Understanding and Improving Human Data Relations

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Table of Contents

# 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**[15](#fn15) - [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