Understanding and Improving Human Data Relations

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# Appendices

## A The Pilot Study: Published CHI 2018 Paper

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## B Ethics Approvals

The following 8 pages include three different ethical approvals

– the original ethics approval focused on Case Study One, - the original ethics approval for Case Study Two, and - the ethics-reapproval of Case Study Two for COVID-19 mitigations.

# Index of Key Ideas, Insights and Contributions

This section serves as an index to easily locate key HDR-related concepts, ideas and contributions that this thesis contributes.

### The Six Wants in Data Relations

Direct Data Relations:

1. Data Visibility - [6.1.1](#Xecaf8be5654f259a19f021dd696c8aed0425326)
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### HDR Obstacles

The obstacles are collectively shown in [Figure 8.1](#figure-8.1) and are explained in the following subsections of [Chapter 8](#chapter-8)]:

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* Complex and Invisible Personal Data Ecosystems - [8.3.1](#X67529724ac20fabfa5e886f9bb50f1f655f98d7)
* Diminishing Individual Agency - [8.4.2](#X06b01f722148eb1b6ddf37464ad8f18232e6422)
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* Inaccessible Data - [8.1.1](#Xfaff11acbd25d0758b7c5294b4ff9d37debac19), [8.2.1](#X81f0d3632905f8bf54a0c328d13cc85a1da4a1d)
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* [Insight 1](#insight-1) - Life Information Makes Data Relatable.
* [Insight 2](#insight-2) - Data Needs to be United and Unified.
* [Insight 3](#insight-3) - Data Must be Transformed into a Versatile Material.
* [Insight 4](#insight-4) - Ecosystem Information is an Antidote to Digital Life Complexity.
* [Insight 5](#insight-5) - We Must Know Data’s Provenance.
* [Insight 6](#insight-6) - Data Holders use Four Levers of Infrastructural Power.
* [Insight 7](#insight-7) - Human-centred Information Systems Must Serve Human Values, Relieve Pain and Deliver New Life Capabilities.
* [Insight 8](#insight-8) - We Need to Teach Computers to Understand Human Information.

Insights in [Chapter 9](#chapter-9):

* [Insight 9](#insight-9) - Individual GDPR Requests can Compel Companies to Change Data Practices.
* [Insight 10](#insight-10) - Collectives can Compare and Unify their Data and Use it to Demand Change.
* [Insight 11](#insight-11) - Automating the Identification of Entities can enhance Machine Understanding and Unburden Life Interface Users.
* [Insight 12](#insight-12) - The ‘Seams’ of Digital Services need to be identified, exploited and protected.
* [Insight 13](#insight-13) - It is Possible (and Necessary) to Demonstrate Business Benefits of Transparency and Human-centricity.

### HDR Approaches

The four approaches are collectively summarised in [9.6](#X5b7e6d36dc0113f61b36c700817d42b96f7b037), and explained and illustrated as follows:

* [Approach 1](#Xa16e203872bcacabe78d1385e9c7faf62c4c5be) - Discovery-Driven Activism - [9.2](#Xa16e203872bcacabe78d1385e9c7faf62c4c5be), [Figure 9.2](#figure-9.2)
* [Approach 2](#X1f7a3a299f62225cba076fc6d3d6e677f303482) - Building the Human-centric Future - [9.3](#X1f7a3a299f62225cba076fc6d3d6e677f303482), [Figure 9.3](#figure-9.3)
* [Approach 3](#X84473f470864e067ee3a22e64b47b0a1c356f29) - Defending User Autonomy and Hacking the Information Landscape - [9.4](#X84473f470864e067ee3a22e64b47b0a1c356f29), [Figure 9.19](#figure-9.19)
* [Approach 4](#X6d06bb31b570b94d7b4325f511f853dbe771c21) - Teaching, Championing and Selling the HDR Vision - [9.5](#X6d06bb31b570b94d7b4325f511f853dbe771c21), [Figure 9.21](#figure-9.21) -

### Thesis Contributions

* [Contribution C1](#c1) - An understanding of What People Want in Direct Data Relations
* [Contribution C2](#c2) - An Understanding of What People Want in Indirect Data Relations
* [Contribution C3](#c3) - The Synthesis and Formulation of the Field of Human Data Relations (HDR)
* [Contribution C4](#c4) - A clear delineation of two primary motivators for individuals seeking better HDR
* [Contribution C5](#c5) - A map of the HDR landscape, identifying obstacles and insights
* [Contribution C6](#c6) - Four identified trajectories for advancing Human Data Relations
* [Contribution C7](#c7) - A reframing of data literacy for the HDR space
* [Contribution C8](#c8) - Validation and enumeration of supported families’ attitudes and needs around civic data
* [Contribution C9](#c9) - *Shared Data Interaction* - A proposed model for more efficient and empowering social support relationships that embraces human-centricity
* [Contribution C10](#c10) - A model to understand the five different origins of held personal data
* [Contribution C11](#c11) - A rich understanding of the lived experience of accessing data using GDPR rights and of motivations for GDPR data access
* [Contribution C12](#c12) - Evidence for the impact of knowledge about data handling practices on provider trust and perceived individual power
* [Contribution C13](#c13) - Guidance for policymakers, data holders and individuals on how to improve HDR
* [Contribution C14](#c14) - A proto-methodology for educating individuals about held data, data access and the data ecosystem

### Major Concepts of This Thesis

* **Auditing Data Holders** - [9.2.2](#Xe21f5ae91679b9ef901a482b35d885033afa643)
* **Categories of Family Civic Data** - [ARI4.1](#ari-fcd-types)
* **Categories of Personal Data** - [Figure 3.6](#figure-3.6)
* **Data Access & Understanding Services** - [9.2.4](#X91fc4bbef52671befa265217426c790a591053e), [9.4](#X84473f470864e067ee3a22e64b47b0a1c356f29)
* **Data Literacy in an HDR Context** - see HDR Literacy
* **Data Cards** - [Figure 3.5](#figure-3.5), [3.5.2](#X464e9f2e5e0cf52e9c26d3864e71249d73ea33a), [4.2.1](#Xc2fcfc265ab40ba82ed064a42903a2f576bb84b), [4.4.2](#X2ad50ca4cbd63a3f83ddbd28315b55b52f600fb), Bowyer *et al.* ([2018](#ref-bowyer2018family))
* **Data Wants** - [Chapter 6](#chapter-6)
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* **Data Relations, Indirect** - [6.2](#X86a6a7bbe6a4ae5c1502558f013f6ed6b9ae6f2)
* **Digital Self Curation** - [4.4.3](#X8a50e98458a9c28886ed15ffb2cc666b2d3d49b), [5.5.2](#X279d3e70c4a8279cdfb499a60bef2c4f405d995), [6.3](#X3c10c50990743199cc887aaacd3f88a0a0a026e)
* **Ecosystem Detection** - [Insight 4](#insight-4)
* **Ecosystem Information** - [7.7](#Xa53a7020f5014c3c46abf7c2e460206e04bf007), [Insight 4](#insight-4)
* **Ecosystem Information Display** - [Insight 4](#insight-4)
* **Ecosystem Negotiability** - [7.7](#Xa53a7020f5014c3c46abf7c2e460206e04bf007), [8.4](#X32cb5b70a3f71ce180c165205647e8909d4e8a0)
* **Empowerment (in the context of data wants)** - [6.3](#X3c10c50990743199cc887aaacd3f88a0a0a026e)
* **Free Data Interfaces** - Bowyer ([2018](#ref-bowyer2018freedata))
* **Hacking the Seams** - [Insight 12](#insight-12)
* **Human Data Relations (HDR)** - [7.2](#Xd90f00e19f5543904caf9ab2abd5b800e0613c0)
* **HDR Literacy** - [9.5.1](#X4c673bb6afbb79ddba8a78416c822e2d34085bb)
* **Human Information Operating System** - [8.2](#info-os)
* **Human Information** - see Life Information and Ecosystem Information
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* **Information Standards** - [5.5.1](#X18b35402f3fbcb74b8e5bbc8aa2c0e3e784e473), [8.5](#X1f15683c2b3e08fe96ef083dd1427b28321d1a3)
* **Landscape of HDR Opportunity** - [Figure 8.1](#figure-8.1), [9](#Xade7c2cf97f75d009975f4d720d1fa6c19f4897), \*\*[Figure 9.23](#figure-9.23)
* **Life Concepts** - [8.1.1](#Xfaff11acbd25d0758b7c5294b4ff9d37debac19)
* **Life Information Utilisation** - [7.6](#X4035664301b06859586cb750fd8f8ad988856ea), [Figure 7.1](#figure-7.1)
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* **Locus of Decision Making (LDM)** - [4.4.3](#X8a50e98458a9c28886ed15ffb2cc666b2d3d49b)
* **Meaning in Data** - [Figure 2.1](#figure-2.1), [4.3.2](#X4bf33bfd9c3793655f2a19fca0ee1ca41e62e6e), [5.4.2](#Xd9a9eb3723d36c07bbcef114c168744dedfa05e), [6.1.2](#X238446be5e2d7d8b7b5d3c3f92842c91d895c1e), [Insight 1](#insight-1)
* **Perceived Individual Power** - [5.3.4](#X17fee6fbf9ee82826dccbd5118d485029a82ebe)
* **Personal Data Diaspora, the** - [8.1.2](#Xf6dec2858357bbc639b59b877f24fb902711e9e)
* **Personal Data Ecosystem Control** - [7.6](#Xdca50b5cb1feb03950b48f4419acb02a57783cb), [Figure 7.1](#figure-7.1)
* **Personal Data as a Proxy for Involvement** - [5.4.4](#X38f625be2c0c748970e0e254c020e238dedd97d), Bowyer *et al.* ([2018](#ref-bowyer2018family))
* **Personal Data Stewardship** - [4.3.3](4.3.3.4), [5.6](#X2246273db175b4d951c8ae09a9b87d55b422463)
* **Proxy Representations of Immobile Data** - [Insight 4](#insight-4)
* **Shared Data Interaction** - [4.2.4](#Xdecc0e8ff84b4e8fdb98d4490fcb5b15d4e95fa)
* **Surface Information Injustices** - [9.5.1](#X4c673bb6afbb79ddba8a78416c822e2d34085bb), [Insight 12](#insight-12)
* **Storyboarding Action Cards** - [ARI4.3](#ari-storyboarding)
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* **Types of Personal Data (by origin)** - [Table 5.2](#table-5.2)
* **Useability**[10](#fn10) (as distinct from Usability) - [6.1.3](#X7f3cb9988fc4f21a782e780e51ff565a0b00582)]

# Glossary of Pre-Existing Abbreviations, Names and Terms

This section serves as a quick-reference glossary to explain abbreviations and existing terms used.

* **Action (stage of Personal Informatics)** - see SI
* **Action Research** - a mode of research where cycles of investigation shape future studies
* **Accessibility Tags (ARIA)** - tags within HTML code that screenreaders use and which can be exploited for seam hacking
* **Activism** - using vigorous campaigning to bring about political or social change
* **Agency** - the ability, described in HDI, to act for oneself in a system, see HDI
* **Barriers Cascade** - a series of obstacles in SI
* **BBC R&D** - the Research & Development division of the British Broadcasting Corporation, where I did a research internship
* **Boundary Objects** - tangible objects and representations that help different populations that may think in different terms to collaborate effeectively
* **Card Sorting** - a technique used in Participatory co-design where participants arrange cards to convey their thinking
* **CHC - Connected Health Cities** - government initiative behind the SILVER project, which I worked on
* **Civic Hacking** - technologists or enthusiasts working to reconfigure the way society works
* **Civil Libertarianism** - argues for the supremacy of individual rights and personal freedoms over imposition by authority
* **Collection (stage of Personal Informatics)** - see SI
* **Consent, Dynamic** - ongoing and changeable expression of preference
* **Consent, Informed** - initial one-time expression of preference
* **Constructivism** - a belief that new knowledge is formed by developing one’s own mental models in order to explain new experiences
* **Conceptual Anchors** - the mental scaffolds which we use to organise our thinking and human information
* **Context-aware Computing** - designing systems that take account of the user’s situation and varying needs
* **Co-experience** - bringing participants towards a shared perspective
* **Cornmarket** - codename for the BBC R&D PDS project I interned with
* **Critical Algorithm Studies** - research into making computer systems and their behaviour more understandable and accountable
* **Data Access Request** - see Subject Access Request
* **Data Brokers** - third parties that buy and sell user’s data
* **Data Controller** - an organisation responsible for collecting and storing user data
* **Data Download Portal** - a website or service that allows users to access held data in a ‘self-service’ manner
* **Data Flow Auditing** - the use of apps or system services to monitor the communication and data sharing behaviours of consumer apps
* **Data Justice** - research into the relationship between datafication and social justice
* **Data Portability Request** - a particular kind of access request focussed on retrieving data in a machine-readable and useable format
* **Data Processor** - one who handles user data on behalf of a data controller
* **Data Provenance** - the history and origin of a piece of data
* **Data Self** - the representation of an individual in data through which state or commercial actors understand that person when making decisions
* **Data Subject** - the individual about whom data is stored
* **Data Transcendence** - the idea that data should not be tied to a single machine, but should move freely to the places it is needed
* **Data (general)** - digitally-encoded human information
* **Data, Civic / Family Civic** - the data stored about families by social care organisations such as Early Help programmes
* **Data, Acquired** - personal data that has been obtained from an official or public source or a third party
* **Data, Derived** - new data that has been extrapolated through interpretation of existing data
* **Data, Metadata** - data about the data itself, or about the incident recorded in data
* **Data, Observed** - data collected about individuals automatically, as a by-product of other actions or in the background
* **Data, Personal** - data about or related to identifiable individuals
* **Data, Volunteered** - personal data that has been knowingly shared by that individual with an organisation
* **Data, Trapped** - data that is hard to access due to technical, commercial or other restrictions
* **DERC** - Digital Economy Research Centre, funders of the Healthy Eating Web Augmentation project
* **Design, Co-** - researchers and participants collaboratively exploring problems and solutions
* **Design, Adversarial** - the design of systems or processes that challenge current norms
* **Design, Design After** - the ability to repurpose products or services for new objectives that might not have been initially considered
* **Design, Disrespectful** - design practices (often in user interfaces) that prioritise commercial needs over human convenience
* **Design, Experience-centred** - design that focusses on human psychology and lived experience of the situation
* **Design, Magical** - the presentation of technology offerings as powerful and mysterious, that need not be examined or understood
* **Design, User-centred Design** - design approach that builds up an understanding of user needs that is subsequently used by technical experts
* **Design, Value-centred Design** - designing in ways that focus on positive impacts on human life
* **Device Tenancy** - the idea that we are no longer owners of our devices, and lack control and autonomy over their use
* **Digital Civics** - a multi-disciplinary research field encompassing HCI, governance, education, planning, social science and computer science, practiced by - Open Lab, where I studied this PhD
* **Digital Self** - see Data Self
* **DIKW pyramid** - see Wisdom Curve
* **DPA** - Data Protection Authority\*\* - the official authority for regulating data use in a given country
* **DPO** - Data Protection Officer\*\* - the individual legally responsible for managing data use within a company and for handling access requests
* **EPSRC** - Engineering and Physical Sciences Research Council, funders of this PhD research
* **Early Help** - a set of programmes in UK local authorities designed to identify ‘at risk’ families and help them with targeted interventions
* **Effective Access** - ensuring that individuals have all necessary skills, systems and capabilities necessary to see and understand information
* **Embodied Interaction** - allowing users to create their own practices in information interaction
* **Empowerment in Use** - having freedom to use products and services in the way you want
* **Entities** - people, places, organisations, brands, topics or other identifiable ‘things’ that could be a stakeholder of, or related to, a piece of data
* **Entity Extraction** - the process of identifying real-world entities in data
* **Explainable AI** - algorithms whose decision making processes are described to system users
* **Faceted Search** - the ability to search information by its shared aspects
* **File Biography** - the lifetime of past actions on a computer file
* **Files, why they need to die** - article by myself ([Bowyer, 2011](#ref-bowyer2011filesdie))
* **GDPR** - General Data Protection Regulation - the EU’s 2018 regulations that give users rights over the collection and use of their personal data
* **Gatekeeper** - One who controls the flow of data or information between an organisation and an individual
* **HCI - Human Computer Interaction** - research and practice that explores how people relate to and use computer systems
* **HDI - Human Data Interaction** - a subdiscipline of HCI that focuses on people’s relationship with data, rather than with the system
* **Hestia.ai** - Swiss company working in the data access and understanding services space, which I currently work for
* **HII - Human Information Interaction** - a discipline in library sciences that considers how humans relate to information regardless of technology used
* **Humane Technology** - a movement focused on making technology that is more sensitive to people’s lives and needs
* **ICO - Information Commissioner’s Office** - the UK’s Data Protection Authority
* **Ideation Deck** - a participatory design technique that uses ‘ingredients’ cards shuffled in a grid to generate new ideas
* **Individualism** - the pursuit of one’s own objectives as a primary objective
* **Information (general)** - facts and assertions understood by interpreting data
* **Information, Human** - information about people that can be related to their lives or to their digital world
* **Information, Life** - information about people’s lived experience that can be found within data
* **Information, Ecosystem** - information about people’s data, where it is stored, and how it is used and shared
* **Information Landscape** - the general terrain of available information that a user can see and interact with through the services and apps they use
* **Infrastructural Power** - see Power, Infrastructural
* **Integration (stage of Personal Informatics)** - see Self Informatics
* **Interoperability** - getting systems to connect and exchange information through data standards or conversion
* **Interoperability, Adversarial** - making systems connect together in ways that were not intended by manufacturers
* **Legibility** - the ability, as defined in HDI, of being able to understand stored data
* **Lifelogging** - the practice of maximal data capture for personal SI benefit
* **Lenses** - different ways of focussing on some data or information according to the aspect of interest or the current role
* **Life Sketching** - a process of mapping out mental models of one’s life on paper
* **MyData** - an organisation whose members pursue a human-centric change agenda
* **Negotiability** - the ability described in HDI to flexibly adapt and change one’s preferences as the world or digital system changes
* **NER - Named Entity Recognition** - see Entity Extraction
* **Open Lab** - the research lab in Newcastle University in which I conducted this PhD research
* **Orienteering** - an associative process of information-finding
* **PDS - Personal Data Store** - See Personal Data Lockers
* **PIM - Personal Information Management** - the 1990s/2000s discipline that focused on new ways to manage and interact with data and information
* **PIM systems, contextual** - PIM systems that organise information according to what context it relates to
* **PIM systems, networked** - PIM systems that focus on the relationships between different pieces of information
* **PIM systems, semantic** - PIM systems that focus on the underlying meaning of the stored data
* **PIM systems, spatial** - PIM systems that focus on arranging data in a virtual space for easier management
* **PIM systems, subjective** - PIM systems that focus on the varied individual needs of users
* **PIM systems, temporal** - PIM systems that represent information using timelines or other visualisations that highlight change over time
* **PIMS** - Personal Information Management Services\*\* - See Personal Data Lockers
* **Participatory Action Research** - see Action Research
* **PDE - Personal Data Economy** - the emergent marketplace of companies innovating and offering services relating to the management, self-exploitation or - harnessing of one’s personal data
* **Personal Data Ecosystem** - the network of systems, accounts, files and digital information that constitutes an individual’s digital life
* **Personal Data Lockers** - a place to store personal data so that it can be united, unified and interpreted by the data subject
* **Personal Data Vault** - See Personal Data Lockers
* **Personal Informatics** - see SI
* **Preparation (stage of Personal Informatics)** - see SI
* **Perspectives** - different presentations or aspects of information that support different mental models, focus or tasks
* **Point of Severance** - the point at which data is handed over, beyond which data subjects lose visibility, control and influence
* **Power - Behavioural Influence** - persuading others to carry out the desired behaviour
* **Power - Interpretative Influence** - determining how reality is externally represented
* **Power - Network Centrality** - becoming an indispensable hub of a wider ecosystem
* **Power, Authority** - ownership of technology or infrastructure
* **Power, Disciplinary** - using an influential position to affect others’ mental models
* **Power, Infrastructural** - a model of understanding how providers exert power over their users, created as part of the digipower investigation
* **Power, Interpretive** - creating the internal representations of reality within an organisation
* **Power, (power to)** - an individual’s ability to act (see Agency)
* **Power, (power over)** - a dominant actor’s ability to limit or manipulate the actions of others
* **Power, Obscure** - where the subservient cannot tell when they are watched
* **Power, Pervasive** - where the one in power can see everything all the time
* **Power, Processual** - changing processes for competitive advantage
* **Power, Rational** - controlling decision-making processes
* **Power, Resource Control** - controlling the flow of resources
* **Power, Social** - power where the power holder attempts to influence the behaviour of individuals in pursuit their desired outcomes
* **Power, Socially-shaped** - influencing a wide audience to settle upon a preferred interpretation
* **Power, Systems/Structural** - see Infrastructural Power
* **Power, Zero Sum** - winning a battle for ownership/resource control at the other party’s expense
* **Power Imbalance (over Personal Data)** - the established fact that data holders have more power in service relationships than data subjects.
* **Pragmatism** - an epistemology that believes knowledge is constantly renegotiated by individuals
* **QSM - Quantified Self Movement** - see SI
* **R&D** - Research & Development
* **Reflection (stage of Personal Informatics)** - see SI
* **Recursive Public** - a community of people who are attempting to reconfigure society for the better
* **SAR - Subject Access Request** - a request to a DPO of an organisation for a copy of held personal data
* **SI - Self Informatics** - an umbrella term for Personal Informatics and the Quantified Self Movement, where people track their activity in data and reflect - upon it, setting goals and tracking progress
* **SILVER** - the project working in the Early Help space that I worked with for Case Study One
* **Sitra** - Finnish non-profit research organisation for which the digipower investigation was conducted
* **Scraping** - the process of programmatically extracting information from interfaces such as websites that were intended for human browsing.
* **Seams** - the ‘edges’ of products and services, at which service providers can exert restrictions and at which users can find new ways to adapt their product - usage and data access
* **Support Worker** - a specialist social worker who helps a family in an Early Help context
* **Supported Family** - a family participating in an Early Help social care programme
* **Text Mining** - the process of programmatically examining textual data to infer new facts and assertions from the data
* **ToC - Theories of Change** - a model for thinking about how to achieve change in society
* **Things to Think With** - the idea that tangible representations can be useful to aid discussions
* **Timelines** - visual representations of information anchored against points in time
* **TrackerControl** - see Data Flow Auditing.
* **Troubled Families** - historic term for those families targeted for help by programmes such as Early Help
* **VRM - Vendor Relationship Management** - a model where vendors are selected by customers in response to their published needs, instead of relying on - broadcast advertising to find customers
* **Web Augmentation** - the process of modifying a web page to provide new functionality or access data after it has been downloaded to a user’s we browser
* **Web Extensions** - pieces of user code that are loaded into a web browser to modify or programmatically interrogate web pages
* **Wisdom Curve** - the process of converting data, to information, to knowledge, to wisdom
* **world2vec** - a system in Facebook that attempts to understand the world through analysis of social media content

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