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

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* [**HDR Insight 5**](#insight-5)**: We Must Know Data’s Provenance.** - [ADD SECTIONREF]
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* [**HDR Insight 12**](#insight-12)**: The ‘Seams’ of Digital Services need to be identified, exploited and protected.** - [ADD REF]
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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** -
* **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** -
* **Data, Trapped** -
* **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** -
* **Entities** -
* **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** -
* **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 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**
* **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** -
* **Text Mining** -
* **ToC - Theories of Change** -
* **Timelines** -
* **Troubled Families** -
* **VRM - Vendor Relationship Management** -
* **Web Augmentation** -
* **world2vec** -

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

# Bibliography