Understanding and Improving Human Data Relations

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# Appendices

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## 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 that this thesis contributes.

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

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### HDR Approaches

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### 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) **Data Relations, Direct** - [6.1](#X8258c05de79d267cff0777b650c09dd0e24396f) **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 **Inclusive Data Flows** - [9.3.5](#Xa4db109162f9815a249569c36ba52127de23cda) **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) **Life Information** - [Insight 1](#insight-1) **Life Interface Design** - [9.3.1](#X163d5fe340eb813a3cb4eb18ecadabb5a25d0d2) **Life Partitioning** - [9.3.2](#X954f92b164d31ac62328698a1fa3f9b20d5ccc2) **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) **Trust -** [**4.3.4**](#Xbab51b354b67876c6284de28df0e549940fb873)**,** [**4.4.1**](#X1cbcb0941f4181aab74224b7105fd44cb905d42)**,** [**5.3.4**](#X17fee6fbf9ee82826dccbd5118d485029a82ebe)**,** [**5.4.4**](#X38f625be2c0c748970e0e254c020e238dedd97d)**,** [**6.2.1**](#want-i1)**,** [**Insight 13**](#insight-13)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

**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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