Understanding and Improving Human Data Relations

Alex Bowyer

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

* **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]
* **Useability**[15](#fn15) (as distinct from Usability) - [6.1.3](#want-d3)]

### HDR Wants

* [**Direct Data Want 1**](#want-d1)**: Data Visibility** - [ADD SECTIONREF]
* [**Direct Data Want 2**](#want-d2)**: Data Understanding** - [ADD SECTIONREF]
* [**Direct Data Want 3**](#want-d3)**: Data Useability**[15](#fn15) - [ADD SECTIONREF]
* [**Indirect Data Want 1**](#want-i1)**: Process Transparency** - [ADD SECTIONREF]
* [**Indirect Data Want 2**](#want-i2)**: Individual Oversight** - [ADD SECTIONREF]
* [**Indirect Data Want 3**](#want-i3)**: Involvement in Decision-making** - [ADD SECTIONREF]

### HDR Objectives

* [**HDR Objective 1**](#objective-1)**: Data Awareness & Understanding** - [ADD SECTIONREF]
* [**HDR Objective 2**](#objective-2)**: Data Useability**[15](#fn15) - [ADD SECTIONREF]
* [**HDR Objective 3**](#objective-3)**: Ecosystem Awareness & Understanding** - [ADD SECTIONREF]
* [**HDR Objective 4**](#objective-4)**: Ecosystem Negotiability** - [ADD SECTIONREF]
* [**HDR Objective 5**](#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**](#insight-1)**: Life Information Makes Data Relatable** - [ADD SECTIONREF]
* [**HDR Insight 2**](#insight-2)**: Data Needs to be United and Unified** - [ADD SECTIONREF]
* [**HDR Insight 3**](#insight-3)**: Data Must Be Transformed into a Versatile Material.** - [ADD SECTIONREF]
* [**HDR Insight 4**](#insight-4)**: Ecosystem Information Is an Antidote to Digital Life Complexity**] - [ADD SECTIONREF]
* [**HDR Insight 5**](#insight-5)**: We Must Know Data’s Provenance.** - [ADD SECTIONREF]
* [**HDR Insight 6**](#insight-6)**: Data Holders use Four Levers of Infrastructural Power.**] - [ADD REF]
* [**HDR Insight 7**](#insight-7)**: Human-centred Information Systems Must Serve Human Values, Relieve Pain and Deliver New Life Capabilities.** - [ADD REF]
* [**HDR Insight 8**](#insight-8)**: We Need to Teach Computers To Understand Human Information.** - [ADD REF]
* [**HDR Insight 9**](#insight-9)**: Individual GDPR requests can compel companies to change data practices.** - [ADD REF]
* [**HDR Insight 10**](#insight-10)**: Collectives can compare and unify their data and use it to demand change.** - [ADD REF]
* [**HDR Insight 11**](#insight-11)**: Automating the identification of Entities can enhance machine understanding and unburden information management system users.**
* [**HDR Insight 12**](#insight-12)**: The ‘Seams’ of Digital Services need to be identified, exploited and protected.** - [ADD REF]
* [**HDR Insight 13**](#insight-13)**: It is possible to demonstrate business benefits of Transparency and Human-centricity.** - [ADD REF]
* [**HDR Approach 1**](#approach-1)**: Discovery-Driven Activism** - [ADD SECTIONREF]
* [**HDR Approach 2**](#approach-2)**: Building the Human-centric Future** - [ADD SECTIONREF]
* [**HDR Approach 3**](#approach-3)**: Defending Autonomy and Nurturing the Information Landscape** - [ADD SECTIONREF]
* [**HDR Approach 4**](#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