Understanding and Improving Human Data Relations

Alex Bowyer

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Appendices

A The Pilot Study: CHI 2018 Paper

For additional context, see 1.3.1. The paper is on the following pages.

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: Data Visibility** - [ADD SECTIONREF]
- **Direct Data Want 2: Data Understanding** - [ADD SECTIONREF]
- **Direct Data Want 3: Data Useability**10 - [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]

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- **Inaccessible Data** - [ADD SECTIONREF]
- **Increasing Data Holder Hegemony** - [ADD SECTIONREF]
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- **Non-Interrogable Data** - [ADD SECTIONREF]
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- **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 (and Necessary) to Demonstrate Business Benefits of Transparency and Human-centricity.** - [ADD REF]

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- **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]

Contributions and Major Concepts of This Thesis

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- **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]
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- **Family Facts** - [ADD SECTIONREF]

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- **Human Data Relations (HDR)** - [ADD SECTIONREF]
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- **Human Information** - see Life Information and Ecosystem Information
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- **Inclusive Data Flows** - [ADD SECTIONREF]
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- **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**10 (as distinct from Usability) - 6.1.3]

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 DEFINI-TION]
- **Co-experience** - [ADD SECTIONREF] [ADD DEFINITION]
- **Cornmarket** - [ADD SECTIONREF] [ADD DEFINITION]
- **Critical Algorithm Studies** - [ADD SECTIONREF] [ADD DEFINI-TION]
- **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 DEFINI-TION]
- **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 DEFINI-TION]
- **Design, Magical** - [ADD SECTIONREF] [ADD DEFINITION]
- **Design, User-centred Design** - [ADD SECTIONREF] [ADD DEFINI-

TION]
- **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]
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- **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]
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- **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