Acquiring Agency through Personal Data

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# 1 Introduction

[Target 7,000 words]

## 1.1 Personal Data Gathering as a Loss of Agency

[Target X words]

Explaining the current status quo - the inevitability of data collection, and the barriers to individuals and resulting loss of agency and of individual control in relationships with organisations and authorities, including both public sector (chapter 4) and commercial (chapter 5) perspectives.

## 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 capability - getting data in one place, finding things associatively, accessing data for our own ends, using different interfaces, reflection on whole of digital life, etc.

## 1.3 The Research Question

[Target X words]

*How could personal data be used to increase an individual’s control in their everyday lives?*

Sub-questions:

* RQ1. CAPABILITY What awareness of and capabilities do people have over their personal data?
* RQ2. BARRIERS What are the barriers to new data capabilities and how could they be challenged - What capabilities could increase individuals’ control/agency?
* RQ3. DATA/LIFE What relationship do people have with data, what is the role of data in people’s everyday lives
* RQ4. DESIRES What relationship would people seek their data and how would they like to use it?

## 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 data interactions and capabilities
4. Critically review and assess perspectives upon 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 Barriers to Agency

[Target X words]

* The inevitability of being handled through data in the modern world.
* The drive to make people consumers / ad watchers rather than free agents.
* The difficulties in actually accessing and using your data
* …. (more to research here)

## 2.2 Human-centricity

[Target X words]

* Ubicomp: Weiser > Rogers, Abowd. etc.
* Human-Data Interaction > Mortier
* MyData movement
* Humane interfaces / better interaction design

## 2.3 Increasing one’s Agency through and over Data

[Target X words]

* GDPR & other regulatory approaches
* Dynamic Consent
* Shared Decision Making (maybe this should come in Chapter 6 instead)
* Quantified Self, Personal Informatics and Reflection
* Vendor Relationship Management, Pull Computing, Personal Data Stores
* Meaning and Sensemaking, Orienteering, Time, Context & Associativity

# 3 Approach & Methods

[Target 15,000 words]

## 3.1 Research design

[Target X words]

* Explaining how we get from the research questions and literature topics to a set of methods.
* other methodological research approaches I am building upon:
  + Boundary Objects [Star]
  + “Things to think with” [Brandt & Messeter]
  + Participatory co-design
  + Home visits [Mannay]

## 3.2 Methodology

Explaining the methods used, how they relate to research goals.

### 3.2.1 Practical Explorations of real data scenarios [RQ1. CAPABILITY]

[Target X words]

#### 3.2.1.1 GDPR Requests

[Target X words]

Explain the use of GDPR requests to obtain real data, both my own and participants - as an exploration of processes and what is currently possible

#### 3.2.1.2 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).

#### 3.2.1.3 Online Data Review

[Target X words]

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

### 3.2.2 Identifying and overcoming data barriers [RQ2. BARRIERS]

#### 3.2.2.1 Self GDPR

[Target X words]

Explain own explorations with GDPR.

#### 3.2.2.2 Web augmentation and disruption

[Target X words]

Explain work on web augmentation as a way to get data and/or build new capabilities.

#### 3.2.2.3 Prototyping and Data Scripting Experiments

[Target X words]

Explain own explorations with using data from GDPR (saving detail for C5/6)

### 3.2.3 Engaging people with data, understanding their perspectives [RQ3. DATA/LIFE]

[Target X words]

#### 3.2.3.1 Data Cards and Card Sorting Techniques

[Target X words]

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

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.

#### 3.2.3.2 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.

#### 3.2.3.3 Family Facts

[Target X words]

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

#### 3.2.3.4 Private Data Viewing

[Target X words]

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

### 3.2.4 Designing a world with greater agency [RQ4. DESIRES]

#### 3.2.4.1 Co-Design workshops

[Target X words]

Describe use of co-design workshops in family homes and in bigger groups.

#### 3.2.4.2 Qualitative interviews

[Target X words]

Describe use of 1:1 interviews.

#### 3.2.4.3 Ideation Grids

[Target X words]

Quick explainer and reference to Golembewski

#### 3.2.4.4 Sentence Ranking

[Target X words]

Describe sentence ranking exercises done in 2018 study

#### 3.2.4.5 Group Poster Making

[Target X words]

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

#### 3.2.4.6 Data Modelling, Interface Prototyping

[Target X words]

Explain the exploratory work I have done through SILVER & BBC in developing interfaces as well as the work to model different levels of access / mental models of data.

### 3.2.5 Notes

How to give overview of my involvements with study partners/placements (SILVER/councils/BBC…?)

# 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

## 4.3 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

## 4.4 Discussion

[Target X words]

From CHI 2018 paper and From CHI 2019 LBW paper and unpublished journal paper. But also wider discussion with a greater focus on tying everything back to the research question and agency-increasing framing.

include:

### 4.4.1 SILVER project

[Target X words]

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.

# 5 Human-Data Interaction in Everyday Life

[Target 15,000 words]

## 5.1 Research Context and Approach

[Target X words]

without repeating 1.2, explain why people have become disempowered - 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
  + including experiments in what you can do with your data.
* 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 creative work
* 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

### 5.3.5 Note

Any findings from University GDPR interview will also incorporate into one of the above subsections

## 5.4 Discussion

[Target X words]

General analysis of findings above. But also wider discussion with a greater focus on tying everything back to the research question and agency-increasing framing.

### 5.4.1 Challenges of Meaning & Sensemaking & Caring

[Target X words]

#### 5.4.1.1 Finding Meaning in data

[Target X words]

* Data > Information > Knowledge
* Answering questions
* Reflection & goal setting
* Orienteering
* scripts analysing GDPR-retrieved Data
* Gmail API hacking

#### 5.4.1.2 Our lives in data

[Target X words]

* 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 (models & prototypes) I did at BBC
  + different mental models
* how to get people to care

### 5.4.2 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 Increasing Agency Through Web Augmentation

[Target 3,000 words]

This is a short chapter describing the work I did with web augmentation as a means to challenge data-holder power.

## 6.1 Research context

[Target X words]

* Seams [Weiser] and how to overcome them.
* Web augmentation as a means to do that, without provider permission.
* Scraping / webcrawling.

## 6.2 What was Done

[Target X words]

### 6.2.1 Just Eat scenario

* Just Eat web augmentation to show how interfaces can be changed on user side

### 6.2.2 Facebook scenario

* web augmentation to gather Facebook posts to view elsewhere (given Facebook restricts this)

## 6.3 Discussion

[Target X words]

Discussing the implications of this technique, and its limitations, with reference to the overall research question and acquiring agency.

# 7 Discussion

[Target 8,000 words]

In this chapter we bring together the findings of chapters 4 & 5 & 6, to answer the research question and conclude the thesis.

### 7.0.1 The Power of Data holders

[Target X words]

* Looking at gaining agency as shifting the locus of decision Making in a relationship.
* Introduce and reference some models of power/data-power
  + Foucault
  + Zuboff
  + Habermas
  + power of Facebook/data serfs etc
  + other models…
* then moving into the ways in which organisations maintain power today
  + Care side:
    - closed databases
    - non inclusive processes
  + Commercial side:
    - removing the seams
    - lack of human contact
    - limiting data access and use, non-interoperability etc
* What are the practical ways to challenge this
  + web augmentation,
  + GDPR-based relentless pressure>dashboards,
  + greater involvement in processes (though that is challenging)
  + better data literacy and education
  + Personal data stores as solution - huge challenges of building and designing, need to model for everyday life, hard to codify life.

## 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