

Understanding and Improving Human Data Relations

Alex Bowyer

Contents

Appendices	1
Appendix A: The Pilot Study	1
Appendix B: Case Study Two Methodology: Additional Details .	1
Appendix C: Ethics Approvals	1
Appendix D: The Private Data Viewing Monitor	1
Index of Key Ideas, Insights and Contributions	2
HDR Wants	2
HDR Objectives	3
HDR Obstacles	3
HDR Insights & Approaches	3
HDR Approaches	4
Contributions and Major Concepts of This Thesis	4
Glossary of Pre-Existing Abbreviations, Names and Terms	5
Bibliography	9

Appendices

Appendix A: The Pilot Study

See description in 1.3.1

Appendix B: Case Study Two Methodology: Additional Details

Appendix C: Ethics Approvals

Appendix D: The Private Data Viewing Monitor

By removing the filter layer on an old monitor and modifying cinema IMAX glasses, a monitor was created that only allowed viewing by the holder of the viewing glasses, which would be ideal for interviewing someone about their data

while respecting privacy. Face to face interviewing had to be abandoned due to COVID-19, so this technique was sadly never used in practice.



Figure 1: Figure D.1: Private Data Viewing Monitor with Viewing Glasses

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**¹⁵ - [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]

HDR Objectives

- **HDR Objective 1: Data Awareness & Understanding** - [ADD SECTIONREF]
- **HDR Objective 2: Data Useability**¹⁵ - [ADD SECTIONREF]
- **HDR Objective 3: Ecosystem Awareness & Understanding** - [ADD SECTIONREF]
- **HDR Objective 4: Ecosystem Negotiability** - [ADD SECTIONREF]
- **HDR 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]
- **Unreliable Data** - [ADD SECTIONREF]

HDR Insights & Approaches

- **HDR Insight 1: Life Information Makes Data Relatable** - [ADD SECTIONREF]
- **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]

HDR Approaches

- **HDR Approach 1: Discovery-Driven Activism** - [ADD SECTION-REF]
- **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

- **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]
- **Digital Self Curation** - [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
- **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** - [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 Cards** - [ADD SECTIONREF]
- **Trust in Providers, effects upon** - [ADD SECTIONREF]
- **Types of Personal Data (by origin)** - [ADD SECTIONREF]
- **Useability**¹⁵ (as distinct from Usability) - 6.1.3]

[PRODUCTION 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** - [ADD SECTIONREF] [ADD DEFINITION]
- **Accessibility Tags (ARIA)** - [ADD SECTIONREF] [ADD DEFINITION]
- **Activism** - [ADD SECTIONREF] [ADD DEFINITION]
- **Agency** - [ADD SECTIONREF] [ADD DEFINITION]
- **BBC R&D** - [ADD SECTIONREF] [ADD DEFINITION]
- **CHC - Connected Health Cities** - [ADD SECTIONREF] [ADD DEFINITION]
- **Civic Hacking** - [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]
- **Cornmarket** - [ADD SECTIONREF] [ADD DEFINITION]
- **Critical Algorithm Studies** - [ADD SECTIONREF] [ADD DEFINITION]
- **Data Access and Understanding Services** - [ADD SECTIONREF] [ADD DEFINITION]
- **Data Brokers** - [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 Provenance** - [ADD SECTIONREF] [ADD DEFINITION]
- **Data Self** - [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, 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, 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
- **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]
- **Entity Extraction** - [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 [[REF] ()]
- **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]
- **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
- **Keeping** - [ADD SECTIONREF] [ADD DEFINITION]
- **Legibility** - [ADD SECTIONREF] [ADD DEFINITION]
- **Lifeloggging** - [ADD SECTIONREF] [ADD DEFINITION]
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- **Lenses** - [ADD SECTIONREF] [ADD DEFINITION]
- **Life Sketching** - [ADD SECTIONREF] [ADD DEFINITION]
- **Magical Design** - [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, Processual** - [ADD SECTIONREF] [ADD DEFINITION]
- **Power, Rational** - [ADD SECTIONREF] [ADD DEFINITION]
- **Power, Resource Control** - [ADD SECTIONREF] [ADD DEFINITION]
- **Power, Socially-shaped** - [ADD SECTIONREF] [ADD DEFINITION]
- **Power, Systems/Structural** - see Infrastructural Power
- **Power, Zero Sum** - [ADD SECTIONREF] [ADD DEFINITION]
- **Pragmatism** - [ADD SECTIONREF] [ADD DEFINITION]
- **QSM - Quantified Self Movement** - see SI
- **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 [[REF] ()]
- **SILVER** - [ADD SECTIONREF] [ADD DEFINITION]

- **Sitra** - [ADD SECTIONREF] [ADD DEFINITION]
- **Scraping** - [ADD SECTIONREF] [ADD DEFINITION]
- **Seams** - [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]
- **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]

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

Bibliography