Understanding and Designing Human Data Relations

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Table of Contents

# 1 Methodology

In the previous chapter, I described three research areas this thesis seeks to explore: how people think about data and what they want from it, how data fits into people’s relationships with organisations and how they want it to be used, and how could people’s desires for the role data plays in their lives be brought closer to reality. 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 those three research aims.

## 1.1 Forming a Research Paradigm: Ontology & Epistemology

To develop a research paradigm it is important to begin with reflecting upon your outlook on the nature of reality (ontology) and your beliefs on how knowledge of that reality is formed (epistemology) (Guba, [1990](#ref-guba1990)). It will already be evident from the literature review and the framing of this thesis so far that individual human perspectives are at the centre of my research questions. This is a reflection of my ontological stance which is that everyone experiences their own reality, informed by their own concepts and mental models of the world. This is known as *constructivism* (Guba, [1990](#ref-guba1990)), where 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 that needs to be uncovered. However, in parallel to this individual learning through experience, people’s realities are constantly shifting and changing, especially when it comes to the rapidly changing technological landscape we live in today reality – consider that today our reality now includes concepts that did not exist in our youth, from “feeds” and “posts” to “link sharing”, “syncing” and “blocking”. As new technologies and practices emerge, we develop new mental models to help us make sense of and find value in new capabilities. This idea of reality as something constantly renegotiated by the individual is known as *pragmatism* (Campbell, [2011](#ref-campbell2011)). To me this is an overriding truth about reality and this focus on understanding change, as perceived by individuals, is a key research motivation. Where constructivists may focus more upon deeply understanding an individual’s reality at a moment in time, I am more interested in understanding the ways in which people’s understanding of the world, and of themselves, changes as a result of their lived experience. At this point we must consider the individual’s motivation for constructing and pragmatically changing their concepts of the world, and to understand this we can look to *objectivism* (Peikoff, [1993](#ref-peikoff1993)), the philosophy put forward by Ayn Rand, which is a belief that the mind, informed by the senses, is the means by which we discover truths about the world, and it does so by forming concepts and using *inductive reasoning* (Smith, [2011](#ref-smith2011)) (in essence, “if these things are true then what else must be true?”) to acquire knowledge. In essence, people’s conceptions of reality are constantly tested and re-evaluated by their experiences of the world. Objectivism also states that individual’s motivation in life is the pursuit of one’s own happiness and wellbeing, and that this self-interest is what drives his pursuit of deeper knowledge and understanding about the world; in essence, everyone wants to improve their own life, and they need knowledge to do it, and for me this view of understanding the nature of reality, so that one might be able to change it for the better is also a key driver behind my research. As a final philosophical element to incorporate, I also look to *Deweyan pragmatism*, which states that our knowledge and thinking are tested by actions, not just reason, and that this is how we learn - and that communication and interaction with others is a key part of that learning. Dewey recognises that every individual is not solitary, he exists within a society; he “is a social being, a citizen, growing and thinking in a vast complex of interactions and relationships.” (Dewey and Archambault, [1964](#ref-dewey1974)) 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.

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

Based upon this, we can now look to epistemology: how can knowledge be acquired? Having a constructivist rather than a positivist stance means that this is best done not through direct observation of the world and empirical testing of hypothesis, but though interacting and communicating with with individuals so that we can interpret how they view reality; this is known as an *interpretivist* epistemology. Most of the techniques used will therefore be *qualitative* (understanding perspectives and collecting non-numerical data) rather than *quantitative* (measuring behaviours and collecting numerical data). The focus of my research is to acquire understanding of people’s views and mental models around data and digital living, so that I can further these concepts in order to 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. Given my strong focus on pragmatism and interpreting people’s constructed social realities in terms of practical usefulness to them, I will not be deeply analysing their words through language analysis techniques like discourse analysis, but will instead focus on the social, interpersonal level - understanding how people navigate the world of data and data-based relationships and change their understandings as they seek to achieve their goals in practice; and how they are affected by the systems, relationships and society they exist within. It is this practical focus, recognising that within a society there are objective truths that will affect all individuals that means the methods used will not be solely qualitative, but rather a *mixed methods approach* where I will adopt the most appropriate methods, usually qualitative but sometimes quantitative, as appropriate to the particular research context and question being explored.

## 1.2 Research Approach: Participatory Action Research & Experience-centred Design

As we move away from general research approach to the specifics of this study, it is important to be clear about what it seeks to achieve. 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 the world to move from a data-centric (see section 2.1) to being human-centric (see section 2.3) operating paradigm. By learning about people’s understandings of their reality, this will inform my own thinking, and using by an inductive research approach we can identify patterns common to multiple people and form theories that might explain these patterns. As a student of *digital civics* (Vlachokyriakos *et al.*, [2016](#ref-vlachokyriakos2016)) I believe that research can surface the ways in which current service provisions fail to meet people’s needs, and through research we can show 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, this is *adversarial design* (DiSalvo, [2012](#ref-disalvo2012)) and I view this as necessary to counterbalance the strong forces outlined in Chapter 2 that are acting against individual interests; by creating space to reveal and confront power relations and influence, we can identify new trajectories for action (DiSalvo, [2010](#ref-disalvo2010)). Therefore the purpose of the research is to inform myself as adversarial designer, with the acquired insights from the experiences of research participants helping me to develop my own understanding, models and designs.

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](#ref-norman1986)). 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, user persona development to include their perspectives. However such perspectives may ultimately be ignored or diluted in favour of expert designs or organisational motives.

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 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](#ref-kensing1998)). 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](#ref-nygaard1987); Björgvinsson, Ehn and Hillgren, [2010](#ref-bjorgvinsson2010); Smith, Bossen and Kanstrup, [2017](#ref-smith2017)) so that 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](#ref-hosch2017)) which began to reframe digital technology as something to be harnessed for users’ own ends (Jenkins, [2006](#ref-jenkins2006)).

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 the researcher is to elicit the richest possible responses from the participant, by using questions to bring them to consider new questions 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, but equally 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](#ref-campbell2011)). Applying this philosophy in 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* (McCarthy and Wright, [2004](#ref-mccarthy2004)) framework, which emphasises the importance of understanding the user’s experience to inform technology design. It identifies six sensemaking processes users go through. These can be considered to help acquire user empathy:

1. *anticipating*: We never come to technology unprejudiced.
2. *connecting*: We make a judgement in an instant, without much thought.
3. *interpreting*: We work out what’s going on and how we feel about it.
4. *reflecting*: We examine and evaluate what is happening in an interaction.
5. *appropriating*: We work out how a new experience fits with other experiences we have had and with our sense of self.
6. *recounting*: We enjoy storytelling and make sense of experience in stories.

Through my research I will at times be more participatory, to understand these aspects of user experience or to co-design solutions with participants, but I will at other times act more like an expert designer. 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, because by its nature this research involves thinking about data, information, organisational relations and interaction (topics that are not often theorised about as part of everyday life) at a level which the layman 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 research I undertake with participants and which I will develop through theoretical & design work that I will undertake by myself. In doing so, 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? Firstly 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 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, and where an idea is suggested or agreed upon by many participants or where it resonates with my own embedded experience, 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.

The mixed methods approach I will be adopting 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](#ref-lewin1951)) which shows 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](#ref-chevalier2008)). 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](#ref-reason2001)). To embody the three ingredients of PAR (Chevalier and Buckles, [2019](#ref-chevalier2019)) – participation, action, and research – my research will include three types of activity:

1. *participatory co-design activities* – where I will discuss and explore experiences, challenges and possible solutions with participants through conversations and design activities
2. *self-experimentation activities* – where I will 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 will participate as an involved team member, in external organisations’ projects that are trying to change the world in this space, so that I may learn about the challenges faced on the basis of the grounded experience of myself and others (Cheetham *et al.*, [2018](#ref-cheetham2018)).

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](#ref-hayes2011)) and the importance of collecting stakeholder feedback at regular intervals is also seen in the software industry though *agile development* (Fowler and Highsmith, [2001](#ref-fowler2001)) which can be seen as a practical implementation of action research. In startups, terms like ‘fail fast’ (Brown, [2015](#ref-brown2015)) and ‘pivot’ (Ries, [2011](#ref-ries2011)) illustrate the idea that it’s 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 your past learnings and theories and your acquired understanding so far, which will be further developed through its exposure to ‘real life’ in the process of participatory and embedded research activities.

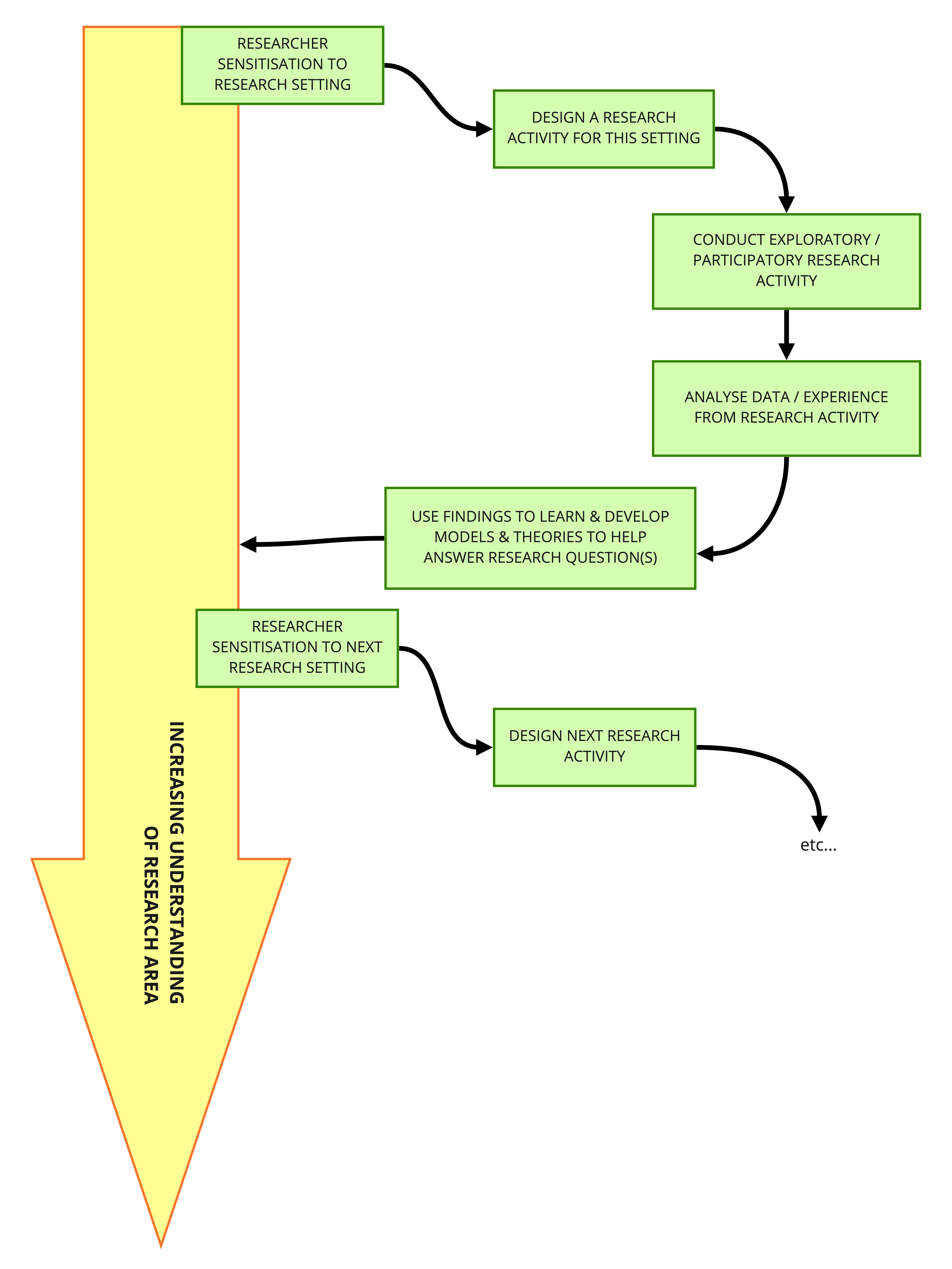


Figure 3: My action research approach

Figure 3 shows the cycle of action research, as I will apply it in this study. In each area of life or context that I identify as a setting for a research activity, I will first carry out initial background reading, experimentation or exploration to familiarise myself with the area, then I will design a research activity that helps to explore my research question in that area. After carrying out the planned activity (be it participatory, self-experimentation or embedded research) I will analyse any data from that activity (or just reflect upon my experience), and then use these findings to update my overall understanding of the answer to my research questions. I will then go on to repeat this cycle, with the next study, but beginning with more developed theories or understandings than the previous. In the case of embedded research activities these are likely to go on for several months alongside other activities, so analysis and learning will happen throughout, resulting in a continually updating current understanding that will form the baseline for later research activities. In the next section I will describe the three specific research objectives that will be targetted through the research activities.

## 1.3 Research Objectives

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

**“What role should people’s data play in their lives, what capabilities do they need, and how could these ideals be achieved?”**

Corresponding to the three research gaps I am focusing on as identified in 2.1.5, 2.2.5 and 2.3.5 respectively, there are three distinct subquestions I will explore using the approach detailed above. Each of my research activities will be designed to advance my understanding and theories towards one of these three research objectives:

### 1.3.1 Research Question 1 (RQ1): What is the human experience of personal data, and what do people want from their data?

As established in section 2.1, personal data, and its collection and use by commercial and civic organisations, is an established and inevitable part of modern life, yet the concept of data is abstract and poorly understood. The first strand of research I will be advancing through this thesis is to establish a solid understanding of what mental models people have constructed about data. We need to understand what makes data meaningful to people, and given HDI’s belief that everyone needs a relationship with their data, we need to understand what relationship people currently have with their data. What *is* data to people? If we are to design new human data relations, we must begin by understanding people’s current relationship to their data, the ways in which that relationship affects them, and their unmet desires for improving their relationship to their personal data. We need to find out what aspects of data cause positive emotions, what problems do people experience with their data, and what people want from their data.

In order to approach this objective, we must take a participatory approach; gathering individual perspectives on data, and looking for patterns or trends in those perspectives, will be the primary means to advance this research objective. 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 layman 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 socio-technical challenge of looking at the reality of personal data today: that it is scattered, inaccessible and largely unusable. There is no way for people to view their data holistically, nor 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 our data. 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](#ref-wef2010), [2011](#ref-wef2011), [2013](#ref-wef2013), [2014a](#ref-wef2014lens), [2014b](#ref-wef2014context)). 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 will be exploring: to gain an understanding of the data world beyond the individual, 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. (Note: for the purposes of this study, we only pay attention to service relationships, not social or interpersonal relationships). In this thesis and its title I use the term “human data relations” to encompass both of these aspects - human-data relations (the individual’s relationship to their data, as imagined by HDI), but also human data relations, i.e. human relationships that involve data.

To tackle RQ2, participatory research approaches are appropriate here, 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 structualist philosopher Michel Foucault said that “meaning comes from discourse” (Adams, [2017](#ref-adams2017)), 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](#ref-dewey1974); Friedman, [2006](#ref-friedman2006)). This implies that any such solutions arising from my research must work for all parties. For both these reasons, I will 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, 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.

### 1.3.3 Research Question 3 (RQ3): What challenges and opportunities are relevant when attempting to establish these ideals for human data relations?

As a software industry professional, and as a pragmatic digital civics researcher, I believe it is important that the outcome of my research is not purely theoretical. While the goal of this PhD is not to build a new data interaction system, it is important that we pay attention to *how* the problems outlined in section 2, and the individual desires and needs we uncover in RQ1 and RQ2, might be achieved in practice. This involves gaining understanding of the technical, economic, political and legal landscape that personal data interaction occurs within. This involves gaining clarity on the motivations that service organisations have for being data-centric, and understanding the current systems and organisational practices that influence current system and process designs. Just as Li showed that users of SI systems experience a barriers cascade as they try and achieve more human-centric data goals (Li, Dey and Forlizzi, [2010](#ref-li2010)), it follows that there are also likely to be a series of obstacles that service organisations would have to overcome if they were to approach these goals. We need to uncover these obstacles so that we can design approaches to overcome them. The third strand of my research is to outline practical steps and guidance, both for researchers and personal data interaction system developers, to make it clearer how they can pursue the goals we identify for improved human data relations.

This strand will be addressed in parallel to RQ1 and RQ2, so that practical discoveries may inform those research questions too. This also means that as new needs and desires emerge from RQ1 and RQ2, they can become “requirements” for the more technical design work of RQ3. As an approach, this will be action research in its purest sense - I will embed myself in projects working in the personal data space, as a developer and a researcher, so that I can gain deep field experience of the constraints and opportunities that affect the design of data interaction systems and processes. Unlike RQ1 and RQ2, this strand of research will be explored not through strictly configured study research engagements but rather through a process of acculturation to the world of building data systems and developing my own knowledge through design, technical prototyping and pushing the boundaries of the systems that do exist so that they may be better understood. Ultimately these insights should allow me to achieve greater expertise, backed by the empirical findings from RQ1 & RQ2, to allow me to draw conclusions about how I believe the discipline of human-centred data relations should proceed in its future research and development.

## 1.4 Overview of Research Activities

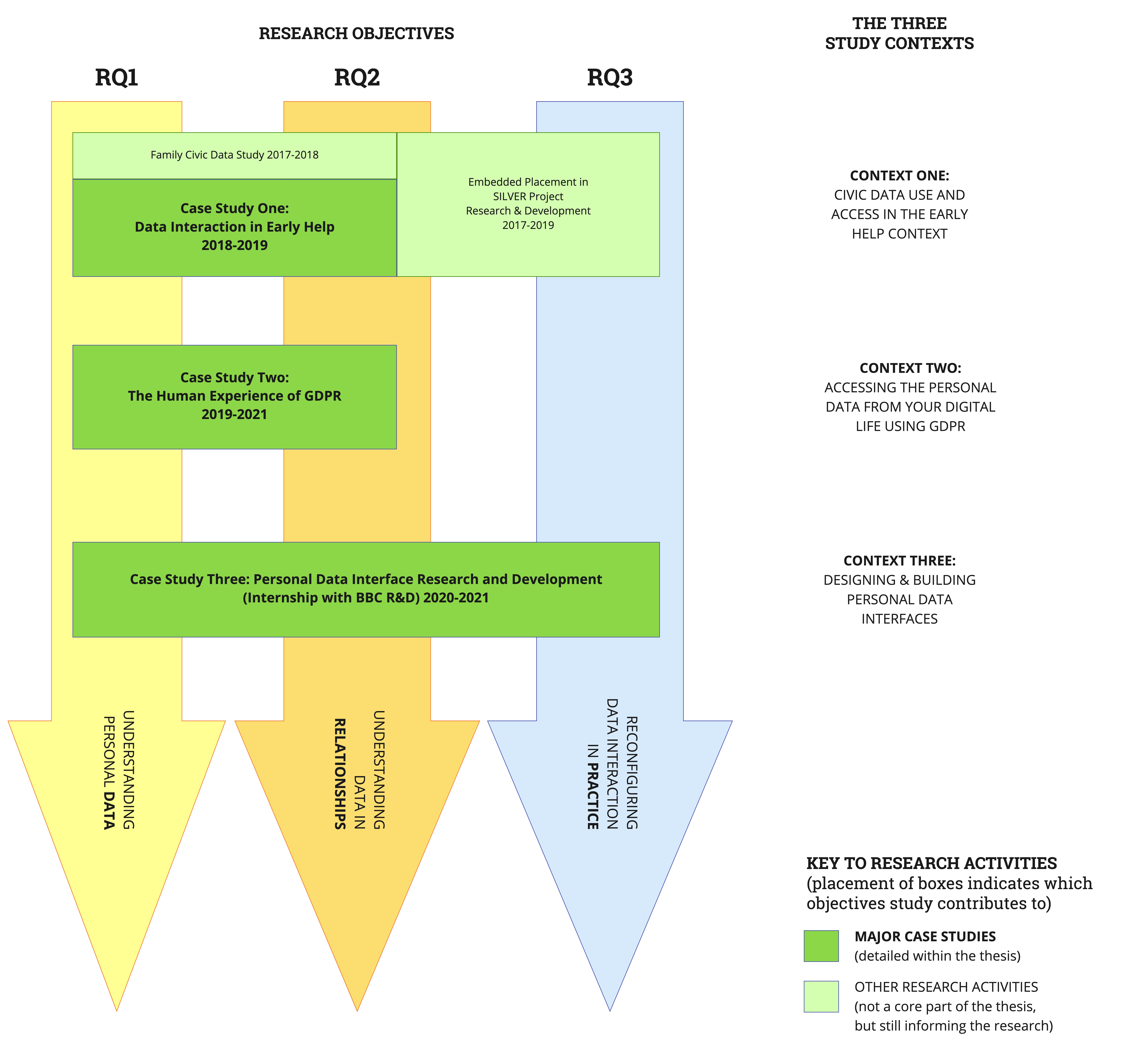


Figure 4: Studies and Contexts

As explained in the last section, the three sub-research questions RQ1, RQ2 and RQ3 have been addressed in parallel throughout this research. They can be considered as three parallel trajectories of research and learning, each informed by some or all of my research activities as they progress, in cycles of action research as described in section 3.2 above. Figure 4 shows these three parallel research objectives as downward arrows. Considered as three areas of understanding, RQ1 can be seen as understanding personal *data*, RQ2 as understanding data in *relationships*, and RQ3 as understanding how to reconfigure data interaction in *practice*. Figure 4 also illustrates how the three contexts of study and three major case studies, which I will explain below, contribute to advancing my understanding of each area - with the positioning of the box over an arrow indicating that it contributes to that area of understanding.

### 1.4.1 Context One: Civic Data Use and Access to Data in the Early Help Context

The first research context I explored in this PhD was “Early Help”. This is explained in detail in Chapter 4, 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 the same data-centric power imbalance described in section 2.1.2. Therefore, this setting provides a very interesting context in which to examine both RQ1 (finding out how these supported families feel about their data) and RQ2 (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:

#### 1.4.1.1 Embedded Research Placement in CHC SILVER Project

From March 2017 to March 2019, I joined Connected Health Cities’ “SILVER” project (Connected Health Cities, [2017](#ref-ConnectedHealthCities2017)) 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 exactly the Early Help context described above. 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: Because it was aiming to build a real-world technical solution, this would provide practical insights that would serve RQ3, and as it was also using direct research with families and support workers to inform the system requirements, this would also provide an opportunity for deeper understanding of the use of data within the 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, 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. This 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 Chapter 4 and Chapter 7. Chapter 7 includes a short section [ADD REF TO CHAPTER 7 SUBSECTION] detailing my high level observations from participating in the project. The final report from the project is available at [ADD REF HERE WHEN AVAILABLE].

#### 1.4.1.2 Understanding Family Civic Data study

In the summer of 2017, in the MRes year of this doctoral training programme, I carried out an initial participatory field study in order to deepen my understanding of data use and attitudes within this context (RQ1) and 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. While this fieldwork took place prior to the start of this PhD, the data analysis and publication of the findings took place within the scope of this PhD. Again, this is not considered a primary study for this PhD, but will be referenced within this thesis. The paper which published the study is (Bowyer *et al.*, [2018](#ref-bowyer2018b)), which is included in [ADD APPENDIX REFERENCE TO CHI2018 PAPER HERE].

#### 1.4.1.3 CASE STUDY ONE: Data Interaction in Early Help study

In the summer of 2018, informed by the SILVER project and the Understanding Family Civic Data 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 conducted by myself and were designed with a dual purpose: to inform the design of the SILVER system but also to serve RQ1 and RQ2 of this thesis. These workshops built upon the Understanding Family Civic Data study, in order to validate the earlier findings – but aimed 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. The third workshop was specifically designed to focus on the use of data within the support relationship, 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 and RQ2 presented in Chapter 6.

### 1.4.2 Context Two: Accessing the Personal Data from your Digital Life 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. It seems that this power imbalance is something that touches 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 our day-to-day digital lives. I designed research activities where I would talk to people about their everyday experiences of data in their lives (RQ1) and their views on the usage of data within their relationships with commercial or civic service providers (RQ2). 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 and to guide my participants through the GDPR process to obtain their data from providers, and then to use this retrieved data as a stimulus for discussion; this I hoped would result in a far more grounded and less theoretical perspective. In parallel to this, I was began to conduct my own experiments using GDPR to see and explore my own data. This allowed me to sensitise myself to the research space, and to enhance my understanding of RQ3 (finding out more about what is and is not possible in practice when it comes to everyday personal data access) but also crucially it enabled me to become a participant in my own research, enabling a deeper understanding of this research context.

Within this context, I carried out four research activities between 2016 and 2020:

#### 1.4.2.1 Smartphone Usefulness study

This early study was carried out in late 2016. Its goal was to deepen my understanding of people’s perceived values around everyday technology use and to validate some of my own perspectives. Using participatory interviewing techniques I explored attitudes to smartphone use, with particular attention to perceived usefulness or barriers. This was designed to provide background on what motivates people as users of technology, an important consideration when looking at disempowerment. The thematic findings from this study are detailed in a report in [INSERT APPENDIX REFERENCE HERE].

#### 1.4.2.2 Digital Life Mapping study

In order to further acclimatise myself to people’s attitudes to data and to provide balance to my own attitudes and opinions, 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. As part of this I also explored the participants’ perceptions of their relationships with service providers, in order to identify the ways in which individuals might feel disempowered by the ways their data was handled or to identify what they would like to change about their data relationships. The interviews were conducted using the Sketching Dialogue (Hwang, [2021](#ref-hwang2021)) technique, which uses collaborative sketches as a basis for a semi-structured interview. A light summary of observations and findings are presented in [INSERT APPENDIX REFERENCE HERE].

#### 1.4.2.3 Self GDPR Experiments

As preparation for Case Study Two, and in order to increase my own empathy and participation in the research, I have throughout the last three years from 2018 made numerous efforts to obtain my own data from companies and organisations in my own 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 (which informs RQ1), they have given me an awareness of the evolving response to GDPR from data controlling organisations (which informs RQ2), and has allowed me to test the limits of what is and is not possible with GDPR (which informs RQ3). A summary of observations and findings are presented in [INSERT APPENDIX REFERENCE HERE].

#### 1.4.2.4 CASE STUDY TWO: The Human Experience of GDPR

As described above, 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 3.4.2.2, using the Sketching Dialogue (Hwang, [2021](#ref-hwang2021)) 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), 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).

This case study is described in detail as Chapter 5, and contributes to the general findings about RQ1 and RQ2 presented in Chapter 6.

### 1.4.3 Context Three: Designing and Building Personal Data interfaces

The third context for this PhD, which has remained a focus throughout, is a more practical one; to go beyond just understanding people’s perspectives but to look, in the context of what we learn about people’s desires for their data and their relationships, at what is currently possible in practice. The goal is to find out what factors shape the design and implementation of real world data interaction systems and processes, to understand what legal, social, economic, technical or political factors come into play and importantly, to explore what technologies or techniques might be able to pursue human-centric design goals in a data-centric world. In scope, this context is a broad one, encompassing all forms of personal data interaction; as such it is able to draw on the findings of RQ1 and RQ2 from the first two contexts, viewing those as “needs” or “requirements” that would ideally be met through the designing and building of new interfaces.

In total four separate research activities between 2017 and 2021 took place within this practical research context:

#### 1.4.3.1 Health Interface Development in the CHC SILVER project

The embedded role I took in the SILVER project described in section 3.4.1.1 contributes also to this context, as part of my role was as a front-end software developer for a personal data health interface intended for use by support workers in the Early Help context. Learnings from that experience also helped to serve RQ3. This aspect of the SILVER project is considered out of scope for this thesis, though reference is made to it in Chapter 7.

#### 1.4.3.2 Reconfiguring Data Interfaces and Obtaining Data through Web Augmentation

As a software developer I have been aware for a long time that one of the biggest challenges in building new data interfaces is to gain programmatic access to the necessary data. As part of the trend towards cloud-based services and data-centric business practices, it has become increasingly difficult to access all of the data held about users by service providers. Application Programming Interfaces (APIs) are a technical means for programmers to access a user’s data so that third party applications may be built using that data. Unfortunately, as a result of commercial incentives to lock users in and keep data trapped (Abiteboul, André and Kaplan, [2015](#ref-abiteboul2015); Bowyer, [2018](#ref-bowyer2018a)), much of users’ data can no longer be accessed via APIs. While GDPR data portability requests do open up a new route for the use of one’s provider-collected data in third party applications, this is an awkward and time-consuming route for both users and developers. *Web augmentation* provides a third possible technical avenue for obtaining data from online service providers. It relies on the fact that a users data is loaded to the user’s local machine and displayed within their web browser everytime a website is used, and therefore it is possible to extract that data from the browser using a browser extension. Similarly, once loaded into the browser, a provider’s webpage can be modified to display additional data or useful human-centric functionality that the provider failed to provide.

In order to better understand what is and is not possible using this technique, I participated from 2018 to 2020 as a researcher and part time web developer in a project which was using the web augmentation technique to improve the information given to users of Just Eat, a takeaway food ordering platform in the UK. While this particular use case does not concern personal data, the technology being used by the project were considered highly relevant, and the goals of the research project were also human-centric, and consistent with our own research goals - tackling power imbalance of service providers in order to better serve individual needs. This research project is not detailed within this thesis, and is not considered a primary study for this PhD, but is referenced within Chapter 7. The paper which published the study is [ADD REF goffe ET AL ], which is included in [ADD APPENDIX REFERENCE TO GOFFE ET AL PAPER HERE].

#### 1.4.3.3 Personal Data Locker Experiments

#### 1.4.3.4 CASE STUDY THREE: Research Internship with BBC R&D Cornmarket Project

including research, market analysis, modelling and information architecture, UX/UCD design activities, hack week prototyping and supporting research activities.

## 1.5 Methodologies Employed in Case Studies

### 1.5.1 Sensitisation

including researcher sensitisation and participant sensitisation grey literature / privacy policies and self GDPR to find out what the data is difference between staff and families getting people into the data world (venn diagram) - family facts / walls of data sentence ranking. - comparison & validation of prior findings

### 1.5.2 Discussion & Exploration

### 1.5.3 Participatory Co-Design

### 1.5.4 Practice & Prototyping

### 1.5.5 Analysis, Learning & Modelling

### 1.5.6 Recruitment

### 1.5.7 Ethics

## 1.6 Thesis Structure

(diagram)

(what goes in what chapter)

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