

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

Figures in Chapter N

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

Index of Key Ideas, Insights and Contributions

- **Categories of Family Civic Data** - [ADD SECTIONREF]
- **Categories of Personal Data** - [ADD SECTIONREF]
- **Data Access & Understanding Services** - [ADD SECTIONREF]
- **Data Cards** - [ADD SECTIONREF]
- **Data Wants** - [ADD SECTIONREF]
- **Ecosystem Information** - [ADD SECTIONREF]
- **Ecosystem Negotiability** - [ADD SECTIONREF]
- **Free Data Interfaces** - [ADD SECTIONREF]

- **Human Data Relations** - [ADD SECTIONREF]
- **Human Information Operating System** - [ADD SECTIONREF]
- **Human Information** - see Life Information and Ecosystem Information
- **Landscape of HDR Opportunity** - [ADD SECTIONREF]
- **Life Concepts** - [ADD SECTIONREF]
- **Life Information Utilisation** - [ADD SECTIONREF]
- **Life Information** - [ADD SECTIONREF]
- **Life Interface** - [ADD SECTIONREF]
- **Life Partitioning** - [ADD SECTIONREF]
- **Locus of Decision-making** - [ADD SECTIONREF]
- **Perceived Individual Power** - [ADD SECTIONREF]
- **Personal Data Ecosystem Control** - [ADD SECTIONREF]
- **Personal Data as a Proxy for Involvement** - [ADD SECTIONREF]
- **Personal Data Stewardship** - [ADD SECTIONREF]
- **Proxy Representations of Immobile Data** - [ADD SECTIONREF]
- **Shared Data Interaction** - [ADD SECTIONREF]
- **Storyboarding Cards** - [ADD SECTIONREF]
- **Trust in Providers, effects upon** - [ADD SECTIONREF]
- **Types of Personal Data (by origin)** - [ADD SECTIONREF]
- **Useability¹⁵** (as distinct from Usability) - 6.1.3]

HDR Wants

- **Direct Data Want 1: Data Visibility** - [ADD SECTIONREF]
- **Direct Data Want 2: Data Understanding** - [ADD SECTIONREF]
- **Direct Data Want 3: Data Useability¹⁵** - [ADD SECTIONREF]
- **Indirect Data Want 1: Process Transparency** - [ADD SECTIONREF]
- **Indirect Data Want 2: Individual Oversight** - [ADD SECTIONREF]
- **Indirect Data Want 3: Involvement in Decision-making** - [ADD SECTIONREF]

HDR Objectives

- **HDR Objective 1: Data Awareness & Understanding** - [ADD SECTIONREF]
- **HDR Objective 2: Data Useability¹⁵** - [ADD SECTIONREF]
- **HDR Objective 3: Ecosystem Awareness & Understanding** - [ADD SECTIONREF]
- **HDR Objective 4: Ecosystem Negotiability** - [ADD SECTIONREF]
- **HDR Objective 5: Effective, Commercially Viable and Desirable HDR Systems** - [ADD SECTIONREF]

HDR Obstacles

- **Closed, Insular and Introspective Practices** - [ADD SECTIONREF]
- **Diminishing Individual Agency** - [ADD SECTIONREF]
- **Immobile Data** - [ADD SECTIONREF]

- **Inaccessible Data** - [ADD SECTIONREF]
- **Increasing Data Holder Hegemony** - [ADD SECTIONREF]
- **Insufficient Machine Understanding of Human Data** - [ADD SECTIONREF]
- **Intractable Data Self, the** - [ADD SECTIONREF]
- **Invisible Data** - [ADD SECTIONREF]
- **Lack of Individual Demand** - [ADD SECTIONREF]
- **Lack of Interoperability** - [ADD SECTIONREF]
- **Lack of Provider Investment** - [ADD SECTIONREF]
- **Non-Interrogable Data** - [ADD SECTIONREF]
- **Unmalleable Data** - [ADD SECTIONREF]
- **Unrelatable Data** - [ADD SECTIONREF]

HDR Insights & Approaches

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

SECTIONREF]

- **HDR Approach 3: Defending Autonomy and Nurturing the Information Landscape** - [ADD SECTIONREF]
- **HDR Approach 4: Teaching, Championing and Selling the HDR Vision** - [ADD SECTIONREF]
- **Data Access & Understanding Services** - [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]

[TODO Move the following Glossary to the end, after references]

Glossary of Pre-Existing Abbreviations, Names and Terms

- **Action (stage of Personal Informatics)** - see SI
- **Action Research** -
- **Activism** -
- **Agency** -
- **BBC R&D** -
- **CHC - Connected Health Cities** -
- **Civic Hacking** -
- **Collection (stage of Personal Informatics)** - see SI
- **Consent, Dynamic** -
- **Consent, Informed** -
- **Constructivism** -
- **Conceptual Anchors** -
- **Context-aware Computing** -
- **Data Brokers** -
- **Data Download Portal** -
- **Data Flow Auditing** -
- **Data Portability Request** -
- **Data Provenance** -
- **Data Self** -
- **Data Transcendence** -
- **Data (general)** -
- **Data, Civic / Family Civic** -
- **Data, Acquired** -
- **Data, Derived** -
- **Data, Metadata** -
- **Data, Observed** -

- Data, Volunteered -
- DERC -
- Design, Experience-centred -
- Design, User-centred Design -
- Design, Value-centred Design -
- Digital Civics -
- Digital Self - see Data Self
- DIKW pyramid -
- DPA - Data Protection Authority -
- DPO - Data Protection Officer -
- EPSRC -
- Early Help -
- Effective Access -
- Embodied Interaction -
- Experience-centred Design -
- File Biography -
- Files, why they need to die -
- GDPR - General Data Protection Regulation [[REF] ()]
- Gatekeeper-
- HDI - Human Data Interaction -
- Hestia.ai -
- HestiaLabs -
- HII - Human Information Interaction -
- ICO - Information Commissioner's Office -
- Ideation Grids -
- Information (general) -
- Information, Human -
- Information, Life -
- Information, Ecosystem -
- Infrastructural Power, and its Four Levers -
- Integration (stage of Personal Informatics) - see SI
- Keeping -
- Legibility -
- Lifelogging -
- Lifestreams -
- Lenses -
- Life Sketching -
- Magical Design -
- MyData -
- Negotiability
- Open Lab -
- Orienteering -
- PDS - Personal Data Store- See Personal Data Lockers
- PIM - Personal Information Management -
- PIM systems, contextual -
- PIM systems, networked -

- **PIM systems, semantic -**
- **PIM systems, spatial -**
- **PIM systems, subjective -**
- **PIM systems, temporal -**
- **PIMS - Personal Information Management Services - See Personal Data Lockers**
- **Participatory Action Research**
- **Personal Data Economy, the -**
- **Personal Data Economy, one's own -**
- **Personal Data Ecosystems -**
- **Personal Data Lockers -**
- **Personal Data Vault - See Personal Data Lockers**
- **Personal Informatics - see SI**
- **Preparation (stage of Personal Informatics) - see SI**
- **Perspectives -**
- **Point of Severance -**
- **Power - Behavioural Influence -**
- **Power - Interpretative Influence -**
- **Power - Network Centrality -**
- **Power, Authority -**
- **Power, Disciplinary -**
- **Power, Infrastructural -**
- **Power, Interpretive -**
- **Power, Processual -**
- **Power, Rational -**
- **Power, Resource Control -**
- **Power, Socially-shaped -**
- **Power, Systems/Structural - see Infrastructural Power**
- **Power, Zero Sum -**
- **Pragmatism -**
- **QSM - Quantified Self Movement - see SI**
- **Reflection (stage of Personal Informatics) - see SI**
- **Recursive Public -**
- **Reminding -**
- **SAR - Subject Access Request -**
- **SI - Self Informatics - Self Informatics [[REF] ()]**
- **SILVER -**
- **Sitra -**
- **Scraping -**
- **Seams -**
- **Subjective Classification Principle -**
- **Subjective Importance Principle -**
- **Subjective Context Principle -**
- **Support Worker -**
- **Supported Family -**
- **ToC - Theories of Change -**

- **Timelines -**
- **Troubled Families -**
- **VRM - Vendor Relationship Management -**
- **Web Augmentation -**

[TODO add all the actions from 2.1.4, 2.2.2, 2.2.3 here]

Bibliography