The Power of Personal Data

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# 1 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

## 1.1 Barriers and Realities of Trying to Effect change

[Target X words]

### 1.1.1 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.

#### 1.1.1.1 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.

### 1.1.2 The Power of Data holders

[Target X words]

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 challenge 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.

## 1.2 Challenges of Meaning & Sensemaking & Caring

[Target X words]

### 1.2.1 Finding Meaning in data

[Target X words]

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

### 1.2.2 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 I did at BBC
  + different mental models
* how to get people to care

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

[Target X words]

### 1.3.1 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

### 1.3.2 Recommendations for future study

[Target X words]

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

# Bibliography