Understanding and Improving Human Data Relations

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Frontmatter

Abstract

Technologies including PCs, smartphones, and cloud computing have transformed the world: In our daily lives we interact with many businesses and public services who (to reduce costs) increasingly seek to rely on data collection and processing rather than face-to-face user interactions to inform their decisions. This creates an *imbalance of power* between those who hold data and the individuals about whom data is stored, who cannot easily see their personal data or how it is used. This *Digital Civics* PhD research explores, from a pragmatic, constructivist perspective, the topic of *Human Data Relations*. Through two qualitative

case studies across public and private sectors, it answers the question, *"What relationship do people need with their personal data?"*. Case Study One focuses on *Early Help* social care: Through four workshops with supported families, social workers and staff, a deep understanding of the individual perspective on civic personal data use is established. *Shared data interaction* is explored as a means to shift the balance of power towards the individual while maintaining an effective care relationship. Case Study Two is a three-month study exploring 10 participants' experience of using *GDPR data access rights* to view their own data, resulting in insights into individual needs and the challenges of data-centric service relationships, and recommendations for improvement of policies and practices. With reference to literature from the fields of *Personal Information Management*, *Human Data Interaction* and *MyData* personal data ecosystems, these case studies contribute to a unified understanding of *six core needs* that people have in Human Data Relations. In the final chapter, the thesis discusses the *practical pursuit* of these goals, drawing on first-hand knowledge acquired from expert participation in industrial research projects at BBC R&D and Hestia.ai/SITRA, mapping out the *landscape for future research and innovation.*

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Glossary of Abbreviations, Names and Terms

- **HDI - Human Data Interaction** -
- **HII - Human Information Interaction** -
- **Quantified Self** - see SI
- **Personal Informatics** - see SI
- **GDPR** - General Data Protection Regulation [[REF] ()]
- **SI - Self Informatics** - Self Informatics [[REF] ()]
- **PIM - Personal Information Management** -
- **MyData** -
- **SILVER** -
- **DERC** -
- **DIKW pyramid** -
- **civic hacking** -
- **VRM - Vendor Relationship Management** -
- **Open Lab** -
- **EPSRC** -
- **CHC** - Connected Health Cities
- **Seams** -
- **Web Augmentation** -
- **Scraping** -
- **PDV** - Personal Data Vaults - See Personal Data Lockers
- **PDS** - Personal Data Store - See Personal Data Lockers
- **PIMS** - Personal Information Management Services - See Personal Data Lockers
- **Personal Data Lockers** -
- **Early Help** -
- **Data Brokers** -
- **Personal Data Ecosystems** -
- **Personal Data Economy** -

- **Troubled Families** -
- **Infrastructural Power, and its Four Levers** -
- **Participatory Action Research**
- **Pragmatism** -
- **Constructivism** -
- **Digital Civics** -
- **Value-centred Design** -
- **Experience-centred Design** -
- **User-centred Design** -
- **Action Research** -
- **Data: Metadata** -
- **Data: Volunteered Data** -
- **Data: Derived Data** -
- **Data: Acquired Data** -
- **Data: Observed Data** -
- **Data Provenance** -
- **Point of Severance** -
- **Dynamic Consent** -
- **Power - Infrastructural Power** -
- **Gatekeeper**-
- **Support Worker** -
- **Life Sketching** -
- **[ADD ALL TYPES OF POWER] -

Bibliography