

# Understanding and Improving Human Data Relations

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## Contents

|   |          |
|---|----------|
| <b>Frontmatter</b>                                    | <b>1</b> |
| Abstract . . . . .                                    | 1        |
| <b>Acknowledgements</b>                               | <b>2</b> |
| <b>Lists of Tables and Figures</b>                    | <b>2</b> |
| Lists of Tables by Chapter . . . . .                  | 2        |
| Tables in Chapter N . . . . .                         | 2        |
| Lists of Figures by Chapter . . . . .                 | 2        |
| Figures in Chapter N . . . . .                        | 2        |
| <b>Index of Key Ideas, Insights and Contributions</b> | <b>2</b> |
| HDR Objectives . . . . .                              | 3        |
| HDR Obstacles . . . . .                               | 3        |
| HDR Insights & Approaches . . . . .                   | 4        |
| <b>Glossary of Abbreviations, Names and Terms</b>     | <b>5</b> |
| <b>Bibliography</b>                                   | <b>6</b> |

## 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

#### Figures in Chapter N

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

## 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**<sup>15</sup> - [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**

- **Insight 1: Life Information Makes Data Relatable** - [ADD SECTIONREF]
- **Insight 2: Ecosystem Information Is an Antidote to Digital Life Complexity** - [ADD SECTIONREF]
- **Insight 3: Data Needs to be United and Unified** - [ADD SECTIONREF]
- **Insight 4: Data Must Be Transformed into a Versatile Material.** - [ADD SECTIONREF]
- **Insight 5: We Must Know Data's Provenance.** - [ADD SECTIONREF]
- **Insight 6: Data Holders use Four Levers of Infrastructural Power.** - [ADD REF]
- **Insight 7: Human-centred Information Systems Must Serve Human Values, Relieve Pain and Deliver New Life Capabilities.** - [ADD REF]
- **Insight 8: We Need to Teach Computers To Understand Human Information.** - [ADD REF]
- **Insight 9: Individual GDPR requests can compel companies to change data practices.** - [ADD REF]
- **Insight 10: Collectives can compare and unify their data and use it to demand change.** - [ADD REF]
- **Insight 11: Automating the identification of Entities can enhance machine understanding and unburden information management system users.**
- **Insight 12: The 'Seams' of Digital Services need to be identified, exploited and protected.** - [ADD REF]
- **Insight 13: It is possible to demonstrate business benefits of Transparency and Human-centricity.** - [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** -
- **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