

# 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
- **Inclusive Data Flows** - [ADD SECTIONREF]
- **Information Standards** - [ADD SECTIONREF]
- **Landscape of HDR Opportunity** - [ADD SECTIONREF]
- **Life Concepts** - [ADD SECTIONREF]
- **Life Information Utilisation** - [ADD SECTIONREF]
- **Life Information** - [ADD SECTIONREF]
- **Life Interface Design** - [ADD SECTIONREF]
- **Life Partitioning** - [ADD SECTIONREF]
- **Locus of Decision-making** - [ADD SECTIONREF]
- **Perceived Individual Power** - [ADD SECTIONREF]
- **Personal Data Diaspora, the** - [ADD SECTIONREF]
- **Personal Data Ecosystem Control** - [ADD SECTIONREF]
- **Personal Data as a Proxy for Involvement** - [ADD SECTIONREF]
- **Personal Data Stewardship** - [ADD SECTIONREF]
- **Pushing the Seams** - [ADD SECTIONREF]
- **Proxy Representations of Immobile Data** - [ADD SECTIONREF]
- **Shared Data Interaction** - [ADD SECTIONREF]
- **Surface Information Injustices** - [ADD SECTIONREF]
- **Storyboarding Cards** - [ADD SECTIONREF]
- **Trust in Providers, effects upon** - [ADD SECTIONREF]
- **Types of Personal Data (by origin)** - [ADD SECTIONREF]
- **Useability<sup>15</sup>** (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 Useability<sup>15</sup>** - [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 Useability<sup>15</sup>** - [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 Life Interface 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 User Autonomy and Hacking 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** -
- **Accessibility Tags (ARIA)** -
- **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** -
- **Cornmarket** -
- **Critical Algorithm Studies** -
- **Data Access and Understanding Services** -
- **Data Brokers** -
- **Data Download Portal** -
- **Data Flow Auditing** -
- **Data Justice** -

- 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 -
- Data, Trapped -
- DERC -
- Design, Adversarial -
- Design, Design After -
- Design, Disrespectful -
- Design, Experience-centred -
- Design, User-centred Design -
- Design, Value-centred Design -
- Device Tenancy -
- Digital Civics -
- Digital Self - see Data Self
- DIKW pyramid -
- DPA - Data Protection Authority -
- DPO - Data Protection Officer -
- EPSRC -
- Early Help -
- Effective Access -
- Embodied Interaction -
- Empowerment in Use -
- Entities -
- Explainable AI -
- Faceted Search -
- Entity Extraction -
- File Biography -
- Files, why they need to die -
- GDPR - General Data Protection Regulation [[REF] () ]
- Gatekeeper-
- HCI - Human Computer Interaction -
- HDI - Human Data Interaction -
- Hestia.ai -
- HestiaLabs -
- HII - Human Information Interaction -
- Humane Technology -
- ICO - Information Commissioner's Office -
- Ideation Grids -

- **Information (general)** -
- **Information, Human** -
- **Information, Life** -
- **Information, Ecosystem** -
- **Information Landscape** -
- **Infrastructural Power, and its Four Levers** -
- **Integration (stage of Personal Informatics)** - see Self Informatics
- **Keeping** -
- **Legibility** -
- **Lifelogging** -
- **Lifestreams** -
- **Lenses** -
- **Life Sketching** -
- **Magical Design** -
- **MyData** -
- **Negotiability**
- **NER - Named Entity Recognition** - see Entity Extraction
- **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**
- **PDE - Personal Data Economy** -
- **Personal Data Ecosystem** -
- **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** -
- **Text Mining** -
- **ToC - Theories of Change** -
- **Timelines** -
- **TrackerControl** - see Data Flow Auditing.
- **Troubled Families** -
- **VRM - Vendor Relationship Management** -
- **Web Augmentation** -
- **Web Extensions** -
- **world2vec** -

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

## Bibliography