Understanding and Improving Human Data Relations

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6 Discussion Part 1: An Understanding of Human Data Relations

It will be already evident to the reader that there are significant overlaps and parallels to be drawn across the findings and discursive insights in Case Study One and Two. In this mini-discussion chapter, I will draw on both Chapter 4 and Chapter 5 to produce a unified summary of findings and insights in terms of the first two research subquestions RQ1 and RQ2. To recap on the research objectives expressed in 3.3, these two RQs are:

- RQ1: "What is the human experience of personal data, and what do people want from their data?"
- RQ2: "What role does data play in people's service relationships and how could relationships involving data be improved?"

The answers to these research questions are best expressed as an understanding of individual *wants* relating to data. The word 'want' is used here in a broader sense than its everyday meaning, referring to the *lack* of something that would be beneficial (which may or may not be accompanied by conscious desire). By framing our accumulated understandings from the Case Studies in this way, we are exposing both the problem - the things that individuals do not have or cannot do, while also identifying the goals that any imagined solutions or improvements to the status quo would need to address. It logically follows that any solution that better delivers on individual *data wants* will lead to improved relations between individuals and their data. This is how we can conceptualise "Human Data Relations" as alluded to in the title of this thesis, and indeed this gives us a yardstick against which to understand what "better" means, which will be explored in Chapter 8. *"Human Data Relations"* is a term that I introduce here to expand upon the established theory of Human Data

Interaction (Mortier *et al.*, [2013](#), [2014](#)) in light of the Case Studies' findings from a more sociotechnical, interpersonal point of view. Humans have two kinds of relationships with data: *direct* interaction (such as through an interface in an app or website) and *indirect* interaction (through interacting with services, providers or individual representatives who themselves have access to personal data about the individual). Thus, Human Data Relations is a term that can encompass both the relationship humans have with their data, but also the relationships they have in which data plays an indirect role. In this context, RQ1 and RQ2 map quite cleanly onto these two types of Human Data Relations, and in answering RQ1 we can identify what people want from direct data relations, while RQ2 helps provide an answer as to what people want from indirect data relations.

6.1 Answering RQ1: What do people want in *direct* data relations?

By comparing and grouping elements of the findings from Case Study One (see 4.3) and from Case Study Two (see 5.4), three distinct data wants are evident when considering *direct* data relations:

1. *Awareness*: People need to have knowledge of the data and an ability to see it,
2. *Understanding*: People need to be able to interpret this data to extract meaningful information from it (and about it), and
3. *Agency*: People need to be able to take action upon this data, use it to serve their goals, and gain personal value from it.

These wants are detailed in the following sections:

6.1.1 Awareness

6.1.2 Understanding

6.1.3 Agency

6.2 Answering RQ2: What do people want in *indirect* data relations?

By comparing and grouping elements of the findings from Case Study One (see 4.3) and from Case Study Two (see 5.4), especially in the context of individual relationships with care providers and digital service providers respectively, three distinct data wants are evident when considering *indirect* data relations:

1. *Transparency*: People need to know what data is being collected or held, and how it is being used, for their accountability and safety,
2. *Oversight*: People need the ability to affect what data is held and how it is used, including deleting data or withdrawing consent for certain uses,
3. *Involvement*: People need to be involved in decision-making based upon their data, so that they are not misrepresented and their needs are not overlooked.

These wants are detailed in the following sections:

6.2.1 Transparency

6.2.2 Oversight

6.2.3 Involvement

Bibliography

Mortier, R. *et al.* (2013) 'Challenges & opportunities in human-data interaction', *University of Cambridge, Computer Laboratory*. Citeseer. doi: 10.5210/fm.v17i5.4013.

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