Understanding and Improving Human Data Relations

Alex Bowyer

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# Appendices

# Appendix A: The Pilot Study: CHI 2018 Paper

For additional context, see [1.3.1](#Xcefc2f8651dab1dca3f5569d5c8495d75f8956a). The paper is on the following pages.

# Appendix B: Ethics Approvals

# Index of Key Ideas, Insights and Contributions

This section serves as both a glossary to explain abbreviations and existing terms used, as well as an index to easily locate key HDR-related concepts, ideas and contributions within this thesis.

### 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**[13](#fn13) - [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**[13](#fn13) - [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 Life Interface 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 (and Necessary) to Demonstrate Business Benefits of Transparency and Human-centricity.** - [ADD REF]

### HDR Approaches

* [**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 User Autonomy and Hacking the Information Landscape** - [ADD SECTIONREF]
* [**HDR Approach 4**](#approach-4)**: Teaching, Championing and Selling the HDR Vision** - [ADD SECTIONREF]

### Contributions and Major Concepts of This Thesis

* **Auditing Data Holders** - [ADD SECTIONREF]
* **Categories of Family Civic Data** - [ADD SECTIONREF]
* **Categories of Personal Data** - [ADD SECTIONREF]
* **Data Access & Understanding Services** - [ADD SECTIONREF]
* **Data Literacy in an HDR Context** - [ADD SECTIONREF]
* **Data Cards** - [ADD SECTIONREF]
* **Data Wants** - [ADD SECTIONREF]
* **Data Relations, Direct** - [ADD SECTIONREF]
* **Data Relations, Indirect** - [ADD SECTIONREF]
* **Digital Self Curation** - [ADD SECTIONREF]
* **Ecosystem Information** - [ADD SECTIONREF]
* **Ecosystem Negotiability** - [ADD SECTIONREF]
* **Empowerment (in the context of data wants)** - [6.3](#X3c10c50990743199cc887aaacd3f88a0a0a026e)
* **Family Design Games** - [ADD SECTIONREF]
* **Family Facts** - [ADD SECTIONREF]
* **Free Data Interfaces** - [ADD SECTIONREF]
* **Human Data Relations (HDR)** - [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]
* **Inclusive Data Flows** - [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 (LDM)** - [ADD SECTIONREF]
* **Meaning in Data** - [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 Action Cards** - [ADD SECTIONREF]
* **Trust in Providers, effects upon** - [ADD SECTIONREF]
* **Types of Personal Data (by origin)** - [ADD SECTIONREF]
* **Useability**[13](#fn13) (as distinct from Usability) - [6.1.3](#want-d3)]

# Glossary of Pre-Existing Abbreviations, Names and Terms

* **Action (stage of Personal Informatics)** - see SI
* **Action Research** - [ADD SECTIONREF] [ADD DEFINITION]
* **Accessibility Tags (ARIA)** - [ADD SECTIONREF] [ADD DEFINITION]
* **Activism** - [ADD SECTIONREF] [ADD DEFINITION]
* **Agency** - [ADD SECTIONREF] [ADD DEFINITION]
* **Barriers Cascade** - [ADD SECTIONREF] [ADD DEFINITION]
* **BBC R&D** - [ADD SECTIONREF] [ADD DEFINITION]
* **Boundary Objects** - [ADD SECTIONREF] [ADD DEFINITION]
* **Card Sorting** - [ADD SECTIONREF] [ADD DEFINITION]
* **CHC - Connected Health Cities** - [ADD SECTIONREF] [ADD DEFINITION]
* **Civic Hacking** - [ADD SECTIONREF] [ADD DEFINITION]
* **Civil Libertarianism** - [ADD SECTIONREF] [ADD DEFINITION]
* **Collection (stage of Personal Informatics)** - see SI
* **Consent, Dynamic** - [ADD SECTIONREF] [ADD DEFINITION]
* **Consent, Informed** - [ADD SECTIONREF] [ADD DEFINITION]
* **Constructivism** - [ADD SECTIONREF] [ADD DEFINITION]
* **Conceptual Anchors** - [ADD SECTIONREF] [ADD DEFINITION]
* **Context-aware Computing** - [ADD SECTIONREF] [ADD DEFINITION]
* **Co-experience** - [ADD SECTIONREF] [ADD DEFINITION]
* **Cornmarket** - [ADD SECTIONREF] [ADD DEFINITION]
* **Critical Algorithm Studies** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Access and Understanding Services** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Access Request** - see Subject Access Request
* **Data Brokers** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Controller** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Download Portal** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Flow Auditing** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Justice** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Portability Request** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Processor** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Provenance** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Self** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Subject** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data Transcendence** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data (general)** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Civic / Family Civic** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Acquired** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Derived** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Metadata** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Observed** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Personal** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Volunteered** - [ADD SECTIONREF] [ADD DEFINITION]
* **Data, Trapped** - [ADD SECTIONREF] [ADD DEFINITION]
* **DERC** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Co-** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Adversarial** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Design After** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Disrespectful** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Experience-centred** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Magical** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, User-centred Design** - [ADD SECTIONREF] [ADD DEFINITION]
* **Design, Value-centred Design** - [ADD SECTIONREF] [ADD DEFINITION]
* **Device Tenancy** - [ADD SECTIONREF] [ADD DEFINITION]
* **Digital Civics** - [ADD SECTIONREF] [ADD DEFINITION]
* **Digital Self** - see Data Self
* **DIKW pyramid** - see Wisdom Curve
* **Double Diamond** - [ADD SECTIONREF] [ADD DEFINITION]
* **DPA - Data Protection Authority** - [ADD SECTIONREF] [ADD DEFINITION]
* **DPO - Data Protection Officer** - [ADD SECTIONREF] [ADD DEFINITION]
* **EPSRC** - [ADD SECTIONREF] [ADD DEFINITION]
* **Early Help** - [ADD SECTIONREF] [ADD DEFINITION]
* **Effective Access** - [ADD SECTIONREF] [ADD DEFINITION]
* **Embodied Interaction** - [ADD SECTIONREF] [ADD DEFINITION]
* **Empowerment in Use** - [ADD SECTIONREF] [ADD DEFINITION]
* **Entities** - [ADD SECTIONREF] [ADD DEFINITION]
* **Entity Extraction** - [ADD SECTIONREF] [ADD DEFINITION]
* **Explainable AI** - [ADD SECTIONREF] [ADD DEFINITION]
* **Faceted Search** - [ADD SECTIONREF] [ADD DEFINITION]
* **Entity Extraction** - [ADD SECTIONREF] [ADD DEFINITION]
* **File Biography** - [ADD SECTIONREF] [ADD DEFINITION]
* **Files, why they need to die** - [ADD SECTIONREF] [ADD DEFINITION]
* **GDPR - General Data Protection Regulation** - [ADD SECTIONREF] [ADD DEFINITION]
* **Gatekeeper**- [ADD SECTIONREF] [ADD DEFINITION]
* **HCI - Human Computer Interaction** - [ADD SECTIONREF] [ADD DEFINITION]
* **HDI - Human Data Interaction** - [ADD SECTIONREF] [ADD DEFINITION]
* **Hestia.ai** - [ADD SECTIONREF] [ADD DEFINITION]
* **HestiaLabs** - [ADD SECTIONREF] [ADD DEFINITION]
* **HII - Human Information Interaction** - [ADD SECTIONREF] [ADD DEFINITION]
* **Humane Technology** - [ADD SECTIONREF] [ADD DEFINITION]
* **ICO - Information Commissioner’s Office** - [ADD SECTIONREF] [ADD DEFINITION]
* **Ideation Grids** - [ADD SECTIONREF] [ADD DEFINITION]
* **Individualism** - [ADD SECTIONREF] [ADD DEFINITION]
* **Information (general)** - [ADD SECTIONREF] [ADD DEFINITION]
* **Information, Human** - [ADD SECTIONREF] [ADD DEFINITION]
* **Information, Life** - [ADD SECTIONREF] [ADD DEFINITION]
* **Information, Ecosystem** - [ADD SECTIONREF] [ADD DEFINITION]
* **Information Landscape** - [ADD SECTIONREF] [ADD DEFINITION]
* **Infrastructural Power, and its Four Levers** - [ADD SECTIONREF] [ADD DEFINITION]
* **Integration (stage of Personal Informatics)** - see Self Informatics
* **Interoperability** -
* **Interoperability, Adversarial** - [ADD SECTIONREF] [ADD DEFINITION]
* **Keeping** - [ADD SECTIONREF] [ADD DEFINITION]
* **Legibility** - [ADD SECTIONREF] [ADD DEFINITION]
* **Lifelogging** - [ADD SECTIONREF] [ADD DEFINITION]
* **Lifestreams** - [ADD SECTIONREF] [ADD DEFINITION]
* **Lenses** - [ADD SECTIONREF] [ADD DEFINITION]
* **Life Sketching** - [ADD SECTIONREF] [ADD DEFINITION]
* **MyData** - [ADD SECTIONREF] [ADD DEFINITION]
* **Negotiability** - [ADD SECTIONREF] [ADD DEFINITION]
* **NER - Named Entity Recognition** - see Entity Extraction
* **Open Lab** - [ADD SECTIONREF] [ADD DEFINITION]
* **Orienteering** - [ADD SECTIONREF] [ADD DEFINITION]
* **PDS - Personal Data Store** - See Personal Data Lockers
* **PIM - Personal Information Management** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIM systems, contextual** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIM systems, networked** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIM systems, semantic** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIM systems, spatial** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIM systems, subjective** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIM systems, temporal** - [ADD SECTIONREF] [ADD DEFINITION]
* **PIMS** - Personal Information Management Services - See Personal Data Lockers
* **Participatory Action Research** - see Action Research
* **PDE - Personal Data Economy** - [ADD SECTIONREF] [ADD DEFINITION]
* **Personal Data Ecosystem** - [ADD SECTIONREF] [ADD DEFINITION]
* **Personal Data Lockers** - [ADD SECTIONREF] [ADD DEFINITION]
* **Personal Data Vault** - See Personal Data Lockers
* **Personal Informatics** - see SI
* **Preparation (stage of Personal Informatics)** - see SI
* **Perspectives** - [ADD SECTIONREF] [ADD DEFINITION]
* **Point of Severance** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power - Behavioural Influence** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power - Interpretative Influence** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power - Network Centrality** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Authority** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Disciplinary** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Infrastructural** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Interpretive** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, (power to)** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, (power over)** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Processual** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Rational** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Resource Control** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Social** - [ADD SECTIONREF]
* **Power, Socially-shaped** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power, Systems/Structural** - see Infrastructural Power
* **Power, Zero Sum** - [ADD SECTIONREF] [ADD DEFINITION]
* **Power Imbalance (over Personal Data)** - [ADD SECTIONREF] [ADD DEFINITION]
* **Pragmatism** - [ADD SECTIONREF] [ADD DEFINITION]
* **Priming a Discussion** - [ADD SECTIONREF] [ADD DEFINITION]
* **QSM - Quantified Self Movement** - see SI
* **R&D - Research & Development** - [ADD SECTIONREF] [ADD DEFINITION]
* **Reflection (stage of Personal Informatics)** - see SI
* **Recursive Public** - [ADD SECTIONREF] [ADD DEFINITION]
* **Reminding** - [ADD SECTIONREF] [ADD DEFINITION]
* **SAR - Subject Access Request** - [ADD SECTIONREF] [ADD DEFINITION]
* **SI - Self Informatics** - Self Informatics [[ADD REF] () ]
* **SILVER** - [ADD SECTIONREF] [ADD DEFINITION]
* **SITRA** - [ADD SECTIONREF] [ADD DEFINITION]
* **Scraping** - [ADD SECTIONREF] [ADD DEFINITION]
* **Seams** - [ADD SECTIONREF] [ADD DEFINITION]
* **Subject Access Request** - [ADD SECTIONREF] [ADD DEFINITION]
* **Subjective Classification Principle** - [ADD SECTIONREF] [ADD DEFINITION]
* **Subjective Importance Principle** - [ADD SECTIONREF] [ADD DEFINITION]
* **Subjective Context Principle** - [ADD SECTIONREF] [ADD DEFINITION]
* **Support Worker** - [ADD SECTIONREF] [ADD DEFINITION]
* **Supported Family** - [ADD SECTIONREF] [ADD DEFINITION]
* **Text Mining** - [ADD SECTIONREF] [ADD DEFINITION]
* **ToC - Theories of Change** - [ADD SECTIONREF] [ADD DEFINITION]
* **Things to Think With** - [ADD SECTIONREF] [ADD DEFINITION]
* **Timelines** - [ADD SECTIONREF] [ADD DEFINITION]
* **TrackerControl** - see Data Flow Auditing.
* **Troubled Families** - [ADD SECTIONREF] [ADD DEFINITION]
* **VRM - Vendor Relationship Management** - [ADD SECTIONREF] [ADD DEFINITION]
* **Web Augmentation** - [ADD SECTIONREF] [ADD DEFINITION]
* **Web Extensions** - [ADD SECTIONREF] [ADD DEFINITION]
* **Wisdom Curve** - [ADD SECTIONREF] [ADD DEFINITION]
* **world2vec** - [ADD SECTIONREF] [ADD DEFINITION]

# Bibliography