

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*.

Acknowledgements

Lists of Tables and Figures

Lists of Tables by Chapter

Tables in Chapter N

- **Table N.n** - Description goes here

Lists of Figures by Chapter

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Index of Key Ideas, Insights and Contributions

- **Human Data Relations** - [ADD SECTIONREF]
- **Life Information Utilisation** - [ADD SECTIONREF]
- **Personal Data Ecosystem Control** - [ADD SECTIONREF]
- **Life Information** - [ADD SECTIONREF]
- **Ecosystem Information** - [ADD SECTIONREF]
- **Human Information** - see Life Information and Ecosystem Information

- **Data Cards** - [ADD SECTIONREF]
- **Storyboarding Cards** - [ADD SECTIONREF]
- **Shared Data Interaction** - [ADD SECTIONREF]
- **Life Concepts** - [ADD SECTIONREF]
- **Categories of Family Civic Data** - [ADD SECTIONREF]
- **Categories of Personal Data** - [ADD SECTIONREF]
- **Types of Personal Data (by origin)** - [ADD SECTIONREF]
- **Trust in Providers** - [ADD SECTIONREF]
- **Perceived Individual Power** - [ADD SECTIONREF]
- **Human Information Operating System** - [ADD SECTIONREF]
- **Proxy Representations of Immobile Data** - [ADD SECTIONREF]
- **Free Data Interfaces** - [ADD SECTIONREF]
- **Personal Data as a Proxy for Involvement** - [ADD SECTIONREF]
- **Locus of Decision-making** - ### HDR Wants {.unnumbered}
- **Data Visibility** - [ADD SECTIONREF]
- **Data Understanding** - [ADD SECTIONREF]
- **Data Useability**¹⁵ - [ADD SECTIONREF]
- **Process Transparency** - [ADD SECTIONREF]
- **Individual Oversight** - [ADD SECTIONREF]
- **Involvement in Decision-making** - [ADD SECTIONREF]

HDR Objectives

- **Data Awareness & Understanding** - [ADD SECTIONREF]
- **Data Useability** - [ADD SECTIONREF]
- **Ecosystem Awareness & Understanding** - [ADD SECTIONREF]
- **Ecosystem Negotiability** - [ADD SECTIONREF]
- **Effective, Commercially Viable and Desirable Systems** - [ADD SECTIONREF]

HDR Obstacles

- **Invisible Data** - [ADD SECTIONREF]
- **Inaccessible Data** - [ADD SECTIONREF]
- **Unrelatable Data** - [ADD SECTIONREF]
- **Immobile Data** - [ADD SECTIONREF]
- **Inaccessible Data** - [ADD SECTIONREF]

- **Unmalleable Data** - [ADD SECTIONREF]
- **Non-Interrogable Data** - [ADD SECTIONREF]
- **Increasing Data Holder Hegemony** - [ADD SECTIONREF]
- **Diminishing Individual Agency** - [ADD SECTIONREF]
- **Closed, Insular and Introspective Practices** - [ADD SECTIONREF]
- **Lack of Provider Investment** - [ADD SECTIONREF]
- **Lack of Individual Demand** - [ADD SECTIONREF]
- **Lack of Interoperability** - [ADD SECTIONREF]
- **Insufficient Machine Understanding of Human Data** - [ADD SECTIONREF]
- **The Inaccessible Data Self** - [ADD SECTIONREF]

HDR Insights & Approaches

- **Life Information Makes Data Relatable** - [ADD SECTIONREF]
- **Ecosystem Information Is an Antidote to Digital Life Complexity** - [ADD SECTIONREF]
- **Data Needs to be United and Unified** - [ADD SECTIONREF]
- **Data Must Be Transformed into a Versatile Material** - [ADD SECTIONREF]
- **We Must Know Data's Provenance** - [ADD SECTIONREF]
- **HDR Systems Must Offer New Life Capabilities and Pain Relief** - [ADD SECTIONREF]
- **We Need to Teach Computers to Understand Human Information** - [ADD SECTIONREF]
- **The Four Levers of Infrastructural Power** - [ADD REF]

[ADD OTHER INSIGHTS HERE]

- **Discovery-Driven Activism** - [ADD SECTIONREF]
- **Building the Human-Centric Future** - [ADD SECTIONREF]
- **Defending Autonomy and Nurturing the Information Landscape** - [ADD SECTIONREF]
- **Teaching, Championing and Selling the HDR Vision** - [ADD SECTIONREF]
- **The Power of Data Collectives** - [ADD SECTIONREF]
- **The Importance of Seams**
- **The Nascent Data Understanding Industry** - [ADD SECTIONREF]
- **Auditing Data Holders** - [ADD SECTIONREF]
- **Life Partitioning** - [ADD SECTIONREF]
- **Entity Extraction** - [ADD SECTIONREF]
- **Digital Self Curation** - [ADD SECTIONREF]
- **Inclusive Data Flows** - [ADD SECTIONREF]
- **Surface Information Injustices** - [ADD SECTIONREF]
- **Data Literacy in an HDR Context** - [ADD SECTIONREF]

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 -**
- **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 -**
- **The Four Levers of Infrastructural Power -**
- **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** -
- ****[ADD ALL TYPES OF POWER]** -

Bibliography