

Understanding and Improving Human Data Relations

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1 Introduction

“My data is everywhere, and I am nowhere.” – Imogen Heap (musician and digital rights advocate), speaking at MyData 2019.

1.1 Background and Motivation for this Research

We live in an increasingly **data-centric** world, where direct and indirect interactions with computer systems depend upon the collection, storage and use of personal data about individuals. Motivated to reduce costly human interaction and scale to serve more customers, organisations **capture and represent individuals as data** and rely increasingly on the **interpretation of those datapoints to make decisions** - decisions that affect our everyday life in myriad ways, from determining eligibility to access particular services, benefits or products or targeting advertisements or recommendations to influence how people behave. Thus, data about people has become extremely valuable; *‘the new oil’* (Toonders, 2014) at the core of a model of **surveillance capitalism** (Zuboff, 2019) that extracts and exploits data for profit.

This multi-party use of data has resulted in a splintering (Lemley, 2021) of our ‘digital selves’ across hundreds of different organisations’ computer systems, creating “*a chaos of multiplicity*” (Bødker, 2015) where data becomes **trapped** (Abiteboul, André and Kaplan, 2015) and hard to manage. Current data practices **cause harm to individuals** through anxiety, distraction and a sense of being overwhelmed (Fu *et al.*, 2020; Timely, 2020). Many people believe **data use harms society too**, due to the ease with which people’s attention and beliefs are manipulated, risking radicalisation and a loss of democratic freedom (Thompson, 2011; Chan, 2019). It is generally accepted that there is **a power imbalance** “*in the amount of information about individuals held by industry and governments, and the lack of knowledge and ability of the same individuals to control the use of that information*”(Hoffman, 2014).

To address this power imbalance, people need to achieve **a more effective relationship with their own data**. This has been conceptualised as a lack of *agency* (the ability to act for oneself), *negotiability* (the ability to exert influence over data use within the system as things change), and *legibility* (the ability to understand one’s data and its implications) (Mortier *et al.*, 2014). Currently, users of today’s digital services typically experience a ‘*point of severance*’ (Luger and Rodden, 2013): they are forced to sacrifice their data and are then cut out of the loop. Without understanding of how they are currently seen through data, people **face risks of unfair treatment, or physical or psychological harm** (Bowyer *et al.*, 2018). Left unexplored and unchallenged, the situation will not improve, as the datafication of society grows, and user agency continues to diminish.

This thesis focuses on the apparent power imbalance and explores ways in which individual agency, legibility and negotiability can be improved. First, through academic inquiry, it makes a novel contribution to knowledge, examining deeply how people relate to data, what capabilities people need, and how they would like service providers to handle their data. The thesis takes a broader perspective than current work in the field of Human-Computer Interaction (HCI), which tends to focus upon the mechanisms by which humans interact with data without considering the problem of asymmetric power over data from a sociotechnical perspective, which is necessary if societal benefits are to be achieved.

1.1.1 Personal Motivation and Context

[TODO update per JG feedback - split into short motivation here, and longer reflection later (8.1)]

This PhD and this thesis represent the culmination of my lifelong passion to help people get more value from our computers. Over 30 years ago, I learned from an early age about computers by programming my Acorn Electron, one of the many 1980s home computers that taught their users that the computer was a tool to be exploited, one that you could master and bend to your will. In my formative years at University and beyond, I lived through the birth of the public Internet

and marvelled at the ability for computers to connect people across the world, empower individuals as creators, innovators and broadcasters, level the playing field and transform the way people interact. Keenly tracking and embracing the Web 2.0 revolution while observing the digitisation and disruption of so many industries, I became fascinated with the ways in which humans were shaping computer systems which in turn were shaping our habits and our society.

As a graduate software engineer at IBM in the 2000s, I podcasted about new ways to be more productive with computers, and participated in an innovation club with colleagues imagining new ways to relate to digital information, and I gradually moved from back-end development to front-end development to user experience, getting closer to a place where I could help end users benefit from technology. From 2009-2011, while working in Canadian startups, I founded and was a lead writer on a blog called Human 2.0¹, examining the inter-relationship between society and emerging technology. I was witness to a changing world, where we were gaining new capabilities, but also, through the digitalisation of businesses and the shift to data-centric cloud-centric business models, losing our agency to harness computers for our own ends. I presented short talks on my developing ideas about these changes and what better human data interaction might look like four times at Bitnorth conferences² and had essays published at O'Reilly Radar (Bowyer, 2011) and in print (Bowyer, 2012).

Despite seeing further potential for smarter, more helpful computer systems through my participation in the Semantic Web community and being a senior developer of semantic text analysis software at Open Text, by 2014 it was beyond doubt to me that the software industry had lost its way, prioritising business goals over user agency, reducing features and creating technology designed to limit and corral users to behave in certain ways. Web 2.0's revolutionary potential of a 'people's internet' was squashed and withered away in the face of new data giants Google, Facebook, Apple and Amazon and their reshaping and usurping of Internet and smartphone technologies. Against a backdrop of a social media revolution which was literally breaking society and democracy to further the pursuit of profit (Tufekci, 2017; Hall, Tinati and Jennings, 2018), I took the leap to escape corporate, for-profit IT in order to seek ways to research, design and help to build a better digital future, with the objective of making computers useful again. This led me, via a web science architect position at citizen science platform Zooniverse that gave further understanding of user motivation and of the power of collaboration around data, to join the Digital Civics CDT programme (Open Lab, 2014), where I was finally able to work full-time on this most important of problems – understanding and improving Human Data Relations.

It has been a tremendous privilege to spend six years understanding in great detail the nature of the problems facing our data-centric society, to map those impacts into tangible needs, and to be able to map out the landscape for improving

¹Archived at <https://web.archive.org/web/20111231165329/http://www.human20.com/>

²<http://bitnorth.com/shortbits/>

the way we relate to data. As well as allowing me to discover grounded evidence to quantify and qualify the losses of agency I had observed and theorised, this programme has given me space to experiment with using both GDPR and web-scraping to access data and push boundaries, and to design and prototype new models and views of data and of information which have transformed the way I look at digital information and how we relate to it, and which I hope can help others in the same way. Looking forward, this opportunity has opened doors that have enabled me to begin to put these learnings into action, working on important projects [see 7.1.1] with Connected Health Cities, BBC R&D, and Hestia.ai to explore how data interaction reforms can be realised in practice, and how we can come not just innovators but social data activists to begin to have an impact and to build that better future. It is the journey of a lifetime, and also one that is in many ways just beginning. I hope that my work and this thesis can, in some small way, contribute to a better, more human-centric digital world, and I can't wait to see where this leads.

1.1.2 Research Objectives and Purpose

The aim of this thesis is to research **how people relate to data**, how they understand and use it, and **what they need from it and its holders** in order to thrive and to meet their own goals.

The thesis is informed by a constructivist ontology and a pragmatist, individualist epistemology [3.1], and employs a multi-disciplinary *Digital Civics* (Vlachokyriakos *et al.*, 2016) approach, conducting an academic inquiry to answer two key research questions (RQ):].

C11: Guidance for policymakers, data holders and individuals on how to improve HDR

Synthesis and analysis of participant experiences in Case Study Two enabled the production of specific guidance [5.5] for parties involved in data relationships:

1. Policymakers and DPOs should do better at **enforcing GDPR rights**, and regulate to **improve response quality** and legislate to mandate data holders to **support data subjects in understanding data**.
2. Data-holding service providers should **improve transparency** over data and data handling process, and could seize the opportunities of **more inclusive and collaborative models of individual data access** to improve trust, empower users and reduce their own liability.
3. Individuals should recognise the critical role of held personal data in modern life, embrace opportunities to **access and exploit their own data** and **use data access rights to hold service providers to account**.

C12: A proto-methodology for educating individuals about held data, data access and the data ecosystem

While it was not designed as a methodological contribution nor formally evaluated as such within the scope of this thesis, the guided-data-retrieval-and-

interview approach of Case Study Two [5.2] has proven to be **highly valuable and replicable** as means to connect people with their held data and conduct research at that intersection point. Indeed my creation of this methodology was the primary reason why I was approached and employed as lead researcher of Hestia.ai/Sitra’s digipower investigation (Härkönen and Vänskä, 2021), which **adopted Case Study Two’s methodology**, with some adaptation and broadening of scope, for an important EU study auditing and understanding the power of data holders in the data economy (Bowyer, Pidoux, *et al.*, 2022; Pidoux *et al.*, 2022; Härkönen *et al.*, 2022).

1.2 Publications arising from and connected to this research

[TODO address JG feedback]

1.2.1 Pilot Study

My Doctoral Training programme at Open Lab began with a Masters in Research in Digital Civics. For my MRes project³, I conducted a pilot study, interviewing and exploring issues around data with families who had experience of social care services. During the first months of this PhD, I conducted new analysis of the data collected, resulting in the synthesis into a full first-author paper published and presented at CHI 2018:

- “Understanding the Family Perspective on the Storage Sharing and Handling of Family Civic Data” (Bowyer *et al.*, 2018)

This study is given a special status in this thesis; while it is not officially to be examined, it plays a critical role as a pilot study for Case Study One and its findings and insights are built upon in Chapters 4, 6 and 7. The paper is included in full in Appendix A.

1.2.2 Primary Case studies

1.2.2.1 Publications from Case Study One The work exploring shared data interaction in Early Help carried out in Case Study One has been initially published as an Extended Abstract at CHI 2019:

- “Human-data interaction in the context of care: Co-designing family civic data interfaces and practices” (Bowyer *et al.*, 2019)

This work was also presented at the conference in the form of a poster, which is shown in Figure 1.1. A full journal paper of Case Study One is in prep.

1.2.2.2 Publication from Case Study Two The work exploring the human experience of GDPR data access carried out in Case Study Two has been

³MRes result awarded: Distinction.

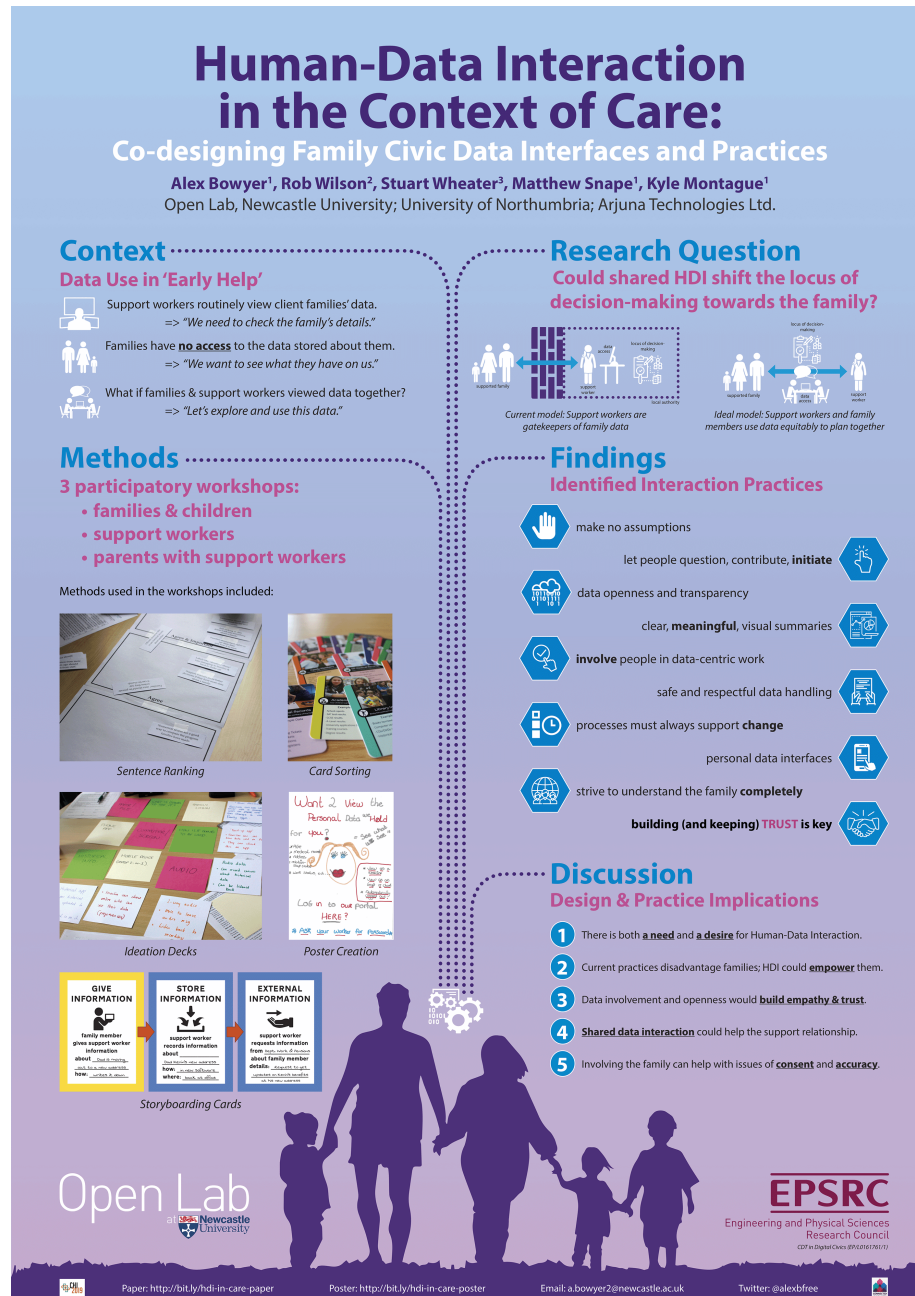


Figure 1: Figure 1.1: Poster Presentation of Case Study One

published and presented as a full first-author paper at CHI 2022, where it was awarded an *Honorable Mention*:

- “Human-GDPR Interaction: Practical Experiences of Accessing Personal Data” (Bowyer, Holt, *et al.*, 2022).

I carried out all field research myself. Data analysis and paper writing were jointly executed by myself and Jack Holt.

1.2.3 Workshop papers & presentations

During the PhD, I gave a number of additional presentations and published three workshop papers which included material from, or directly contributed to, this thesis and its arguments.

- “Designing For Human Autonomy: The next challenge that civic HCI must address” (Bowyer, 2017) - a short talk I presented to my peers at Open Lab in January 2017 laying out the landscape of reduced agency and possible avenues for improving humans’ relationships to their data that my PhD would explore;
- “Free Data Interfaces: Taking Human-Data Interaction to the Next Level” (Bowyer, 2018b) - a CHI 2018 workshop paper formalising my pre-PhD design thinking and outlining a vision for unconstrained and useful data interaction interfaces;
- “A Grand Vision for Post-Capitalist HCI: Digital Life Assistants” (Bowyer, 2018a) - a CHI 2018 workshop paper where I imagined a form of digital computer assistant that is far more helpful and human-data-centric than the digital voice assistants of today;
- “Personal Data Use: A Human-centric Perspective” (Bowyer, 2020) - in early 2020 just prior to the pandemic, I was invited to give lectures on my research to undergraduate students at both Northumbria University and Newcastle University;
- “My Thesis in 3 Minutes: Understanding and Designing Human Data Relations” (Bowyer, 2021b) - in April 2021, I presented my thesis in Newcastle University’s 3 minute thesis competition, and was co-winner of the people’s choice prize;
- “Human-Data Interaction has two purposes: Personal Data Control and Life Information Exploration” (Bowyer, 2021a) - A workshop paper I presented at CHI 2021, where I first outlined my model of the two motivating factors for interacting with personal data.

1.2.4 Publications from other work

During the same timeframe as this PhD, I have also contributed to a number of publications tangential to my primary research agenda:

- As a researcher and developer on the Connected Health Cities SILVER project [3.4.1.1], I contributed to work published through Newcastle Uni-

versity’s internal report to CHC (not publicly available) and the overall impact report (Connected Health Cities, no date, pp. 129–130), and more directly published demonstration videos (Bowyer and Wheeler, no date) of a health data interface prototype developed by myself and Stuart Wheeler.

- As a researcher and developer on DERC’s Healthy Eating project, I developed interface prototypes (no longer online) and was co-author to two research publications at BCS 2021 (Goffe *et al.*, 2021) and in *Interacting with Computers* (Goffe *et al.*, 2022).
- As a research intern on BBC R&D’s Cornmarket project [ADD REF], I published an internal research report[ADD REF] into personal data store design, as well as a ‘stimulus presentation’ to launch an internal hack week and a BBC blog article about the work (which was not officially published) [ADD REF].
- As project leader, data access coach and researcher at Hestia.ai, I was a lead author on a research report auditing the data economy (Bowyer, Pidoux, *et al.*, 2022), and co-author on a research report on power mechanisms in the data economy (Pidoux *et al.*, 2022).

1.3 The structure of this thesis

[TODO address JG feedback]

The overall structure of this thesis is illustrated in Figure 1.2. This introduction is followed by a literature review [Chapter 2] and a methodology chapter [Chapter 3]. Both research questions RQ1 and RQ2 are examined in both Case Studies, and these studies are documented as self-contained pieces of research in [Chapter 4] and [Chapter 5] respectively. In [Chapter 6] the findings and insights from the Case Studies are synthesised into common findings as to what people want from data and from data holders, which concludes the academic investigation of the two research questions. [Chapter 7] looks beyond the theoretical to the practical, setting the stage for future research and innovation in the HDR landscape, building on both the research conclusions in Chapter 6 as well as my practical experiences from other related research and development activities conducted outside of this PhD research but during the same timeframe. Each chapter finishes with a summation section. Chapter 8 concludes the thesis.

Chapter 2 is a literature review divided into three key sections. The first [2.1] examines the difference between data and information, outlines the central role data has taken in our society, why people need effective access to their data and how laws have been introduced to try and deliver this. The second [2.2] serves as history of personal data interaction, from Personal Information Management to the emergence of complex digital lives involving relationships with many data-holding providers. Finally [2.3] charts a path from HCI and Human-Data Interaction foundations through to the embracing of sociotechnical thinking around data and the current bleeding edge (Collins Dictionary, no date) of human-centred innovation, leading to the primary academic Research Question (RQ) of this thesis: “*What relationship do people need with their personal data?*”

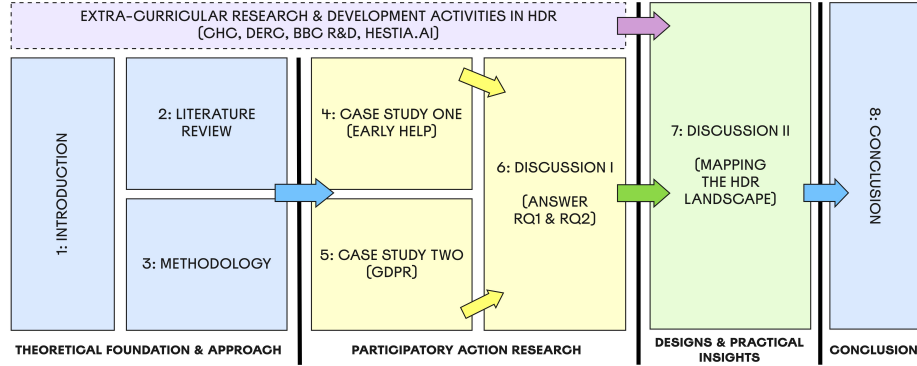


Figure 2: Figure 1.2: The Structure of This Thesis

[2.4].

Chapter 3 describes the methodology used in this research, explaining first the constructist ontology and pragmatist epistemology behind the approach [3.1]. Then the choice of participatory action research and co-design from a Digital Civics standpoint is explained [3.2]. The two research questions (RQs) are explained in more detail [3.3] and the contexts for the Case Studies are introduced from a personal ‘what did I do?’ perspective [3.4]. Finally the specific methods and techniques adopted in the research are explained and illustrated, including sensitisation, workshop activities, recruitment strategies and modelling [3.5].

Chapter 4 is a detailed, self-contained account of Case Study One. This begins [4.1] with a detailed introduction to the UK’s Early Help social care context, including its history of data-centrism and the inherent contradiction between that and the empowerment goals of Early Help which make it an ideal setting to explore my research questions. In 4.2, prior findings on family and staff perspectives are introduced, motivating the ‘*Shared Data Interaction*’ vision and structure of the workshops, whose participants’ shared values are introduced. The thematic findings are detailed extensively [4.3] including participant quotes, and then contextualised in the discussion [4.4] in terms of the value of involving people with their data, the link between HDI and effective data access, and the implications of shifting the locus of decision-making.

Chapter 5 is a thorough and self-contained write-up of Case Study Two. The first section [5.1] provides additional context on the need for data access, prior GDPR research and the human-centric approach to this study, whose design and configuration is detailed in 5.2. Findings are shared: firstly [5.3] the largely quantitative outcomes of the participants’ GDPR requests, interview responses and trust/power scores, then the thematic findings 5.4, illustrated with participant quotes. The discussion [5.5] contextualises and synthesises the findings into human-centric, GDPR-improving guidelines for policymakers, data

holders and individuals.

Chapter 6 synthesises the two case studies, and answers RQ and RQ2, bringing the thesis’s central academic research to a close based on findings and discursive insights from both studies backed by literature references. The answer to RQ1 is provided [6.1] as people’s three wants from direct data relations (for it to be visible, understandable and useable), and the answer to RQ2 is provided [6.2] as people’s three wants from indirect data relations (process transparency, individual oversight, and involvement). The chapter concludes [6.3] by outlining this thesis’s perspective power and positioning the pursuit of these six ‘*data wants*’ as *empowerment* relative to that perspective and thus as ‘*better HDR*’.

Chapter 7 looks beyond the original research question, and is a deliberately broad, shallow and open-ended chapter synthesising designerly insights acquired through practical experience. Here I move beyond a traditional thesis structure, with the goal of providing real-world ideas on *how such human-centric empowerment might be achieved in practice*. In tackling this more practical question, the thesis becomes a *valuable and actionable anthology of reference material* for future researchers, activists and innovators. First [7.1], the peripheral contexts that I worked in alongside this PhD from with the additional insights arise are introduced. In [7.2], the findings of the thesis are expanded upon to frame the pursuit of this thesis’s ‘*data wants*’ as a defined field of future research, called *Human Data Relations* (HDR), whose practitioners act as a *recursive public*, pursuing four ‘*landscape objectives*’ that could address the data wants in reality.

The landscape of HDR is mapped out in two parts. First [7.3], I outline the identified *obstacles* to pursuit of the HDR objectives. Then [7.4], using a *Theories of Change* (ToC) framing, my identified *opportunities for progress* are introduced, divided into *four different trajectories of change* that could be executed to pursue better HDR. 7.3 and 7.4 are interspersed with actionable *insights* that could help tackle the obstacles and pursue the change trajectories. 7.5 is a summation of the chapter.

Chapter 8 is a brief conclusion of the thesis, summarising its contributions and positioning HDR and this thesis as call to arms for activist research and innovation that can tackle the power imbalance in society. [TODO check this once Chapter 8 is split out separately]

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