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*.

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[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