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. All data about them needs to be:

1. *Visible*: People need to have knowledge of data about them and an ability to see it,
2. *Understandable*: People need to be able to interpret this data to extract meaningful information from it (and about it), and
3. *Useable*: People need to be able to take action upon this data, including exploring it, using it to serve their goals, and gaining personal value from it.

These wants are detailed in the following sections:

6.1.1 Visible

1. Data matters now, where previously it did not.
2. Data sacrifice is demanded, creating a risk.
3. Once data enters the closed and opaque ecosystem, they lose access and become unaware of storage and use.
4. People want to be informed and able to see what is hidden from them.
5. Access to this data has to be effective.
6. Access needs to be available at the right time, and ongoing.
7. Systemic support is needed, including governancy, advocacy and asssistance
8. If data is not visible, this leads to subjection and exclusion.

6.1.2 Understandable

1. Access to data is not enough, need to be able to interpret it.
2. Understandable summaries of information content and context are needed.
3. Information and visualisations should be arranged and optimised for understanding.
4. Information becomes most meaningful when it is recognisable and relatable and can be mapped back to life experiences.
5. In practice, ongoing human support is needed to facilitate the understanding of data.
6. If data is not understandable, distrust can arise.

6.1.3 Useable

1. People need to be able to explore and interrogate data and ask questions of it.

2. The data needs to be useable, which means correctly formatted and explained in a portable and standardised form.
3. The data needs to be explorable from a temporal perspective, which implies the ability to interact with the data is necessary.
4. If holders make data unusable, this is a barrier to individual agency and power.
5. Unusable data leads to disengagement and impairs individual independent action in society.

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 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 invited and 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

1. People need a window into how one's data is used - process transparency.
2. Process transparency is required to enable accountability.
3. There is no accountability, processes are not transparent, and thus power remains imbalanced.
4. Even after using available transparency rights, people face an incomplete picture from and of their data.
5. Trust of data holders is needed, and gaps in transparency create distrust and a risk of broken expectations, harming relations.
6. Trust can be gained through transparency, which offers an opportunity to improve relations.
7. Transparency of data and processes enables individual action and facilitates the levelling of power balance.

6.2.2 Oversight

1. Data visibility + Process transparency naturally lead to a desire for individual oversight - if you see something that is 'not right', you are motivated to want to fix it.
2. We need to be able to oversee data use for fairness, accuracy and the reduction of risk.
3. The ability for individuals to meaningfully oversee the use of their data requires governance, so that they can effect the changes they desire.
4. Individual oversight of data use brings the individual back to the centre of their data ecosystem as as an active participant.
5. Given the changing nature of human life, all data is dynamic, consent is never complete, so longitudinal participation and oversight is needed.
6. There is very little oversight and governance available today.

7. Ultimately oversight means having choices, which is essential in the data-centric world. Without individual oversight, there is no choice and people remain powerless.

6.2.3 Involvement

1. There is a need to consider the human behind the data, people are not records and can never be fully reduced to data.
2. Consent to access and use data needs to be dynamic and meaningful, which can only happen through ongoing involvement.
3. A human channel for conversation is needed, to enable explanations, questions, and consultation.
4. Individuals should be consulted in decision-making, which improves accuracy, consideration, and fairness.
5. Effective collaboration can be achieved by bringing data subject and data holder together around the data, using it as evidence (of facts or opinions) and as a boundary object.
6. Being involved means being able to learn and act at any time, including on one's own and away from official contact or interactions with service representatives.
7. Data use enforces an uneasy trust; services need a human face or point of contact, in order to earn trust and improve relations.
8. Without involvement, people can never take a full and equitable role in processes that affect their life.

6.3 Achieving Individual Empowerment

1. Through these summarised insights, I have shown a multifacted set of needs and opportunities around data access and use. While all six of these data wants can produce improvements in their own right, the combination of all six is likely to produce more than the sum of its parts, an empowered form of digital citizen.

2. Giving people a role as co-stewards of their own data and involved in decision-making would be progressive and transformative, and this could be applied in different domains across society.

3. We can envision from this a new fully human-centred (or at least power-balanced) future - cooperative data stewardship and empowered, involved citizens.

Bibliography

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

Mortier, R. *et al.* (2014) 'Human-data interaction: The human face of the data-driven society', *Available at SSRN 2508051*. doi: 10.2139/ssrn.2508051.