

Understanding and Improving Human Data Relations

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1 Methodology

“Research is defining the invisible.” —Steven Magee (author and researcher)

In the previous chapter, I described the two research areas this thesis seeks to explore: how people think about data and what they want from it; and the role data takes and should take in people’s relationships with organisations. In this chapter, I will explain my approach to conducting research in this area, detail

the types of methods used, and explain how the different research activities I carried out contribute to the research objectives.

1.1 Forming a Research Paradigm: Ontology & Epistemology

To develop a research paradigm, one must reflect on two things (Guba, 1990):

- *ontology*: your outlook on the nature of reality, and
- *epistemology*: your beliefs on how knowledge of that reality is formed.

It will already be evident to the reader that individual human experience is at the forefront of my thinking. I believe that everyone experiences their own reality, informed by their own concepts and mental models of the world. This ontological stance, known as *constructivism* (Guba, 1990) argues new knowledge is formed by developing one's own mental models in order to explain new experiences, as distinct from the positivist view that there is a single universal reality one can uncover. In today's rapidly evolving technological landscape, people have no choice but to develop new mental models to make sense of new concepts such as *posts*, *feeds*, *link sharing*, *syncing* and *blocking*, in order that we might find value in them.

This idea that reality is constantly renegotiated by the individual is known as *pragmatism* (Campbell, 2011). People's developing conceptions of reality are not purely an intellectual endeavour though; As *Deweyan pragmatism* states, our knowledge and thinking are tested by actions, not just reason, and that this is how we learn. Communication and interaction with others are key parts of that learning. Dewey recognises that every individual is not solitary, he exists within a society as 'a social being, a citizen, growing and thinking in a vast complex of interactions and relationships' (Dewey and Archambault, 1964). People create systems and meanings through those interpersonal interactions—which they can then use to understand everyday life. This is particularly important in the social world, as unlike the physical, natural world, many concepts are abstract and subject to individual interpretation. This drives my research motivation to understanding how people make sense of their world, and how that changes as a result of their lived experience.

Constructivists tend to believe that people are motivated by a desire to solve problems combined with a confidence to learn (Prawat and Floden, 1994). In this regard, I look beyond traditional constructivism, as I think *individualism* (Lukes, 2020) offers a better explanation. Much though we might not like it to be the case, people are self-interested, pursuing their own individual happiness and wellbeing, and it is this self-interest is what drives the pursuit of deeper knowledge and understanding about the world. In essence, everyone wants to improve their own life, and they need to acquire knowledge about how the world works so that they might be able to change it. This path of acquiring and sharing individual understandings about the world, which can then be used to effect change upon the world, is a key driver behind my research. Taken further, this

can be seen as *civil libertarianism* (Gulite, 2014), which argues for the supremacy of individual rights and personal freedoms over imposition by authority. The human-centric movement [2.3.4] clearly subscribes to this philosophy, as do I, and this explains why my research moves from simply understanding the world in Part One, to functioning as an activist trying to change it in Part Two.

My established ontological stance, then, is that individuals construct concepts, and continually update them through sensory experience, action, and social interaction. They do this in order to maintain a pragmatic knowledge that they can practically exploit to effect change in society and in the world, in order to pursue their own happiness and self-interest.

Looking to epistemology: how can knowledge be acquired? Constructivism suggests that this is best done not through direct observation of the world and explicit testing of hypothesis, but though interacting and communicating with individuals so that we can interpret how they view reality; this is known as an *interpretivist* epistemology (Dudovskiy, 2012). This motivates my choices to favour *qualitative* (understanding perspectives and collecting spoken/narrative data) rather than *quantitative* (measuring behaviours and collecting numerical data) investigation. By understanding people's views and mental models around data and digital living, I can look for commonalities and develop *theories*—powerful explanations that can be understood and benefitted from by ordinary people—to fill the knowledge gaps in existing research that I have identified [2.4]. Given my pragmatic focus on interpreting people's constructed social realities in terms of practical usefulness (in individualist terms: individual benefit) to them, I will not be deeply analysing their words through language analysis techniques like discourse analysis. I will instead focus on the social, interpersonal level—understanding how people navigate the world of data and data-based relationships. I want to explore how they change their understandings as they pursue their goals in practice, and how they are affected by the systems, relationships and society they exist within. This pragmatic approach and search for commonalities motivates a *mixed methods approach* (UK Health Security Agency, 2020), combining qualitative or quantitative methods as appropriate to the particular sub-question being explored.

Thus, my epistemological stance is an interpretive one, that also recognises that in order to identify commonalities and *shared meanings* (Dudovskiy, 2012), the researcher must employ a mixture of qualitative and quantitative techniques.

1.2 Research Approach

1.2.1 Participatory Action Research & Experience-centred Design

Moving from general research philosophy to specifics of this PhD, the purpose of the research is to formulate theories that can facilitate change - to map out a research and development agenda that might help the world to move from a data-centric [2.1] to a human-centric [2.3] operating paradigm. Learning about people's understandings of their reality informs and enables an inductive research

approach where patterns common to multiple people can be identified to form general understandings of what people *want*¹⁰ in relations with data and with those who hold it. Based on the premise of individual betterment laid out above, these desires serve as justification for the thesis to take a moral stance on personal data: That access to data held about you by others is a fundamental right, and that the to empower individuals to be able to understand and use their data for their own purposes is a fundamental good that will benefit individuals and society at large.

As a student of *Digital Civics* (Vlachokyriakos *et al.*, 2016), I believe that research can surface the ways in which current service provisions fail to meet people's needs, and how the world might better empower citizens if it were configured differently with services closer to what they desire. The role of the researcher is to understand the world and to figure out how to change it. It is an accepted view that research cannot be value-free, but in fact we can go further. The researcher can be an activist, seeking to correct an imbalance in the world through their research. As such, the design elements of this research can be considered as political. In this thesis, especially Part Two, I embrace *adversarial design* (DiSalvo, 2012). I view this as necessary to counterbalance the strong forces outlined in Chapter 2 that are acting against individual interests, and in order to pursue the moral imperative laid out above. By creating space to reveal and confront power relations and influence, we can identify new trajectories for action (DiSalvo, 2010). Therefore, the purpose of the participatory research in Part One is to inform myself as adversarial designer. Acquired insights from the experiences of research participants can help me to develop my own understanding and models.

When designing for people and trying to incorporate their views, there are traditionally two schools of thought: *user-centred design (UCD)* and *participatory co-design (PD)*. In UCD, design is carried out by experts, who have undertaken user research to build up understandings of user needs (Norman and Draper, 1986). This approach places a high value on expertise, but it carries the risk that certain user needs may be overlooked, especially those that are less common (and therefore less likely be present in a designer's concept of 'the average user'). UCD is the most common approach used by technology companies today, not least because commercial motives must be incorporated into designs, and therefore design can never be fully democratised. UCD as implemented in modern software development practice does however recognise the importance of representing the user perspective in the design process, and uses processes such as *focus groups*, *user experience testing*, and *user persona development* to include their perspectives. However, such perspectives may ultimately be ignored or diluted in favour of expert designs or organisational motives, as observed in 2.4.

Recognition of this inherent problem—that users carry less influence than designers and that this imbalance must be tackled head on—lead to the ideas of co-creation (also known as *co-design*) and PD. PD is based upon the idea that those who will use or be affected by technology have a legitimate reason to be involved in its

design (Kensing and Blomberg, 1998). PD is seen as an attempt to design in a more democratic fashion. PD proponents argue that it is not sufficient to study users and go away and design in isolation. Instead, the users and technologists work together in design workshops, with users bringing their lived experiences and perspectives and technologists bringing their expertise on technical and market possibilities and constraints (Bjerknes *et al.*, 1987; Björgvinsson, Ehn and Hillgren, 2010; Smith, Bossen and Kanstrup, 2017). In such a collaboration, a collective, democratic design is created, taking into account all perspectives. In the 2000s, PD grew in popularity across public and private sector organisations, coincident with the growth of internet and social media into its *Web 2.0* phase (Hosch, 2017) which resurfaced the potential to reframe digital technology as something to be harnessed for users' own ends (Jenkins, 2006).

As design approaches, I see merit in both UCD and PD. The participant should play a role as an *informant*—one who can provide critical insights into their own perspective on a design space and help us understand how the world is to them—but also as a *designer*—one who can imagine how they would like the world to be. As we involve the participant, our role as researcher is to elicit the richest possible responses from the participant, by using questions to bring them to consider new possibilities and by giving them stimulating materials to trigger their thinking. The researcher also often needs to *sensitise* the participant to a design space, so that they may properly engage with the questions being posed. Conversely, the researcher cannot arrive at a model or theory unless he has developed *empathy* for the participant's perspective. One of pragmatism's founding philosophers, Peirce, put forward the *pragmatic maxim*, which states that the meaning of anything we experience in the world is understood through the conception of its practical effect, and that theories that are more successful at controlling and predicting our world can be considered closer to the truth (Campbell, 2011). Applying this philosophy to the challenge of design, I find merit in the different, less political, take on involving users as participants in design exhibited in McCarthy and Wright's *experience-centred design* framework, which identifies processes to improve user empathy including *interpreting*, *reflecting* and *appropriating* (McCarthy and Wright, 2004).

Through this research I will at times be more participatory, to understand these aspects of user experience or to co-design solutions with participants. I will at other times act more like an expert designer, especially in Part Two. Taken to the extreme, the PD view is that designs made without the direct involvement of users are invalid, because they inherently no longer represent the desires of those people the designs claim to serve. I oppose this view, because I believe that new ideas will not always arise from participants themselves, especially for this research area—where a more expert-led experience-centred design approach is the most pragmatic way to proceed. By its nature, this research involves thinking about data, information, organisational relations and interaction at a level which the layperson is not accustomed or well-equipped to do. Therefore, while I strive to always include participant viewpoints, I give ultimate precedence in design to my own position of learning that I will acquire through the participatory research

as well as peripheral design and development work [7.2]. In incorporating both approaches, I will also be a participant in my own research, incorporating my own experiences of living in a data-centric world (and my attempts to challenge it) into my learnings.

It is important to be clear about what constitutes good research in this context; if the outcome of the research is to be my own interpretations and theories, how will we know these are sound? First, it is important to say that this is not about measuring the effectiveness of proposed changes upon the world. There will be no deployment of systems to test the ideas I put forward. This is not because such an activity would not be worthwhile—it would—but simply because by its nature, to develop, build and deploy new data interaction paradigms that function in real life with real personal data at the sociotechnical level would be too large an endeavour for a single researcher (or even a single academic research group) to undertake. Therefore, what I seek in this thesis is not to change the world, but to articulate with the greatest possible clarity discrete theories on how the world should, and could, be changed. Good evidence for the proposed changes will be achieved by ensuring that findings, themes and discussion contributions are backed up by participant quotes or extant work and literature, and where an idea is suggested or agreed upon by many participants or where it resonates with the practical experiences of myself or of others, that can be seen as adding weight or validation to that idea. However, each person's experience is unique and needs to be put into context; not every insight will be shared by many participants and individual unique insights remain important.

1.2.2 Action Research

The mixed methods approach I adopt closely follows the discipline of *participatory action research (PAR)*, which is an approach to research that encompasses both the involvement of participants' perspectives while also retaining a role for the reflection and learning of the researcher themselves. PAR's creator Kurt Lewin observed that 'there is nothing so practical as a good theory' (Lewin, 1951), highlighting the pragmatic nature of this approach. PAR combines self-experimentation, fact-finding, reasoning and learning, and makes sense of the world through collaborative efforts to transform the world rather than just observing and studying it (Chevalier and Buckles, 2008). Central to this is the idea that research and action must be done with, not on or for, people; participants are not subjects but co-researchers, evolving and addressing questions together (Reason and Bradbury, 2001). To embody the three ingredients of PAR (Chevalier and Buckles, 2019)—participation, action, and research—my research includes three types of activity:

1. *participatory co-design activities* - where I discuss and explore experiences, challenges and possible solutions with participants through conversations and design activities
2. *self-experimentation activities* - where I carry out experiments, ranging from thought exercises to practical tests of what is possible, to develop

- ideas and explore the problem space myself, and
3. *embedded research activities* - where I participate as an involved team member, in external organisations' projects that are trying to change the world in this space, learning about the challenges faced and the viability of different approaches, on the basis of the grounded experience of myself and others (Cheetham *et al.*, 2018).

In order to simplify the thesis, my embedded research activities (3) and self-experimentation (2) are not considered a core part of the academic research of the thesis. The Case Studies focus solely on participatory co-design. First, in Part One the thesis will work with participants to understand human needs around data, answering the research question through academic inquiry at this level in Chapter 6. Then, Part Two, beginning with Chapter 7, makes a conscious shift from PD to UCD, from investigatory research to adversarial design, using the Case Studies' findings as requirements. At this point, those other activities will then take centre stage.

Action research also carries with it the idea that research is done in cycles: you learn something, carry out some action in the world based on your learning, learn from what happened, and repeat. This has become an established approach in HCI research (Hayes, 2011). The importance of collecting stakeholder feedback at regular intervals is also seen in the software industry though *agile development* (Fowler and Highsmith, 2001) which can be seen as a practical implementation of action research. In start-ups, terms like *fail fast* (Brown, 2015) and *pivot* (Ries, 2011) illustrate the idea that it is crucial to test ideas on real people then adapt quickly based on how that goes. To me, action research does not mean that you must test every single idea with an audience for it to be considered valid, but rather that user engagement is not a one-off, but a repeated component that affects the research path. Each new research activity will draw from past learnings and theories and acquired understandings so far, which are then developed through their exposure to real life in the process of participatory and embedded research activities.

Figure 3.1 shows the cycle of action research, as I apply it in this PhD. In each area of life or context I identify as a setting for a research activity, I first carry out initial background reading, experimentation or exploration to familiarise myself with the area, then design a research activity that helps to explore the research questions in that area. After carrying out the planned activity I analyse any data from that activity (or just reflect upon my experience) and then use these findings to update my overall understanding of how we might answer the research questions. I then go on to repeat this cycle, with each subsequent activity, but beginning anew with more developed theories or understandings. In the case of the peripheral research activities these run alongside the core PhD work, so analysis and learning happens throughout, resulting in a continually updating current understanding that forms the baseline for later research activities. In the next section, I will describe the two specific research objectives that are targeted through the Case Studies.



Figure 1: Figure 3.1: My Action Research Approach

1.3 Research Objectives

At the end of chapter 2, I introduced my research question, which is:

“What relationship do people want with their personal data?”

As identified in 2.1.5 and 2.2.5, there are two distinct research gaps to be explored. The Case Studies, as well as preliminary explorations that feed into them, will both be focused on exploring these two gaps, which I now formulate as two research questions RQ1 [3.3.1] and RQ2 [3.3.2]:

1.3.1 Research Question 1 (RQ1)

What is the human experience of personal data, and what do people want from their data?

Personal data, and its collection and use by commercial and civic organisations, is an established and inevitable part of modern life [2.1], yet the concept of data is abstract and poorly understood . The first objective therefore is to establish a solid understanding of what mental models people have constructed about data. What makes data meaningful to people? Given HDI’s belief that everyone needs a relationship with their data, what relationship do people currently have with their data? What *is* data to people? How does that relationship affect them, and what are their unmet desires for improving their relationship to their personal data? What aspects of data cause positive emotions? What problems do people experience with their data? What people want from their data?

I will use a participatory approach to address these questions: gathering individual perspectives on data, and looking for patterns or trends in those perspectives. The first challenge here will be to find ways to sensitise participants to be able to conduct an informed and productive conversation about the topic of data, which to the layperson may seem a dry, boring topic. This challenge will be addressed by leading participants into the subject of data using meaningful representations of data as stimulus for conversation, or starting with the individual’s own life experience to discover the data in their life, which they are more likely to have opinions and emotions about, rather than talking about the subject in the abstract.

1.3.2 Research Question 2 (RQ2)

What role does data play in people’s service relationships, and how could relationships involving data be improved?

In section 2.2 and 2.3, I established that as of yet, designers of PIM and personal data interfaces have not yet risen to the sociotechnical challenge of looking at the reality of personal data today: it is scattered, inaccessible and largely *un-useable*¹⁰. There is no way for people to view their data holistically, as lamented by Ms. Heap in the quote atop Chapter 1. Nor are there any tools to help people manage the many relationships that individuals have with companies,

employers, councils, governments and other organisations that rely heavily upon the collection and processing of their personal data. Almost every civic or commercial service we use today handles data about us. We know that the world is data-centric, and that data controllers use data as an asset to inform their decision making, creating a serious imbalance of power (Hoffman, 2010, 2011, 2013, 2014a, 2014b). But what is like to conduct a relationship with an organisation that holds your data? What emotions do people experience? How does it affect their daily life, and what sort of problems do people face as a result of this data-centricity? If your data is used in ways you do not understand or consent to, how does this affect your outlook on the world?

This is the second strand of research I explore: to gain an understanding of the data world beyond the individual [2.2.5], so that we can design not just better individual relationships to one's data, but improve people's relationships with organisations that hold and use data. For the purposes of this study, I only pay attention to service relationships (the primary place where data is held), not social or interpersonal relationships.

To tackle RQ2, participatory research approaches are again appropriate, as our questions relate to the individual mental constructs that people have about their wider digital lives and relationships. But there is another aspect here, and that is that a relationship involves two parties. Consistent with Dewey's belief in the importance of interaction in creating meaning, the structuralist philosopher Michel Foucault said that 'meaning comes from discourse' (Adams, 2017), in other words people do not construct their reality in isolation, but in fact it is shaped by the social constructs and systems they operate within. Deweyan pragmatism also takes the view that research must seek solutions to real world problems that are generalisable to use in society at large (Dewey and Archambault, 1964; Friedman, 2006). This implies that any such solutions arising from my research must work for all parties. For both these reasons, I aim to conduct participatory research to understand both perspectives: that of the data controller and that of the data subject, and where possible I will engage both parties together in discourse so that the two parties' worldviews can be brought together to design solutions that could work in practice for all involved.

This second research objective will be tackled in tandem with the first, so that in each research setting we can examine the situation at two levels—to look introspectively at the individual's own relationship in service of RQ1 [3.3.1], but also to take a step back and look at the wider social context the individual is operating within, so that we might be better placed to answer RQ2 [3.3.2].

1.4 Overview of Activities by Research Context

In this section, I will introduce the two contexts in which the research questions are explored, and both the preliminary activities and Case Studies undertaken in each context.

1.4.1 Context One: Civic Data Access in the Early Help Context

The first research context I explored in this PhD was *Early Help*. This is explained in more detail in 4.1, but in brief: Early Help is a particular type of social support offered by UK local authorities as voluntary help to families who are considered to be at risk of falling into poverty, crime, truancy, addiction or other issues which are both problematic for the individuals and costly to the state. Families enrolled in the scheme meet a social worker (called a *support worker* in this context) regularly who can provide advice and connect the family with appropriate health, lifestyle and social services to their needs. As part of this, the support worker has access to a variety of data from civic sources: school records, employment and benefits data, social housing data, criminal records, and more, so that they might be better informed about the family's situation. However, the families do not have any access to this data, and thus despite this being a scheme that is on the face of it intended to empower families to help themselves, it runs the risk of *disempowering* the families through a data-centric power imbalance 2.1.2. Therefore, this setting provides a very interesting context in which to examine both RQ1 [3.3.1] (finding out how these supported families feel about their data) and RQ2 [3.3.2] (examining the impacts of data use within a service relationship) as well as to explore how the families and support workers could imagine their data relations being improved.

Within this context I carried out three research activities between 2017 and 2019:

Embedded Research Placement in CHC SILVER Project

From March 2017 to March 2019, I joined Connected Health Cities' *SILVER* project (Connected Health Cities, 2017) as a part-time research engineer alongside my PhD. This research project was funded by the UK's Department for Health (now the Department of Health and Social Care) and brought together local authorities, health authorities, University researchers and technology partners in the North East of England, in the Early Help context. Its goal was to explore how to unify civic data about a supported family, with their consent, to allow support workers to provide better care to those families. This made it an ideal place to explore my research objectives. It used direct research with families and support workers to inform the system requirements. This also provided an opportunity to deepen understanding of the use of data within Early Help support relationship (RQ2), and both parties' attitudes to this highly personal and real civic data (RQ1). My role was two-fold: as a software engineer, to design and develop user interfaces that would be used to view this unified data (forming the first peripheral research setting [7.2]), and as a participatory researcher, to assist with the design and execution of focus groups and workshops with staff and supported families that could inform the proof-of-concept data system being built. The embedded placement is not considered a major case study of this thesis; however, it has contributed to the research objectives and the developing understandings of this context so will be referenced in the subsequent chapters,

especially Chapters 4, [8](#chapter-8) and 9. The final report from the project was not published but a public summary is available (Northern Health Science Alliance, 2020).

Pilot: Understanding Family Civic Data Study

In the summer of 2017, in the MRes year of this doctoral training programme (alongside my involvement with the SILVER project), I carried out an initial participatory field study in order to deepen my understanding of data use and attitudes within this context and to develop appropriate research methods. This study consisted of home visits to four different families in the North East who had interacted in the past with social care & support services. During the course of these two-hour visits, I carried out participatory co-design activities and interviewed the families (both adults and children) about their civic data, and in particular their views on how risky different types of data were and how that data should be handled. Fieldwork took place prior to the start of this PhD; however, the data analysis and publication of the findings took place within the scope of this PhD, and directly inform the main Case Study, both methodology and as prior work to build upon. The pilot study was published as a first author paper (Bowyer *et al.*, 2018), as described in 1.3.1, which is also included in full in Appendix A.

Case Study One: Data Interaction in Early Help Study

In the summer of 2018, informed by the SILVER project and the pilot study, I designed and conducted my first major case study of this thesis: a series of three participatory co-design workshops with people directly involved in *Early Help* relationships in North East England. The workshops were funded by CHC, and were led by myself. They were designed with a dual purpose: to inform the design of the SILVER system but also to serve RQ1 [3.3.1] and RQ2 [3.3.2] of this thesis. These workshops sought initially to validate findings from SILVER's earlier research and my pilot study. Once this had been done, the main objective of this phase was to develop a deeper understanding of what supported families (workshop 1) and support workers (workshop 2) perceive as problems with data use in the Early Help context, and to explore perceived solutions to these problems. A second phase workshop (workshop 3) was specifically designed to focus on the use of data *within the support relationship* [4.2.4], and was a joint workshop involving staff and parents working together. This case study is described in detail as Chapter 4, and contributes to the general findings about RQ1 [3.3.1] and RQ2 [3.3.2] presented in Chapter 6.

1.4.2 Context Two: Accessing Your Personal Data Using GDPR

From the start, a core motivation for my interest in this research has been to look at the power imbalance around personal data from the *everyday life* perspective—to explore our relationship with and through the data that we hold, use or live with as we go about our lives, online and in person. This power imbalance seems to touch everyone, and therefore for my second research context

I chose not to focus on a particular community or group but to look at these problems at the level of ordinary day-to-day digital life. I designed research activities where I would talk to people about their everyday experiences of data in their lives RQ1 [3.3.1] and their views on the usage of data within their relationships with commercial or civic service providers RQ2 [3.3.2]. In 2018, during this PhD, the European Union's GDPR regulations came into force, enabling people to obtain copies of their own data. This enabled me to take the research deeper than a simple conversation. I was able to guide my participants through the GDPR process to obtain their data from providers, and then to use this retrieved data as stimulus for discussion. This would, I hoped, result in a far more grounded and less theoretical perspective.

Formative Research in Personal Data and Digital Life

As initial explorations into this context, I carried out three pilot activities between 2016 and 2019:

In late 2016, during the MRes programme, I conducted qualitative research in order to validate my own perspectives on usability¹⁰ and to explore attitudes to everyday technology use. I interviewed three participants about smartphone use, with particular attention to perceived usefulness or barriers. I sought to understand what motivates people as users of technology, an important consideration when looking at disempowerment. Findings from this pilot (Bowyer, 2016) contribute to the interpretations expressed through Chapter 5 and Chapter 7.

In order to dig deeper into data attitudes and trial methodological approaches, I conducted 5 two-hour interviews with individuals about their digital lives, looking at how they mentally segment their life, and the roles and functions of different technologies, and especially of data, across those different parts of their lives. I began to explore participants' perceptions of their relationships with service providers, identifying potential disempowerment or pain points. The interviews were conducted using the Sketching Dialogue (Hwang, 2021) technique, which uses collaborative sketches as a basis for a semi-structured interview. A light analysis of the recordings and data was carried out. This trial investigation helped to inform design of the main study, but findings were not formally documented or published.

As preparation for Case Study Two, it was vital to become well-versed in the GDPR. Since 2018 I have practiced obtaining my own data from companies and organisations in my life. This has entailed over 70 GDPR requests to a variety of organisations including retailers, device manufacturers, online service providers, local and health authorities, banks and leisure services. Additionally, I have experimented with self-service download dashboards and third-party 'get my data' tools. In some cases, I have engaged providers in communication to try and get better data or ask questions about my data. These activities have provided multiple benefits:

- they have enabled me develop a detailed understanding of what actual

- stored personal data looks like [Figure 3.6];
- they have given me an awareness of the evolving response to GDPR from data-holding organisations and an understanding of the limits of what is and is not possible with GDPR.
 - These investigations also contribute as peripheral research activities to Part Two, and one particular self GDPR experience with Spotify is used to illustrate how an individual can influence a provider using GDPR [Insight 9].

Case Study Two: The Human Experience of GDPR

The major study for this context was to guide participants through the process of GDPR and retrieving their own personal data, to enable a conversation that included not only attitudes to personal data and the use of data within service relationships, but discussion of how those attitudes were changed by the experience as it happened and how well expectations and hopes were met by the process. 11 participants were engaged 1-on-1 in a 4- to 5-hour process over a series of months which involved five stages:

1. Sensitisation, using a set of wall posters about data holding organisations, types of personal data, GDPR rights and possible uses for your retrieved data
2. A life mapping exercise, similar to that in 3.4.2, using the *Sketching Dialogue* (Hwang, 2021) technique, at the end of which 3-5 target companies were selected for GDPR.
3. A discussion and guided walkthrough of the target organisations' privacy policies, in particular their stated data collection practices.
4. Guidance and support in making and seeing to conclusion a GDPR request from each individual to each of their target organisations
5. A 2-hour interview in which participants were guided through the reviewing their data and were asked about their experiences and reactions to the data and the GDPR process.

Through these stages the objectives were to understand how people view the data that exists about them as they go about their everyday life and what they would ideally want from it (in service of RQ1 [3.3.1]), as well as what role data plays in their relationships with companies and other data-holding organisations in their lives, and what they would ideally want from those relationships with respect to data (in service of RQ2 [3.3.2]).

In the final data exploration interviews, which were conducted online over Zoom due to COVID-19 restrictions, a spreadsheet-based approach was used, where participants were walked through a series of Yes/No questions about different categories of their data, and then asked to expand verbally on their reasoning. This produced both qualitative and quantitative data for later analysis. This case study is described in detail as Chapter 5, and contributes to the general findings about RQ1 [3.3.1] and RQ2 [3.3.2] presented in Chapter 6.

1.5 Methodologies Employed in Case Studies

Having introduced my research approach and explained the research contexts, Case Studies and activities, I will now explain the methods were used across the Studies and why they were chosen. Loosely the methods used can be grouped into five stages, though not every activity involved all stages:

1. Sensitisation of Researcher and Participants
2. Discussion and Exploration with Stimuli
3. Participatory Co-Design of Possible Solutions
4. Practical Data Experiments, Interface Design and Prototyping
5. Data Analysis and Thematic Synthesis

I will now explain each of these stages, with examples from the different Studies, as well as providing information about recruitment and ethics at the end of this section.

1.5.1 Sensitisation of Researcher and Participants

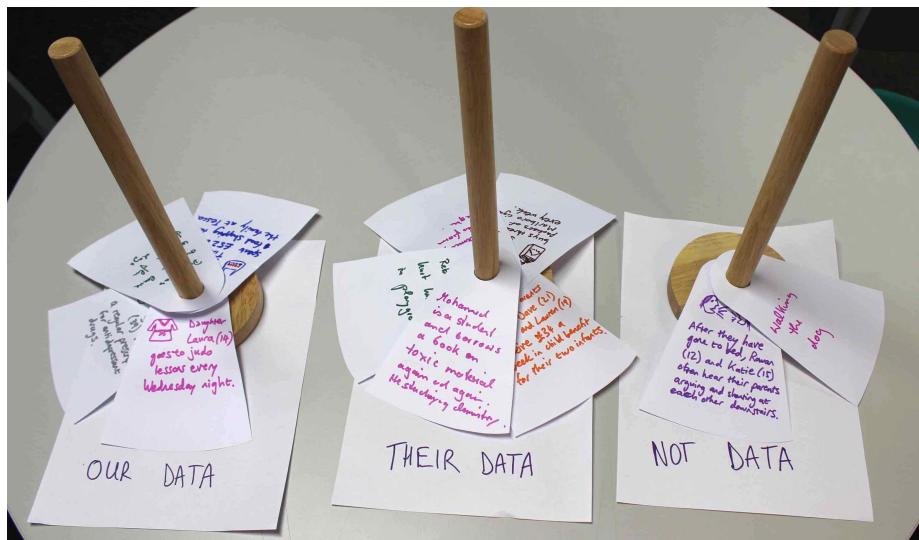


Figure 2: Figure 3.2: Family Facts - What is Data?

As I described in 3.2.2, an important first step before each research activity is to *sensitise* myself as researcher to the context, which means to become familiar with relevant issues, systems and practices and increase my empathy for the participants. In the pilot study [3.4.1], this entailed a grey literature review to identify the different types of civic data that councils store, and conversations with colleagues and partner organisations within the SILVER project to deepen my understanding of Early Help. The pilot study [1.3.1] combined with this to serve as researcher sensitisation for Case Study One, as participating families



Figure 3: Figure 3.3: Walls of Data - Sensitising Participants to the World of Commercially-held Data and GDPR



Figure 4: Figure 3.4: Sentence Ranking - Bringing Support Workers and Families to a Shared Problem Space

had had some contact with the care system. This increased my empathy for, and understanding of, supported family perspectives. Working with support workers through the SILVER project also provided empathy for the data needs of staff within the care service. In Case Study Two, my self-experiments with GDPR as well as researching privacy policies and GDPR rights provided me similar sensitisation before engaging participants.

Participants need to be sensitised too; when planning participatory research activities such as interviews or workshops, it is important to begin the session with an activity that will acclimatise participants both to the specific area of discussion, but also to the problem-solving mindset required for constructive conversation. This goes beyond ice-breaking, and into thinking about what the participants bring and lack at the start of the engagement. For example, in the pilot study, I felt that data would be a hard topic for families to engage with, so I designed the *Family Facts* activity [Figure 3.2]. This required family members to consider simple facts about their lives (some provided, some created by the family members) and discuss whether or not such a fact would be considered data, and additionally whether such a fact should be in the family's control or that of the authorities. This served a double purpose of teaching families that data is simply 'stored information about you', while also getting them used to thinking critically about data ownership. The technique is discussed further in (Bowyer *et al.*, 2018).

For Case Study Two, I wanted participants to think about the data involved in their everyday lives, especially that stored by commercial service providers. So, I put up a series of posters in the common room of my research lab which showed logos of companies that might store data, types of data that might be stored, information about GDPR rights, and possible uses that an individual might have for data they obtain from a GDPR request. Some of these posters are shown in Figure 3.3. These posters served both as a recruitment tool for the project and a discussion prompt for participant onboarding.

Sensitisation activities can also serve an additional purpose of bringing disparate participants to be 'on the same page'. This is known in participatory research as *co-experience* (Battarbee and Koskinen, 2005). An example of this is the *sentence ranking* exercise used at the start of all workshops in Case Study Two [Figure 3.4]. Here, a series of sentences were prepared containing opinions about civic data that had been observed from staff and families in earlier research. Participants were asked to rank these according to *agreement* and *importance*. This allowed me to validate whether previous findings still held with these participants, but also acclimatised the participants to considering and discussing the civic data context and the problems experienced by families and staff. Since the sentences included both staff and family viewpoints, and the activity was carried out in all workshops regardless of whether staff, families or both were present, it served to establish a common set of 'requirements' that would be in participants' minds as they began the subsequent co-design activity within each workshop.

1.5.2 Discussion and Exploration with Stimuli



Figure 5: Figure 3.5: Family Civic Data Cards - Things to Think With

As discussed in 3.2.1, my research seeks to uncover individual perspectives and worldviews. The primary method that I used in both Case Studies was traditional qualitative interviewing - talking to people about the topic being explored. In Case Study Two, this was largely done on 1-on-1 basis (largely because of the sensitivity of dealing with one's own personal data, and because it allowed me as researcher to get closer to the participant's individual experience). In Case Study One, group discussions and activities were mainly used, which brought the advantage of being able to *prime* a discussion between participants and then sit back into more of an observational role, which proved particularly insightful when observing intergenerational conversations between family members in the pilot study [3.4.1], and in Case Study One it allowed me to observe the negotiation of a 'middle ground' between support workers and supported families. In some cases, such as the home visits in the pilot study and local authority visits for SILVER, I was able to conduct interviews-in-place (Pink *et al.*, 2013) in participants' own environments, which allowed for additional ethnographic observations to be made as 'life happens around' (Mannay and Morgan, 2015) the participants, as discussed in (Bowyer *et al.*, 2018).

I wanted to go beyond 'just talking' to achieve a deeper and more detail-oriented

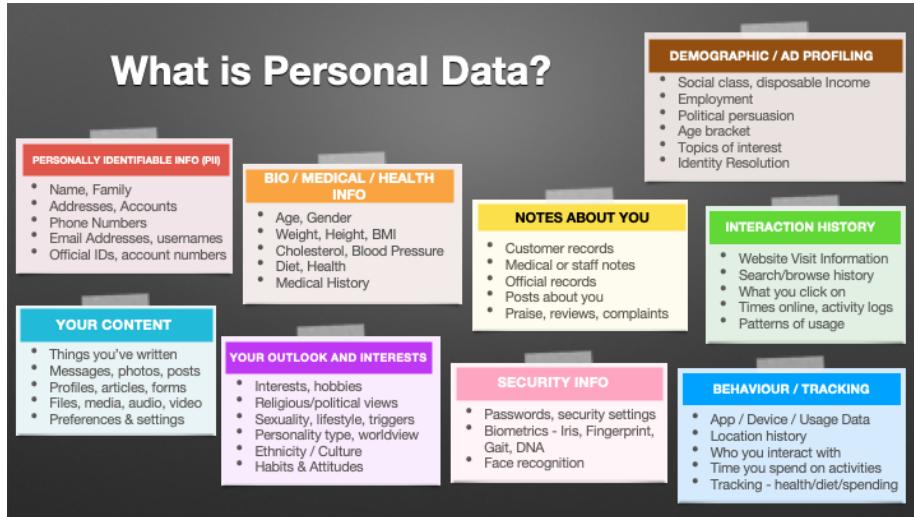


Figure 6: Figure 3.6: Personal Data Examples - Making Data Relatable

conversation. In all of my interviews and group engagements, I also ensured that suitable stimuli were created to seed and progress the discussion. Given the abstract nature of the topic of data, it does not always carry a clear meaning in people's everyday lives, so I needed to find a way to make the topic more vivid and real. Having sensitised myself to civic data as mentioned in the previous section, I constructed a taxonomy and lexicon for Family Civic Data, and created *Family Civic Data Cards* [Figure 3.5] for use in activities and discussions. These serve as *boundary objects* (Star, 1989, 2010; Bowker *et al.*, 2015) - representational artefacts that are understandable by people who come from different perspectives, providing a common vocabulary for discussion (as well as serving to enable co-experience, detailed above). Each card represents a different category of data, including a *summary* and *meaningful examples* to make them be easy to digest, yet still containing sufficient detail to stimulate thinking. The cards were designed to be bright, child-friendly and appealing to engage with. The tangibility of these artefacts was important too. They became *things to think with* (Papert, 1980; Brandt and Messeter, 2004) in discussions and in activities. Researchers have had success with the use of tangible objects to embody discussion concepts in order to stimulate and structure discussion, for example Coughlan's use of a dolls' house to explore attitudes to home energy use (Coughlan, Leder Mackley, *et al.*, 2013) or more recently Xie's Data City which used AR-enhanced cardboard models to represent data-processing functions (Xie, Ho and Wang, 2021). These approaches have their roots in Dourish's concept of *embodied interaction* (Dourish, 2001). The cards were used throughout the Civic Data research in both sensitisation and *card sorting* (Spencer and Warfel, 2004) tasks, for example asking participants to position the cards on a pinboard according to perceptions about risk and ownership [Figure 3.7], or sorting them



Figure 7: Figure 3.7: Home Interviewing: Card Sorting with a Family in Their Living Room

into trays according to relative personal importance. The cards proved very effective at enabling a personal and detail-oriented discussion. Participants voluntarily opened up about sensitive topics (e.g. domestic violence or criminal records) raised by the cards because of their detached-but-relatable nature (Bowyer *et al.*, 2018). In Case Study Two, discussions around data did not use data cards, but the importance of meaningful examples to make the topic relatable persisted, in this case being demonstrated through posters [3.5.1] and in particular a categorisation of example data by category [Figure 3.6], similar to the examples on Case Study One's data cards. I went on to develop data cards for use in participatory research at BBC R&D [Figure 9.16; Figure 9.17].

The sketching dialogue technique [Hwang (2021); Figure 5.2] used in the digital life context can also be used as another stimulus technique; by putting both participant and researcher's focus upon the page, rather than on each other, it can feel less invasive, more collaborative and makes it easier to focus on details. The ideal stimulus for discussion about data is to view the actual data itself. Due to the sensitivity of personal data, this is more easily done 1-on-1 than in a group. Exploring data together with participants to elicit opinions and insights is a well-established technique (Coughlan, Brown, *et al.*, 2013; Chung *et al.*, 2016; Puussaar, Clear and Wright, 2017). This is the technique used within Case Study Two, asking participants about the data they retrieved from GDPR requests, using a spreadsheet-based approach 3.4.2. This allowed the Zoom-based interviews to retain a 'gathered around the table looking at things together' ambiance despite the remoteness necessitated by COVID-19 restrictions.

1.5.3 Participatory Co-Design of Possible Solutions

Participatory Design (PD) [3.2.1] becomes particularly important when exploring solutions and ideals to identified problems. It involves bringing participants into a *new mental space* where they can imagine the realm of the *possible*, rather than just their current lived experience. PD was an important part of Case Study One research with all participants. In the early stages of a PD activity, it is important that participants are able to generate a wide range of ideas, even fantastical ones, without constraints, self-censoring or judgements. This is known as the *discovery* phase in the UK Design Council's *double diamond* framework. (Design Council UK, 2004). Golembewski's *ideation decks* technique (Golembewski and Selby, 2010) was chosen for this purpose [Figure 3.8], as it allows participants to both select 'ingredients' of a design based on their own experience but also to combine them in a variety of different ways to generate novel ideas, guiding them into a previously unconsidered solution space.

After generating a wide range of ideas using the ideation decks, participants were then invited to pick just one or two ideas to develop into posters, each with three 'features' highlighted. An example is shown in [Figure 3.9]. This activity corresponds to the *define* phase of the double diamond, where participants narrow down options.



Figure 8: Figure 3.8: Ideation Decks - Combining Random Design Ingredients to Generate New Ideas

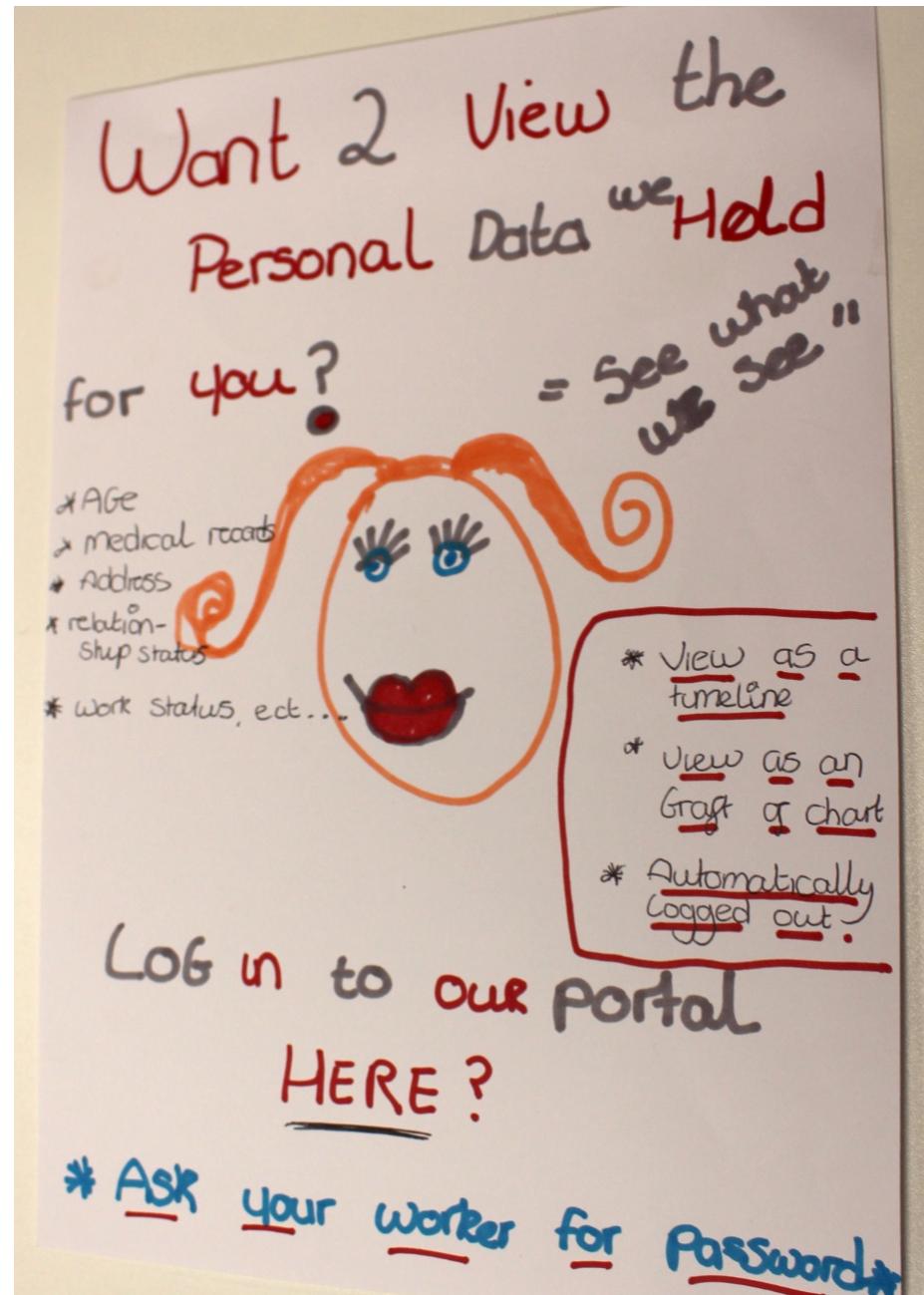


Figure 9: Figure 3.9: Group Poster Design - A Participant-designed Poster to Advertise Features of Imagined Data Interface Products



Figure 10: Figure 3.10: Storyboarding Cards - A Collaboratively-constructed Narrative Created through Discussion from a Palette of Possible Parent and Staff Actions

For the final workshop of Case Study One, where both parents and staff were brought together to explore possibilities of shared data interaction within the support relationship, I used a *storyboarding* activity. Drawing from the world of film production, storyboarding is a well-established technique in participatory design (Spinuzzi, 2005; Moraveji *et al.*, 2007). Usually it involves the participants drawing out a series of sketches in the form of a comic strip ‘telling the story’ of an interaction, encounter or activity. However, given the need [1.1.2; 3.2.1] to focus on interpersonal relations and process rather than the visual aspects of storytelling or interface design, and drawing upon earlier successes with data cards, I used a card-based approach to storyboarding, where participants selected actions from a palette of action cards representing different possible human or data interaction possibilities and annotated these with specific details. These cards are shown in Figure 3.10 and described in more detail in ARI4.3.

1.5.4 Data Analysis

In order to find common viewpoints and extract insights from the many participatory activities I conducted in Case Study One and Two, I needed to analyse the qualitative data. The general approach taken was to audio record (and, in some cases, video record) all interviews and workshops, and to produce a written transcript of the words spoken. Digital photos were taken to capture card arrangements, rankings and other transitory choices, as well as designs, life sketches and other participant creations. While it is possible to analyse participant designs in more detail, I chose to give them the sole purpose of adding contextual understanding to conversation transcripts and did not examine them further. Field notes were captured during or soon after each engagement. Then a process of thematic analysis was undertaken. This involved examining the text of the transcripts (with reference to all relevant digital artefacts to add context), and identifying the underlying ideas, themes and opinions of the participants. Thematic coding is a well-established technique in qualitative research (Braun



Figure 11: Figure 3.11: Thematic Analysis of Qualitative Data using Quirkos for Case Study One



Figure 12: Figure 3.12: Spreadsheet-based Quantitative Analysis of Interview Data for Case Study Two

and Clarke, 2006). I selected the *Quirkos* software for this purpose, as shown in Figure 3.11, due to it having a more visual organisation and simpler approach than the more commonly used *nVivo*. After initial coding of transcripts, a process of reductive data display cycles (Huberman and Miles, 2002) was used to group codes into themes which became the key findings of Chapters 4 and 5.

While the participant data in Case Study One and Two was largely free-flowing and very loosely-structured conversation, the structure of some activities allowed some data to be captured numerically, notably the sentence rankings and data card placements in Case Study One and the trust/power ratings and GDPR spreadsheets produced in Case Study Two. These datapoints were captured into Excel spreadsheets, and where appropriate analysed using formulae to produce weighted mean averages and standard deviations to help contextualise the findings. An example is shown (as evidence rather than explanation) in Figure 3.12. Due to the qualitative focus of the research, participant numbers were too low to seek statistically significant findings, so all quantitative findings are not intended to be representative of any population at large.

1.5.5 Recruitment

Table 1: Table 3.1 - Context One (Civic Data & Early Help): Participants involved in Research Activities leading into Case Study One.

Research Activity	Engagement	Stage or Phase	Duration	Number of Participants	Recruitment Method
Pilot Study	4 x Home-based Interview	preliminary	4 x 2 hours	7 adults and 6 children from 4 families	Posters and Visits to Local Community Centre
Case Study One	1 x Group Design Workshop for Families	1A	1 x 2 hours	8 adults and 9 children from 5 supported families	Selected by Local Authority Care Services

Research Activity	Engagement	Stage or Phase	Duration	Number of Participants	Recruitment Method
Case Study One	2 x Group Design Workshop for Staff	1B	2 x 2 hours	36 supporters workers & related staff	Selected by Local Authority Care Services
Case Study One	1 x Combined Staff and Parents Group Design Workshop	2	1 x 2 hours	3 supporters workers and 4 parents from supported families	Selected by Local Authority Care Services

Tables 3.1 and 3.2 summarise the participants involved in this research. In Case Study One, recruitment was initially attempted using posters placed in local libraries as shown in Figure 3.13 below. When this approach was unsuccessful, participants were successfully recruited with the assistance of a local community centre, which allowed me to visit a community social meeting and talk to residents about my study. This community was located in a low-income area that was known to include a number of supported families; this was chosen with a view to reaching a similar population as SILVER.

For the main engagement of Case Study One, I was able to work with two local authorities, Newcastle City Council and North Tyneside Council, who were partners on the SILVER project, and provided suitable participants who were actively involved in their Early Help programmes. In the pilot study and in the first families workshop of the main study (stage 1A), activities were designed to include children as active participants in the research. It was felt they would bring valuable contributions to the somewhat abstract creative co-design work and this also allowed observation of intra-family conversations. The final combined workshop with staff (stage 2) was designed to only include adult participants. This is because the focus on processes and on the care relationship itself was thought to be too boring and potentially sensitive for the children to participate.

Have you ever wondered what happens to
YOUR FAMILY'S INFORMATION
when you speak to councils, doctors and officials?

**Are you a parent? Can you spare 3-4 hours of your time?
Help us with our research and get a £50 family day out voucher!**



Every week, doctors, council staff and other officials collect and store about you and your family as you go about your daily life. We call this **Family Civic Data**.

Authorities often **share** this data with each other (for example, your social worker calling your doctor) to try and give you better help and support and know you better.

We'd like to meet you to chat about this and do some creative activities so you can **have your say** on how your family's information should - or shouldn't - be shared.

We need your ideas to help make sure that computer systems that councils might build are **family-friendly**, and don't make your life harder.

To find out more, visit yourfamilydata.com where you can find answers to your questions and sign your family up!



Open Lab
at Newcastle University

Examples of Family Civic Data			
Names & birth dates	Relationships	Childcare	Living arrangements
Criminal Records	School attendance	Council housing	Medical records
Job interviews	Benefits claimed	Library usage	Adoptions
Child support	Social worker visits	Youth offences	Complaints

Volunteer and earn £50!
Sign up at www.yourfamilydata.com

Figure 13: Figure 3.13: Recruitment Poster - Poster Used to Recruit Participants for Pilot Study

Table 2: Table 3.2 - Context Two (Digital Life): Participants Involved in Digital Life Research Activities Leading into Case Study Two.

Research Activity	Engagement	Stage or Phase	Duration	Number of Participants	Recruitment Method
Pilot: Digi-tal Life Map-ping Study	5 x 1-on-1 interview	preliminary	5 x 2 hours	5 adults	Convenience sample
Case Study Two	11 x 1-on-1 interview(Life Sketching)	1	11 x 1 hour	11 adults	Convenience sample
Case Study Two	10 x 1-on-1 interview(Privacy Policy Reviewing)	2	10 x 1 hour	10 adults	Continuation ¹
Case Study Two	10 x 1-on-1 interview(Viewing GDPR returns)	3	10 x 2 hours	10 adults	Continuation

In Case Study Two, no special population was needed, as the issues of living in a data-centric world affect everyone. Therefore, a convenience sample (largely 20-to-40-year-old postgraduate students from Newcastle University) was used. Care was taken to find an even split of male and female participants, but other than that no selection criteria were applied. Given their proximity to the Digital Civics programme, the participants for this study were thought likely to have a larger awareness of societal issues around personal data use and greater familiarity with participatory co-design than the layperson. This was considered an advantage as they would require less sensitisation.

In all cases² for both case studies, participants were compensated for their time with vouchers—either online/offline shopping vouchers or vouchers for a family day out.

¹One participant withdrew from the study after the first interview of the Guided GDPR study due to COVID-19. The other 10 participants took part in all three stages.

²(with one exception - the staff workshops within Case Study Two. Because the participants were attending the workshops through their employers (the local authorities), we were not allowed to provide vouchers for participation.)

1.5.6 Ethics

All research activities referenced in this thesis were planned in advance, with interview schedules, information sheets, debriefing sheets, participant consent forms and ethics forms being completed and submitted to Newcastle University's SAgE faculty ethics board, which approved all the studies before they commenced. Ethics approvals are included in Appendix B. Most of the engagements were routine interviews and therefore did not require any special measures for safety or ethical reasons. It was made clear to all participants that they were free to withdraw from my research at any time without giving a reason. The following special measures were included in plans in order to satisfy ethical considerations:

1. *Visiting private homes:* In order to protect myself and other researchers from any physical risks or any accusations of impropriety, all home visits took place with two researchers present, and contact was made with a colleague before and immediately after the interviews to confirm everything was ok.
2. *Working with children:* Activities were designed to be child-friendly (not just safe, but engaging). The families workshop took place at in a function room within a park with a nearby cafe and playgrounds for children, and catering was provided. Within the room, an activity area was provided for smaller children who were not directly participating to play while their parents and older siblings engaged. There was always more than one researcher present and the research team was never alone with children.
3. *Protecting personal data privacy:* In Case Study Two, particular care was taken to design ways for researchers to talk to people about their personal data without violating participants' right to privacy. The research was positioned that the data retrieved from companies was participants' own data, that would never be directly collected or handled by the research team. It was made clear that the researchers were only interested in what was said, not personal data itself. Initially, a privacy monitor was developed which could only be seen with viewing glasses that were in the participant's control [See ARI3.1]. This would allow a researcher to sit next to a participant who was viewing his/her personal data, without the researcher being able to see it. Additional measures to protect users' data included clear instructions on how to keep data safe before, during and after the study. A complaints procedure was also written at the request of the Ethics board.
4. *Adapting to COVID-19:* As COVID-19 changed working and living conditions in early 2020, Case Study Two was adapted to no longer rely on face-to-face engagement. The in-person privacy monitor approach mentioned above was abandoned and replaced with an online Zoom-based approach. In this model, participants would share parts of their data using screen sharing instead, and could move windows off screen to protect their privacy. The full study plan for Case Study Two was rewritten for

online-based participation and was re-approved by the Ethics Board.

1.6 Summation: Towards an Understanding of Better Data Relations

As established earlier [1.4; 3.2.1], the primary focus of the participatory co-design research in this PhD is to arrive at an understanding of what people want from data and in relationships involving data. Figure 3.14 shows three parallel research objectives as downward arrows, considered as three trajectories of evolving understanding. The first two of these correspond to RQ1 [3.3.1] (which can be seen as understanding personal *data*), and RQ2 [3.3.2] (which can be seen as understanding *data in relationships*). The positioning of activities as boxes along these arrows throughout the period of this PhD, indicates that that activity contributes to that area of understanding, and collectively this shows how all activities contribute towards delivering that understanding - in Chapter 6, as an answer to RQ1 [3.3.1] and RQ2 [3.3.2].

Figure 3.14 also shows how the peripheral adversarial design and industrial research & development activities run alongside the Case Studies, developing an understanding of how human relationships with data can be improved *in practice* (the third downward arrow). These peripheral activities [detailed in 7.2] form the basis of Part Two of the thesis. Given they ran in parallel, they also informed the participatory research work throughout the PhD, and vice-versa, in line with the action research approach shown in Figure 3.1.

Using the methodologies in this chapter, Case Studies One and Two will answer RQ1 [3.3.1] and RQ2 [3.3.2], with the findings across the two studies being synthesised in Chapter 6 to conclude Part One, before Part Two moves forward from investigatory research into adversarial design and activism techniques (detailed in that chapter), to chart opportunities for bringing the identified individual desires of the main thesis research into reality [Chapter 9].

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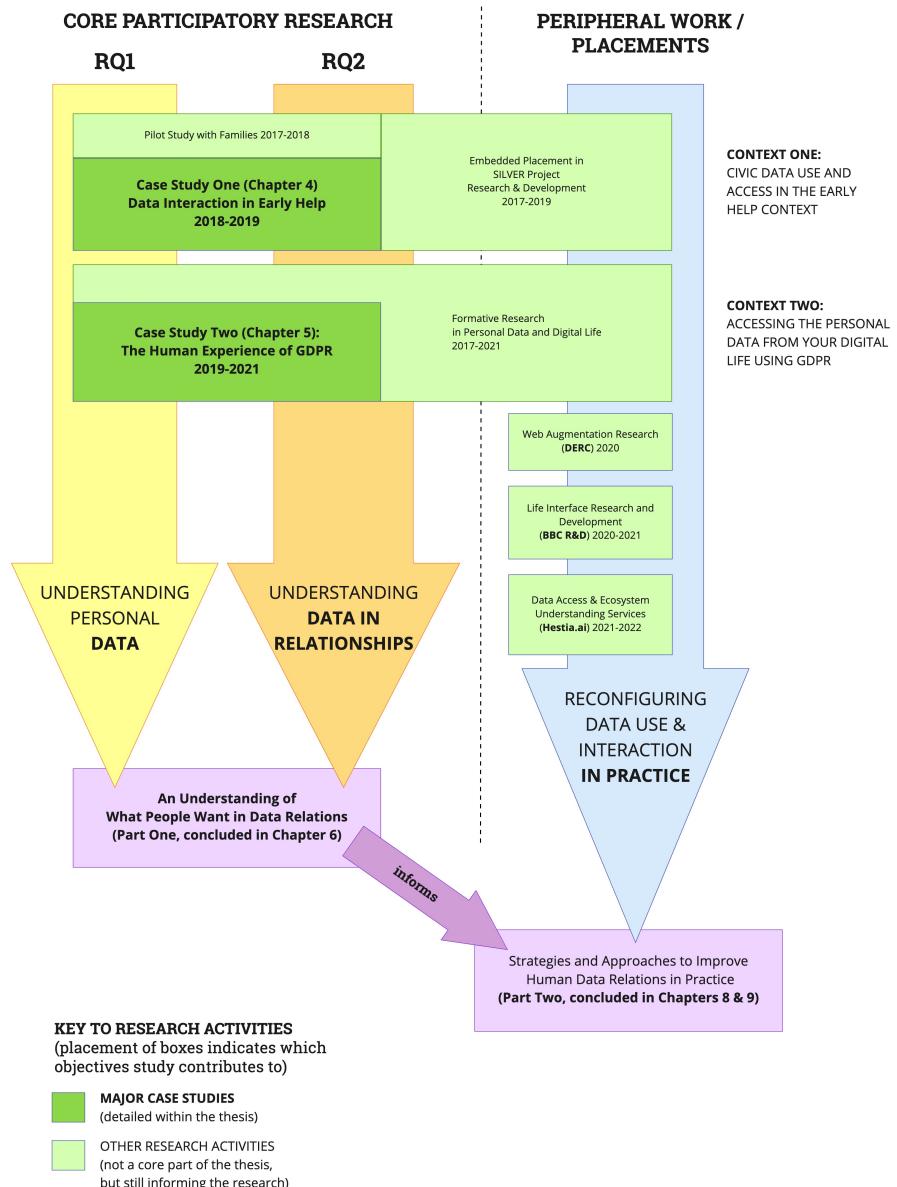


Figure 14: Figure 3.14: How the Case Studies and Peripheral Activities Contribute to This Thesis

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