The Power of Personal Data

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# 1 Introduction

[Target 8,000 words]

## 1.1 The Power Imbalance

[Target X words]

Explaining the current imbalance of power between individuals and those who hold our data as well as the barriers to individual power. Need to be careful to explain this in such a way that encompasses both commercial power (chapter 5) and state-citizen power (chapter 4).

## 1.2 What We Need & Don’t Have

[Target X words]

Highlighting the things we can’t do today and some of the key ideas that would give us more power.

## 1.3 The Research Question

[Target X words]

What data capabilities do people need in order to exert and maintain power in their everyday lives? (and subquestions)

## 1.4 My Approach

[Target X words]

Give an overview of the approach which is:

1. Connect people with data meaningfully.
2. Understand their perspectives on their current and ideal relationship with that data and those that hold it.
3. Design/prototype/co-design alternative interactions
4. Research people’s perspectives on these imagined alternatives

## 1.5 Thesis Structure

[Target X words]

Explain the structure of the thesis.

### 1.5.1 Notes

Does a very high level overview of studies need to go in here somewhere, if so does it need its own section or which one does it go in?

# 2 Literature Review

[Target 12,000 words]

## 2.1 The Nature of Power

[Target X words]

* Foucault - normalising power
* Bentham’s Panopticon - structural power
* Types of power - resource control, centrality etc.

## 2.2 Human-centricity

[Target X words]

* Ubicomp: Weiser > Rogers, Abowd. etc.
* Human-Data Interaction > Mortier
* MyData movement

## 2.3 Paradigms for claiming Power

[Target X words]

* Freedom of Information Requests, GDPR & other regulatory approaches
* Vendor Relationship Management, Pull Computing, Personal Data Lockers
* Dynamic Consent
* Shared Decision Making (maybe this should come in Chapter 6 instead)

## 2.4 Other relevant areas

[Target X words]

(not sure whether this should be a separate section or integrated to above sections) - Interaction Design - Meaning and Sensemaking - Reflection, Orienteering, Time, Context & Associativity

# 3 Approach & Methods

[Target 10,000 words]

## 3.1 Theories on engaging people with data

[Target X words]

* Boundary Objects [Star]
* “Things to think with” [Brandt & Messeter]
* Participatory co-design
* Home visits [Mannay]

## 3.2 Explanations of all methods used throughout this Thesis

[Target X words]

### 3.2.1 Family Facts

[Target X words]

Describe the facts-on-poles technique used in 2017 study.

### 3.2.2 Data Cards

[Target X words]

Describe and show both the Family Civic Data cards used in 2017 study and the data cards developed at the BBC.

### 3.2.3 Card Sorting Techniques

[Target X words] Describe the card-sorting techniques used - the riskiness vs who-should-control-it corkboard technique used in 2017 study - card sorting done in 2018 study as warm up.

### 3.2.4 Ideation Grids

[Target X words]

Quick explainer and reference to Golembewski

### 3.2.5 Storyboarding cards

[Target X words]

Explain origins in filmmaking etc and later software design, then explain the technique used in the 2018 study (show the storyboard cards).

### 3.2.6 Sentence Ranking

[Target X words]

Describe sentence ranking exercises done in 2018 study

### 3.2.7 Group Poster Making

[Target X words]

Not sure if this really needs a section, but was used in 2018 study.

### 3.2.8 Sketch Interviewing

[Target X words]

Describe technique used in late 2017 and in late 2019/pre-covid 2020. Reference Euijin Hwang’s thesis and wherever he got it from.

### 3.2.9 Private Data Viewing

[Target X words]

This possibly should get cut - but I did develop the technique (privacy monitors etc)

### 3.2.10 Online Data Review

[Target X words]

Explain the spreadsheet based semi-quantitative approach developed and used in post-COVID 2020.

### 3.2.11 Notes

Not sure if I should say anything about other research done with COVID, e.g. interviews and visits with councils. Not sure if I should mention work done at BBC e.g. data modelling, prototyping, hack weeks etc. or whether to leave that for chapter 6.

# 4 Human-Data Interaction in the Early Help Context

[Target 15,000 words]

## 4.1 Research Context & Rationale

[Target X words]

Explaining the early help context and why it is relevant. Explaining my involvement with the SILVER project as both researcher and developer (or does this statement go somewhere else as declaration of interest?)

## 4.2 Understanding Family Perspectives on Data - 2017 Home Visits

[Target X words]

### 4.2.1 The study

[Target X words]

From CHI 2018 paper

### 4.2.2 Findings

[Target X words]

From CHI 2018 paper

### 4.2.3 Discussion

[Target X words]

From CHI 2018 paper (Or does this go into Chapter 7?)

## 4.3 Exploring the Role of Data in the Support Worker Relationship - 2018 Workshops

[Target X words]

### 4.3.1 The study

[Target X words]

From CHI 2019 LBW paper and unpublished journal paper

### 4.3.2 Findings

[Target X words]

From CHI 2019 LBW paper and unpublished journal paper

### 4.3.3 Discussion

[Target X words]

From CHI 2019 LBW paper and unpublished journal paper (Or does this go into Chapter 7?)

# 5 Human-Data Interaction in Everyday Life

[Target 12,500 words]

## 5.1 Research Context and Approach

[Target X words]

without repeating 1.2, explain why the power imbalance has arisen - shift to cloud, black box design, removal of seams, etc. - this will draw a lot on my presentations Explain the approach - trying to understand as much of the picture as possible, of actually getting your data, trying to have conversations about it, trying to use it.

## 5.2 Overview of Activities done

[Target X words]

Explaining the various activities done: - 2016 mobile phone usefulness interviews - 2017 digital life sketch interviews - 2018-2020 my own GDPR Requests - including 2020 University GDPR request - 2019-2020 GDPR Viewing Your Data study - including privacy policy analysis - and the work with personaldata.io on mapping out Data - including the lab chat I ran - use of visual stimulus

## 5.3 Findings

[Target X words]

The analysis is still to be done here, but it will be something like:

### 5.3.1 What can we currently do?

[Target X words]

This section will bring together all the practical experiences and data on how much you can actually get back from data holders, what works and what doesn’t, etc. Usability vs understandability, etc.

### 5.3.2 How do people feel about their data?

[Target X words] Not sure if this is exactly the right place for this, but need a place to bring in ideas around the different ways people think about data: - Data as property - Data as insights into a person - Data as part of oneself - Data as memories - Data as a medium for communication and expression

### 5.3.3 How do people feel about current capabilities?

[Target X words]

This section will bring together all the different perspectives on how people feel - what frustrates and excites, etc. Especially looking at what affects people’s trust, and sense of having power.

### 5.3.4 What is missing?

[Target X words]

This will bring together all the observations and desires for things you can’t currently do. Looking to the future

# 6 Reclaiming Power in Practice

[Target 7,500 words]

This chapter will focus on the practicalities of trying to effect change, through the lenses of : - the work done with SILVER developing a health data interface - the exploration of shifting the locus of decision making (from chapter 5) - the work done with the BBC designing and prototyping personal data store interfaces and data models - the individual prototyping work I have done - web augmentation / Facebook post gathering - web augmentation / Just Eat - scripts analysing GDPR-retrieved Data - Gmail API hacking - life data models and abstract data models from the BBC

It is largely discursive as a chapter, putting forward my own ideas but informed by all the practical work I have done throughout the PhD

## 6.1 Barriers and Realities of Trying to Effect change

[Target X words]

### 6.1.1 SILVER project

What we did and didn’t achieve in building a health data interface. Including critique of the project’s positioning as “a staff data interface is the answer” and the challenges of building for a dynamically changing, messy, secretive, proprietary world of interconnected systems and changing standards. #### Notes This could become a more general section on “building data interfaces” incorporating some learnings from BBC. not sure if that is best place for this.

### 6.1.2 The Power of Data holders

Starting by looking at idea of shifting the locus of decision Making, linked into the context of chapter 5 (referencing models of power) then moving into the ways in which organisations maintain power today (closed databases - care side, removing the seams and limiting data access and use, non-interoperability etc - commercial side). What are the practical ways to challege this - web augmentation, GDPR-based relentless pressure>dashboards, etc. Personal data stores as solution - huge challenges of building and designing, need to model for everyday life, hard to codify life.

## 6.2 Challenges of Meaning & Sensemaking & Caring

[Target X words]

### 6.2.1 Finding Meaning in data

* Data > Information > Knowledge
* Answering questions
* Reflection & goal setting
* Orienteering

### 6.2.2 Our lives in data

* How to not overwhelm people with Information
* the need to model things in the context of people’s everyday lives
  + bring in life modelling stuff I did at BBC
  + different mental models
* how to get people to care

## 6.3 Where we are and where we need to go

[Target X words]

### 6.3.1 Levels of Access to Data - GDPR critique

[Target X words] My analysis of the effectiveness of GDPR and how i position it as a better-than-it-was but not-good-enough level of access - introduce my model for access

### 6.3.2 Recommendations for future study

Bringing the chapter to a close by recommending the key *practical* ways forward that have the best hope of effecting change.

# 7 Discussion

[Target 10,000 words]

In this chapter we bring together the findings of chapters 4&5 and the insights/learnings/ideas from Chapter 6, to answer the research question and conclude the thesis.

## 7.1 Contribution

[Target X words]

Probably needs a better title but in this section i essentially synthesise the whole thesis to make its specific contributions crystal clear - Understandings of people’s thinking about data - Models for thinking about data, human-data interaction and data within relationships - Practical techniques for taking power - and their limitations

## 7.2 Answering the Research Question

[Target X words]

In short, people need to see, understand, ask questions of their data, and use it, in the context of their own lives.

### 7.2.1 People need to see and understand their data

[Target X words]

* Access
* Legibility
* Meaningfulness
* effectiveness
* Exploration, orienteering, Associativity

### 7.2.2 People need to be able to ask questions of their data

[Target X words]

* who/why/where/what/when
* provenance
* errors
* completeness
* Reflection - more complex questions

### 7.2.3 People need to be able use their data in the context of their lives

[Target X words]

* Whose data is it
* Data as a usable resource for individuals (actually, as information, not data)
* Overcoming platform independence and silos
* Modelling the world and its challenges - mental models and fuzziness

## 7.3 Conclusion/Future Work

[Target X words]

Wrapping up everything in a few simple paragraphs and making recommendations for the future (research wise, whereas c6 focussed more on the practical). Talk about positioning digital civics wise.

# Bibliography