition of complex moral dilemmas by the media and digital technology consumers, ethics education has become imperative for future professionals and it consists of one of the most critical design aspects of digital health interventions. Efforts to include topics on computing ethics in teaching materials should be encouraged, and the way these materials are delivered should be mindful of the challenges discussed in this paper.

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Supplementary Material

1 TEMPLATES

The following templates were provided to the students as examples of how to use the five normative principles explained in class. The first template is an expert checklist created to help the students verify if their design proposals attend to the principles and then reflect on how their prototypes could be improved. A second template is a form for collecting peer (or user) feedback, also contemplating the same five items as the expert checklist, but meant to consult others outside of the design team. The templates served as guidance to the students' assignment on evaluating the ethical dimension of their work.

1.1 Expert Checklist

- Choice:
 - The system allows users to choose and select their preferences
 - The system does not force single options to users (example: I accept)
 - The system allows users to change their mind and select a different option later
- Transparency:
 - The system provides enough information about how it works
 - The system is transparent about how data is used and shared
 - The system does not hide important information on purpose
- Well-being:
 - The system is designed to help users to improve their well-being
 - The system does not make users' well-being worst (example: by making them anxious)
 - The system provides direct support to users in case they suffer physical or emotional harm
- Inclusion:
 - The system is directly targeted to attend the needs of at least one marginalised group
 - The system does not exclusively target only over-represented groups
 - The system does not exclude people of different races, disabilities, gender and cultures
- Reciprocity:
 - The system is useful by offering direct and significant benefits for the users
 - The system does not use manipulation techniques to get users to spend money
 - The system is not built to take advantage of users for business gains

1.1.1 Peer Feedback

From not at all (0) to completely (7), how much do you think the system...

1. ... allows users to choose and select their preferences? Why?
2. ... is transparent and clear about how it works? Why?
3. ... promotes well-being and protects users from harm? Why?
4. ... can be used by diverse races, gender identities and physical mental abilities? Why?
5. ... provides mutual benefits for owners and users without manipulation? Why?

2.8 What is the Future of Data Sharing for Research?

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What Is the Future of Data Sharing for Research?

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Digital data collection for health research usually follows well-established methods. In many of the labs that work with mobile sensing, research subjects are provided with consent forms, task instructions, and sensor devices or apps. Once the research subjects agree to participate, the expectation is that they will comply with the procedures and allow their lives to be digitally tracked. After that, they are usually dismissed.

Even though participants are such a vital part of scientific discoveries, they are often considered objects to be observed—one more entry in a database. Such well-established ways of placing those being monitored into passive roles have gained even

more prominence. With the surge of Covid-19, there has been a noticeable increase in initiatives for health surveillance. From contact tracing to apps that monitor daily symptoms, the pervasiveness of smartphones is being exploited to collect data from large segments of the population. It is a blossoming field for those who work in this area, as the urgency to

Aggregated data might mean better healthcare now and in the future, but it is also a tool for power and mass control.

understand this illness is pushing mobile sensing in ways never before seen.

Given this sudden demand for broader behavioral monitoring, the debates over population-level surveillance have gone mainstream. In the particular case of contact tracing, academics are now discussing issues of individual privacy, the consequences of false positives (and negatives), and the actual efficacy of such an approach [1]. On the other hand, the media, governments, and tech companies are claiming that transmission speed may be reduced only if a significant part of the population is monitored continuously. Contact tracing has been enforced in countries in Asia and framed as a way to “help authorities identify virus hotspots and better target health efforts” [2].

By providing arguments that surveillance is the right path for recovery, governments and the media are forging a positive-only view of the subject. A consequence of the support for contact tracing and other symptom-tracking approaches could be a radical change in how people perceive privacy threats and accept being monitored for the “public good.” It could be speculated that efforts from the public sector and big corporations to convey the benefits of surveillance could lead the masses to believe this one-sided version of the story, without weighing its risks. Decisions about disclosure are known to involve a trade-off. If the perception of social or individual benefits is stronger than the identified possible risks, people are willing to share sensitive information [3].

If a shift toward more public acceptance of health surveillance indeed prevails, national-level repositories of the mobile-sensing data could also become very attractive to governments and scientists [4]. Large-scale platforms containing information such as clinical diagnoses, mobile-sensing data, and behavioral tracking data could allow incredible epidemiological discoveries. Before Covid-19, the landscape of such platforms was dominated by genetic bio-banks and clinical-trials repositories. Mobile-generated data was still a novelty. Nowadays, massive centralized data centers containing information about thousands (or millions) of individuals are growing around the world, such as All of Us (<https://allofus.nih.gov/>) in the U.S. and iCarbonX (<https://www.icarbonx.com/en/>) in China; they include digital sensors as a data source.

However, if a shift toward more acceptance does not prevail, large-scale surveillance will be at risk of low cohort diversity. First, to derive significant and fair conclusions from a dataset, a diverse range of people with different characteristics is required. Unless most of the population is tracked, the knowledge acquired will not be representative and may benefit only those who were available and agreed to be monitored. As Daniela and Nicole Rosner discuss in this issue, “prioritizing the most likely to be reachable tends to benefit well-educated white people who have already long benefited from the healthcare system” (page 76). What can HCI, UX, and technology design practitioners and academics offer to facilitate more inclusive recruitment for data platforms? What knowledge, tools, and evidence have we produced (or can we provide) that can be useful in this context?

Besides inclusive recruitment, the search for public acceptance should not overwrite the need to consider possible impacts on all segments of the population. Individuals from different backgrounds might have a different understanding of potential privacy risks, and people with stigmatized clinical diagnoses might suffer from the consequences of a data leak asymmetrically [5]. Broader acceptance should not result in less public diligence about privacy and how data can be abused. Such individual differences need to be taken into account because ill-intentioned initiatives may lure people with the promise of future advances in research, but come with a hidden agenda [6]. As Christopher Frauenberger writes in this issue, “We

might see the coronavirus serving as the scapegoat to implement modes of mass behavior manipulation by private companies” (page 74). How can HCI knowledge and approaches be used to support and protect citizens from these scenarios? Can HCI help overcome the uneven understanding of risks and help tackle vulnerabilities in case of privacy breaches?

are given to those who store the data, not to those who provide it [4]. This serves to strengthen the already existing inequalities between contributors and receivers.

The most significant change that the pandemic should bring is not that surveillance becomes more broadly accepted. A real change would be to see those proposing surveillance platforms finally placing



Singapore, May 2020: Man at Rower's Bay Park scanning a QR code via SafeEntry, a digital contact tracing tool.

As mentioned earlier, digital data collection for health research often follows well-established approaches. The pandemic has brought more attention to the subject of population surveillance, as seen in the reflections from Rosner and Frauenberger. However, the Covid-19 emergency has not changed the passive role attributed to those having their symptoms and contacts monitored. Most of the decisions about what data will be tracked, how it will be used, and who will have access to it are made from the top: by governments, health authorities, research institutions, and big corporations. When data repositories are built this way, power and knowledge

citizens at the core of their decisions, by listening to their concerns and providing them with direct protection and benefits. If people are to be asked to open up their lives for health surveillance or research, they should be respected, and their preferences prioritized. It is about time we put more efforts into understanding the needs from the different segments of the population and design for more inclusive participation and agency in research. The well-established approaches for data collection do not suffice anymore, as behavioral monitoring is being considered at a national level. Aggregated data might mean better healthcare now and in the future, but it is also

▶ A RESPONSIVE KIND OF DESIGN



Aarogya Setu, an app developed by the government of India to track Covid-19.

a tool for power and mass control [6]. The path to reach acceptance should involve respect, transparency, and an ethic of involvement by communities from all backgrounds [7].

More than ever, those who are in public, academic, and industry positions hold the responsibility of taking into account any potential for harm that novel ideas can bring to each individual. This pandemic, or any other alarming situation in the future, should not mean that moral principles and personal autonomy are put aside. Large-scale digital surveillance for public health may now gain momentum with contact tracing. Still, we need to keep reflecting, discussing, and pushing for an ethical development in the field, through the papers we write, the products we build, and the ideas we share with others.

The pandemic has been a challenging time in many aspects, but it can also mark a moment when meaningful changes began. It forced many to stop, and some to reconsider how things have been done until now—and how different they could be. From this process, hopefully, a brighter future can emerge for data sharing, health surveillance, and research

platforms alike—a future in which acceptance does not mean renouncement of rights and values, but rather a conscious choice based on terms and conditions that are negotiated and never imposed. This should become the new normal. The next advances in data-collection practices depend on us, researchers and designers in the HCI and health tech field, as we

choose how we conduct our own projects and support those of our community.

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