

# Understanding and Improving Human Data Relations

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## 1 Discussion II: Designing and Pursuing Better Human Data Relations

*“Civilizations advance not by the technology they know about, but by the technology they don’t have to know about.”* – Anonymous proverb

### 1.1 Introduction & Background

Through the Case Studies (Chapter 4 & 5) and the discussion in Chapter 6, a clear understanding of what people want from direct and indirect data relations (RQ1 & RQ2) has been established. In this chapter, we turn our attention from theory to practice, from what is needed to *what is possible*. Specifically, this chapter will return to the overall research question and consider “*How might [better Human Data Relations] be achieved?*”, and answer this question by describing practical approaches for future research, innovation and policy that are either novel or already emergent.

This chapter is deliberately broad and open ended. It does not pretend to be complete or definitive in its interpretation of the outlook for HDR. It is not a roadmap, but rather a snapshot of ongoing work, identified challenges and known opportunities, forming an **anthology of reference material**, based on my research and design experience from my six years working to understand and advance HDR.

The rationale here is that it will be valuable for anyone working in the HDR space to have a good high-level understanding of the landscape as well as specific ideas to work with; the goal is to boost and strengthen any such activities so that they might benefit from the insights gained.

The shape this chapter takes is to consider the the six HDR wants that this thesis has uncovered [Chapter 6] as a basis for defining **objectives** for the HDR landscape, then to to illustrate what specific **obstacles** and **opportunities** are relevant when attempting to pursue those objectives, as well as to highlight specific **designerly insights** that are relevant.

There are many aspects to the wide-reaching objective of better HDR in practice: technical, design, commercial, legal, moral, social and political and this chapter does not cover them all, nor is it formal empirical research. Instead, detail is provided in the form of **real world practical designs and insights** from four industrial and academic research projects I was part of during the same timeframe as the empirical research, as well as from the work of other innovators

and activists. This detail is contextualised relative to existing literature and the thesis' earlier contributions.

In section 7.1.1 the peripheral R & D activities I undertook are described; forming the primary point of reference for this chapter, as this peripheral work has informed and allowed me to build upon the core HDR understanding from the empirical research, and much of the work has often aligned well to the six data wants [Chapter 6]. Often the work has exposed evolving areas where different actors are trying to bring about better HDR.

In section 7.1.2, I explain some important context about the nature of the ideas presented in this chapter and how to attribute them fairly.

In section 7.2, I formalise and expand the Human Data Relations concept. Additional insights into how people relate to data are identified, as well an important dichotomy of two distinct drivers that motivate people's needs for better relations with their data. I also conceptualise those who would pursue better HDR as *HDR reformers* and reflect on the researcher-turned-activist stance that drives this chapter, to conceptualise this community as a *recursive public*.

Section 7.3 and 7.4 form the main body of this chapter, beginning with a focus on the main obstacles that one must face in pursuit of the HDR objectives identified. Specific insights that can inform research, design and activist thinking are shared in inset boxes throughout 7.3 and 7.4.

7.4 is solution-focused, considering the nuts-and-bolts of *how* we might, using these insights begin to tackle the obstacles of 7.3 in pursuit of the HDR objectives. In 7.4.1 I introduce the concept of *Theories of Change (ToC)*, which are used as a framing device for structuring the four approaches to pursuing change that follow in 7.4.2 to 7.4.5. Each for these four approach sections is modelled as a different possible trajectories for change. Within each of these four trajectories, specific named opportunities are described or referenced in varying detail <sup>1</sup>.

Section 7.5 concludes the thesis, summarising the insights presented in 7.3 and the change trajectories presented in 7.4, reflecting on my journey as a researcher and summarising the thesis' contributions as a whole.

### **1.1.1 Peripheral Research & Design Settings**

[TODO Move 3.4.3 etc. to here and remove all refs to 3.4.3]

The majority of examples and learnings shared in this chapter come from my participation as an expert researcher and designer in two industrial research projects:

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<sup>1</sup>Some of the challenges and opportunities herein are described in greater detail than others, corresponding only to my proximity and depth of engagement with those ideas rather than their relative merit, complexity or impact potential. Given the broad aim of mapping out a new field, I consider that it is more useful to introduce a range of applicable ideas even if some are only lightly detailed, rather than to detail just a few.

1. **BBC R&D's Cornmarket Project**, which explored through user experience design, technical prototyping and participatory research, how individuals might interact with data through a Personal Data Store interface (see 3.4.3.3)
2. **Sitra/Hestia.ai's #digipower Project**, a successor to Case Study Two, in which European politicians examined companies' data practices through exercising data rights and conducting technical audits (see 3.4.3.4) [TODO add links to both the page, and the sitra report, and (Bowyer *et al.*, 2022; Pidoux *et al.*, 2022)]

In addition, my participation as an interface designer and front-end software developer in the following two academic research projects contributes secondarily to this chapter:

3. **Connected Health Cities (CHC)'s SILVER Project**, where I, along with a backend developer and a team of researchers, developed a prototype health data viewing interface for Early Help support workers (see 3.4.3.1).
4. **Digital Economy Research Centre (DERC)'s Healthy Eating Web Augmentation Project**, which explored the use of web augmentation techniques to modify the user interface of takeaway service Just Eat to insert health information, in support of healthy eating (see 3.4.3.2).

### 1.1.2 Attribution of Insights

While this thesis is my own original work, and many ideas presented in this chapter are fully original, some of the specific details, theories and ideas presented in this chapter arose or were developed or augmented through my close collaboration, discussion and ideation with other researchers, including:

- Jasmine Cox, Suzanne Clarke, Tim Broom, Rhianne Jones, Alex Ballantyne and others at BBC R&D;
- Paul-Olivier Dehaye, Jessica Pidoux, Francois Quellec at Hestia.ai;
- Stuart Wheater of Arjuna Technologies and Kyle Montague of Open Lab during the SILVER project; and
- Louis Goffe of Open Lab on the DERC Healthy Eating project
- earlier innovation work with Alistair Croll at Rednod, Montréal, Canada (circa 2011) and with Megan Beynon at IBM Hursley, UK (circa 2006).

Due to these collaborations and the ongoing and parallel nature of many of these projects to my PhD research, it is impossible to precisely delineate the origin of each idea or insight. In practice, ideas from my developing thesis and own thinking informed the projects' trajectories and thinking, and vice-versa. These ideas would not have emerged in this form without my participation, so they are not the sole intellectual property of others, but equally I would not have reached the same conclusions alone, so the ideas are not solely my own either. All diagrams and illustrations were produced by me, except where specified, and the overall synthesis and framing presented in this chapter is my own original work. Where this chapter includes material from the four projects, that material

is either already public, or permission has been obtained from the corresponding project teams.

### 1.1.3 Theories of Change

To provide a structure for cataloguing the insights conveyed by this chapter, I use a *Theory of Change (ToC)* framing. ToC is a set of methodologies commonly used by philanthropists, educators and those trying to improve the lives of disadvantaged populations (Brest, 2010); the theories can be used in different ways including planning, participatory design and field evaluation of the effectiveness of new initiatives. There are many different implementations, but common to most of them is a focus on explicitly mapping out desired outcomes (Taplin and Clark, 2012) with a clear focus on who is acting and whether the change being brought about is a change in action, or a change in thinking (Es, Guijt and Vogel, 2015). In this chapter, ToC theory will be used in a very limited way, not as a methodology but simply to provide a structural frame for proposed changes, as described below. Using ToC to perform evaluation of the effectiveness of proposed change approaches in action in society would be well beyond the scope of this thesis. Nonetheless, this frame is a useful way to map out the different approaches to changing the world in pursuit of the ideal of better HDR.

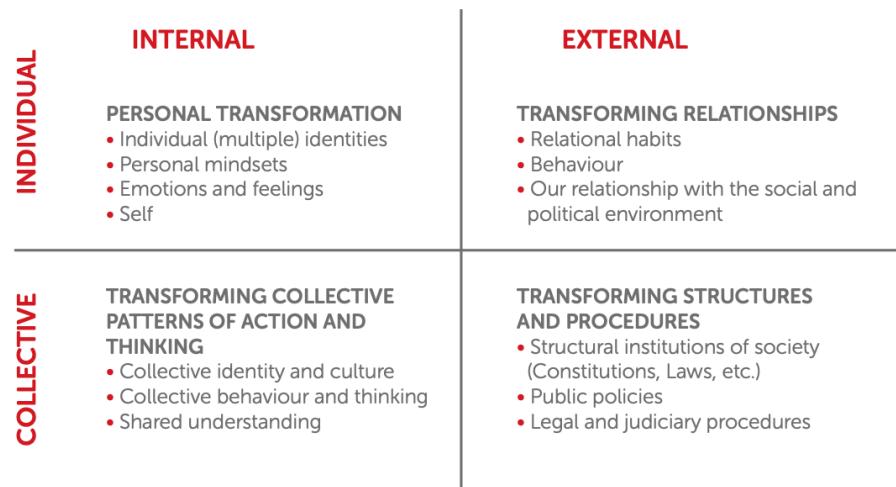


Figure 1: Figure 29: The Four Dimensions of Change<sup>2</sup>

Figure 29 illustrates the aspects of ToC thinking that section 7.4 will use as its frame. Specifically, desired changes can be broken down into:

<sup>2</sup>Diagram used here unchanged from *Hivos ToC Guidelines* (Es, Guijt and Vogel, 2015, p. 90) under a CC-BY-NC-SA 3.0 license, whose authors state that this diagram was adapted from earlier work by Wilber (1996), Keystone (2008) and Retolaza (2010, 2012).

- ***Internal changes***: changes in thinking, feeling, reasoning, understanding, attitudes or identity.
- ***External changes***: changes in actions, behaviour, interactions, structure, policy, technological capability, processes and the external environment.

At the same time, desired changes can be broken down into:

- ***Individual changes***: changes to individual thought or actions
- ***Collective changes***: changes to the thoughts or actions of groups of people together, or to the systems, practices and norms of society at large.

These two splits produce four dimensions of change, and form four quadrants representing different types of change, which are shown in Figure 29 and described here:

- ***Individual/Internal (II)***: This top-left quadrant represents changes to what individuals know and understand, and to how they think, feel and plan to take action.
- ***Individual/External (IE)***: This top-right quadrant represents changes to how individuals' relationships with others; acting (or being enabled to act) differently in their daily lives and when interacting within society.
- ***Collective/Internal (CI)***: This bottom-left quadrant represents changes in the shared knowledge of groups of people or to the collective identity or values of social groups.
- ***Collective/External (CE)***: This bottom-right quadrant represents changes to the structures and procedures within which people operate, including technology, law, societal norms and communications.

Key to ToC thinking is the idea that making changes in one quadrant can stimulate change in others; for example, collective learning about data attitudes and practices, such as the research conducted in this PhD, (lower left quadrant) could inform the design of new technologies, interfaces or processes (lower right quadrant), which if built could make new structures available to have an impact on improving individual-provider relationships (upper-right quadrant). The changes to those relationships could then in turn lead to individuals thinking and feeling differently (upper left quadrant), for example feeling more empowered or having greater awareness of data practices.

## 1.2 Defining and Refining ‘Human Data Relations’ (HDR)

Chapter 6 established six ‘wants’ that people have in their relationships with data: **visible, understandable and usable data; process transparency, individual oversight and decision-making involvement**.

The major contribution of this thesis, beyond the detail and evidence for these wants conveyed in chapters 4 to 6, is to synthesise these findings and conceptualise what people want from data holders into a clearly defined field for future research and innovation. Repurposing the concepts of ‘human-technology relations’ and later ‘human-data relations’ which have been the subject of some study in the

contexts of philosophy, embodied interaction and the performing arts (Ihde, 1990; Hogan, 2012; Windeyer, 2021), I have chosen to name this field “***Human Data Relations***”, or HDR for short. I propose this field as a successor to Mortier *et al.*’s Human Data Interaction (HDI) (Mortier *et al.*, 2014). HDR builds upon HDI but is wider, broader and more sociotechnical; HDR encompasses all aspects of the ways in which people and organisations can and should relate to data, not just interaction with data itself. Through a greater focus on relationships and ecosystems and approaches that target today’s practical data-centric power-imbalanced reality, it can provide a more effective research agenda for the world of the 2020s. The field’s definition draws upon three distinct connotations or readings of its name:

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#### Human Data Relations - A Definition

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The field of human data relations encompasses all the ways in which humans and human organisations relate to, and with, data, specifically:

1. **Human-Data Relations**: the direct interaction of users with data to understand and use it, similar to HDI, and in service of the **direct data wants** [6.1] of visible, understandable and useable data.
  2. **Human “Data Relations”**: the relationships that humans have with organisations that hold data about them, in service of the **indirect data wants** [6.2] of transparency, individual oversight and involvement.
  3. **Human/Data Relations**: the ways that organisations **manage their customers with respect to personal data**. Similar to ‘*public relations*’ or ‘*customer relations*’, this concerns the ways that organisations present their data practices (so as to build trust), and the ways in which they could involve users with data and provide support to understand data to their users (in order to empower individuals and build more effective customer relationships) [4.4.1; 5.5.2; 6.1.2].
- 

[TODO Format this as an inset box not a table]

Having defined the scope of HDR, we can say that ‘better’ HDR can be achieved by working to improve upon the identified six aspects of human data relations. However, as this section will explain, HDR is motivated in two distinct ways, to which those six wants apply differently. As background understanding for this duality of motivation, it is first necessary to examine more closely what role data plays in people’s lives.

#### 1.2.1 The Role of Personal Data

In the modern world, where almost anything can be encoded as data, and given many previously analogue objects and activities now have digital equivalents, the concept of data has become broad and hard to pin down. Underlying Human Data Relations is to explain what roles data can play in people’s lives – what it is to people. Through the Case Studies, external work and my prior learning, I

have so far identified 8 distinct lenses to consider how people might relate to it. These are modelled in Table 15.

Table 2: Table 15. **Eight lenses on data.**

Way of thinking about data	Explanation & Implications
Data as property	Data can be considered as a possession. This highlights issues of ownership, responsibility, liability and theft.
Data as a source of information about you	Knowing that data contains encoded assertions about you and can be used to derive further conjectures enables thinking about how it might be exploited by others, but also how you can explore and use it yourself for reflection, asking questions, self-improvement and planning. It invites consideration of the right to access, data protection, and issues around accuracy, fairness and misinterpretation / misuse.
Data as part of oneself	A photo or recording of you, or a typed note or search that popped into your head could be deeply personal. This lens on data highlights issues around emotional attachment/impact, privacy, and ethics.
Data as memory	Data can be considered as an augmentation to one's memory, a digital record of your life. This lens facilitates design thinking around search and recall, browsing, summarising, cognitive offloading, significance/relevance, and the personal value of data.
Data as creative work	Some of the data we produce (e.g. writing, videos, images) can be considered as an artistic creation. This lens enables thinking about attribution, derivation, copying, legacy and cultural value to others.
Data as new information about the world	Data created by others can inform us about previously unknown occurrences in our immediate digital life or the wider world. This lens is useful for thinking about discovery, recommendations, bias, censorship, filter bubbles, and who controls the information sources we use, as well as who will see and interpret data that we generate and what effects our data has on others.
Data as currency	Many data-centric services require data to be sacrificed in exchange for access to functionality, and some businesses now explicitly enable you to sell your own data. This lens highlights that data can be thought of as a tradable asset, and invites consideration of issues of data's worth, individual privacy, exploitation and loss of control.

Way of thinking about data	Explanation & Implications
Data as a medium for thinking, communicating and expression	Some people collect and organise data into curated collections, or use it to convey facts and ideas, to persuade or to evoke an emotional impact. This lens is useful to consider data uses such as lists, annotation, curation, editing, remixing, visualisation and producing different views of data for different audiences.

When considering HDR, it is important to recognise that people may think of their personal data through any or all of these '*lenses*' [Karger *et al.* (2005);2.2.2] at any given time, and any process or system design involving data interaction should take these into account.

Looking across this set of lenses, it is possible to identify four specific roles that data can serve:

1. Data has a role as an **artifact of value** to your life;
2. Data has a role in **informing** you about yourself, the world, and the prior or recent actions of others that may affect you;
3. Data has a role as a **usable material with which to effect change** in your life;
4. Data has a role as a **means to monitor changes** in data holders' behaviours, digital influences upon you or changes within your life.

### 1.2.2 Human Data Interaction or Human Information Interaction?

To unpack HDR further, it is important to highlight the difference between humans relating to data, and humans relating to information. Human Data Interaction (HDI) concerns the way people interact with data. Mortier *et al.* (Mortier *et al.*, 2013, 2014) defined the field of HDI without distinguishing data (the digital artifact stored on computer) from information (the facts or assertions that said data can provide when interpreted). This is an important distinction. The parallel field of Human Information Interaction (HII) originated in library sciences, and considers the way humans relate to information without regard to the technologies involved (Marchionini, 2008). William Jones *et al.* called for a new sub-field of HII in an HCI context<sup>3</sup>, observing that it is important to include a focus on information interaction because HCI can "*unduly focus attention on the computer when, for most people, the computer is a means to an end – the effective use of information*" (Jones *et al.*, 2006). DIKW theory [2.1] highlights that **interpretation of data to obtain information** is a discrete activity.

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<sup>3</sup>The group of HCI researchers involved in this panel were (with the exception of Raya Fidel) seemingly unaware of the existing HII field in library sciences as they positioned the publication as a call for a 'new field'.

This was borne out in the findings of Case Study Two, where it became clear that participants have distinct needs from data, and from information (5.4.3.2). Access to data **and** information is critical to both understanding and useability, as detailed in section 6.1.2 and 6.1.3.

Drawing on this theory, we can see then that in considering Human Data Relations, there are in fact three distinct artifacts to consider:

1. ***data*** - the stored digital artifacts pertaining to users held by organisations for algorithmic processing and human reference, copies of which can be obtained using individual data rights.
2. ***information about individuals*** - the collection of facts and assertions about the individual and their life, which are obtained through human or algorithmic interpretation of stored data (or in some organisations' case, through analytical inference).
3. ***information about data*** (also categorised in Table 9 / 5.3.1 as ***metadata***)  
- stored facts about the data, such as where it has been stored, who has accessed it, how it was collected, what it means, or when it has been shared externally.

### 1.2.3 The Two Distinct Motivations for Human Data Relations

By making this distinction between the two types of information which people might interact with, and considering the six wants in Chapter 6, it becomes clear that there are two very different reasons why people might want better HDR:

- (i) to acquire *information about one's data*, so that one might exert control over and make informed choices about where *the data* is held and how it is used, in order to be treated fairly and gain more control over the use of one's personal data. This is **Personal Data Ecosystem Control (PDEC)**.
- (ii) to acquire *information about oneself*, so that one might gain insights into one's own behaviour and gain personal benefits from those insights or them to make changes in one's life. This is **Life Information Utilisation (LIU)**.

The two distinct processes that individuals might go through in pursuit of these motives are exemplified in Figure 30. PDEC is a process of holding organisations to account over and managing *what happens to personal data*, often regardless of what it means, whereas LIU is more concerned with *what the data means* and its inherent value as encoded life information, regardless of where it is stored and how it is used<sup>4</sup>. This novel way of modelling the motivations for data interaction

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<sup>4</sup>Of course, there is some overlap; the reason that organisations hold data is so that they can interpret it (usually algorithmically) to inform decision-making. In this way, organisations could be seen to be doing LIU of service users' lives for their own benefit. From a human-centric perspective, this grey area is situated as part of PDEC, as from the individual perspective, how organisations understand you through information will inform decisions that affect your life. Thus, this can be considered part of the reason why one might want to exert control over

were first proposed in my 2021 workshop paper (Bowyer, 2021).

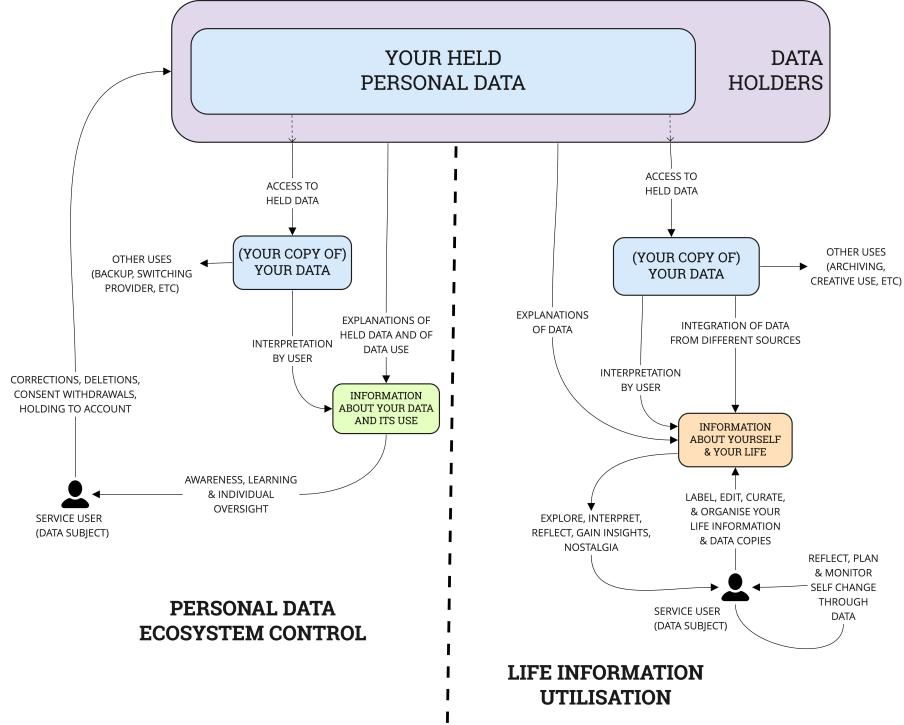


Figure 2: Figure 30: The Two Motivations for HDR: Controlling your personal data ecosystem and utilising your information about your life, with ‘idealised’<sup>6</sup> processes illustrated

**1.2.3.1 Life Information Utilisation** *Life Information Utilisation* is a superset of *Self Informatics (SI)* 2.2.3. It includes all purposes relating to self-monitoring and self-improvement through data, but also includes all other uses of personal data including creative expression, evidence gathering, nostalgia, keeping, and sharing. Many of these desires were expressed in Case Study Two (see Table 12 in 5.3.3), and also hinted at in the Early Help context [4.4.1]. While the existence of digitally-encoded information clearly unlocks new possibilities, LIU has existed in some form throughout human civilisation, as

use of your data, rather than being part of exploiting data to gain self-insights and personal benefits.

<sup>6</sup>The illustrated processes assume reliance on existing data access processes such as GDPR, where the only access is through provision of a copy of one’s data. This is in fact, not ideal, as it creates divergent versions and will quickly become out-of-sync, however for the sake of simplicity this inefficiency is ignored here. Improvements upon this approach are explored in [INSERT REF]

seen through analogue processes such as storytelling, journalling, scrapbooking, arts and crafts.

In the LIU context, the most important wants to focus on improving are *data understandability* (6.1.2) and *data usability*<sup>15</sup> (6.1.3), which relate closely to the HDI concepts of *legibility* and *agency* respectively.

**1.2.3.2 Personal Data Ecosystem Control** Unlike LIU, ***Personal Data Ecosystem Control*** is an individual need that is new; arising as a result of the emergence of the data-centric world (2.1, 2.2.4). Only when organisations began to collect and store facts about people as a substitute for direct communication and involvement did it become necessary. The more data is collected about individuals, and the more parties collect and share that data, the greater the need for individuals to learn about that data so that they might influence its use (or risk their lives being affected in unexpected or potentially unfair ways). PDEC is a direct response to the power imbalance between data holders and individuals that the World Economic Forum described in 2014 [Hoffman (2014);2.1.2].

In the PDEC context, multiple data wants are important: visible data and transparent processes, as well as individual oversight and involvement. For simplicity, the former two wants can be referred to collectively as “*ecosystem transparency*”, and the latter two as “*ecosystem negotiability*” (drawing on the HDI concept of *negotiability*), and these terms will be used below.

#### 1.2.4 Four Objectives for Human Data Relations

In order to provide value to future researchers, activists and innovators, this chapter contributes a map of the HDR opportunity landscape. This map is expressed in two parts across this section and 7.4. As a first step, we can take the “six wants from data relations” Chapter 6, and map reduce those to four simple ‘*landscape objectives*’ which shape our ultimate goals for effective HDR in this landscape of opportunity:

1. Data Awareness & Understanding;
2. Data Useability<sup>15</sup>;
3. Ecosystem Awareness & Understanding and
4. Ecosystem Negotiability.

As Figure X shows, the need for data to be understandable, visible and useable, applies to all types of data, whether that data is interpretable as **life information** (information within the data, that says something about the individual) or **ecosystem information** (information *about* the data, where it is held and how it is used). These two types of information will collectively be referred to as **human information**, and will be used in describing the HDR landscape in subsequent sections.

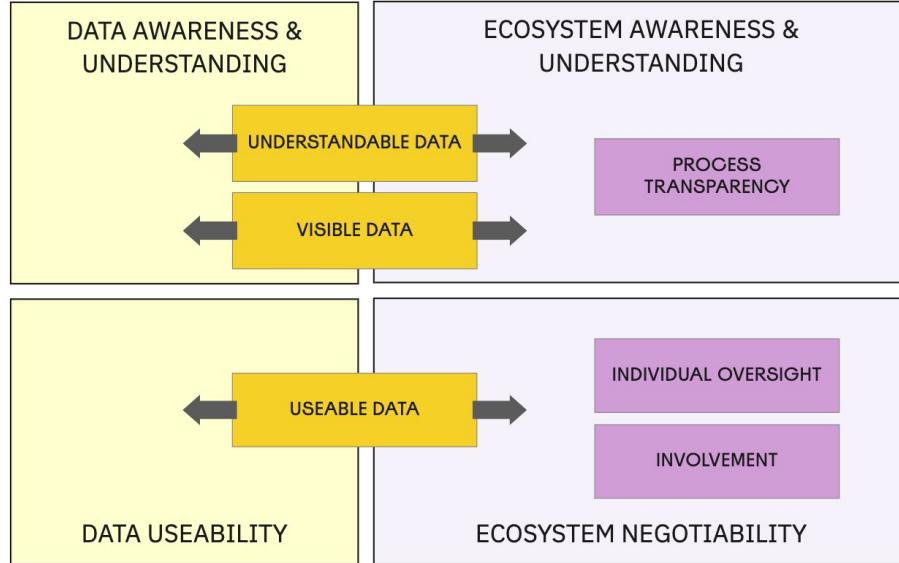


Figure 3: Figure X: Mapping the Six Wants into Objectives for the HDR Opportunity Landscape

### 1.2.5 Better Human Data Relations as a Recursive Public

Before engaging with the practicalities of pursuing these HDR objectives, it is valuable to revisit the stance from which we approach this change. As outlined in 3.2, the research of this PhD has been grounded in participatory action research and experience-centred design; by using a Digital Civics (Vlachokyriakos *et al.*, 2016) frame to gain deep understanding of people’s needs and the ways those needs are not fully met, we can interpret and model how the world needs to change. Section 3.2 already outlined that we can consider such research as political, seeking to correct an imbalance in the world. In this chapter, we look beyond identifying what change is needed, and step into the role of activist, exploring how individuals and groups can actually change the world they inhabit.

In doing so, we can consider ourselves (those who pursue better Human Data Relations, or *HDR reformers* as a shorthand) as a *recursive public* (Kelty, 2008; ‘Recursive Public (Discussion Page)’, no date), albeit a nascent one. This is a term originating in the free software movement to describe a “*collective, independent of other forms of constituted power, capable of speaking to existing forms of power through the production of actually existing alternatives*”. This term captures the idea that through various means at our disposal: participatory research, experience-centred design, engineering software prototypes, exertion of legal rights, and efforts to raise public awareness, we seek to modify the systems and practices we live within in pursuit of our goals. This idea of reconfiguring society in this way has been conceived as *civic hacking* (Crabtree, 2007; Levitas, 2013;

Tauberer, 2014). The collective around better Human Data Relations does not yet exist as a named and identifiable *public* (Le Dantec, 2016) but its members congregate around emergent collectives in interconnected and overlapping spaces, most notably the MyData community (MyData, 2017) and its members, but also research and activism agendas including but not limited to: personal data lockers (CitizenMe, 2021; ‘Digi.me’, no date); digital rights (‘Open rights group: Who we are’, no date), gig economy worker rights (Kirven, 2018; ‘Worker info exchange’, 2022), privacy by design (Cavoukian, 2010), privacy activism (Davies, 1990; ‘Bits of freedom: Our focus’, 2000), data justice (Taylor, 2017; Crivellaro *et al.*, 2019), critical algorithm studies (Gillespie and Seaver, 2016), humane technology (Harris, 2013) and explainable AI (‘Explainable AI: Making machines understandable for humans’, no date).

Whether these disparate groups coalesce into a single identifiable public remains to be seen, and so too whether the term this thesis offers of *Human Data Relations* is sufficient to capture that public. At the least, it provides a descriptive umbrella term. Nonetheless, the breadth of research and innovation and activism happening in this space validates both the need and the desire for such a recursive public around better HDR to exist – in fact, it already does, whether we name it such or not. Therefore, this chapter takes an unashamedly critical view of the status quo, favouring disruptive societal changes that would further the objectives of better Human Data Relations and providing actionable approaches that will be of use to the members of this public. The chapter asks, “*How can we change the world into the one we want?*”

### **1.3 The landscape of opportunity: Obstacles to better Human Data Relations, and how we might overcome them**

Using the four objectives established in 7.2.4 as our goals, and considering how they might be tackled, specific *obstacles* have been identified. These are analogous to Li’s ‘*barriers cascade*’ [2.2.3; Li, Forlizzi and Dey (2010)] and represent the obstacles that individuals or system designers must be empowered to overcome if the objectives are to be met. These obstacles are followed by useful *insights* I have identified that might help overcome those obstacles. This is summarised in Figure X, which shows an HDR-specific barriers cascade: a route of overcoming obstacles through which individuals might be empowered and by which organisations might become more HDR-friendly.

The obstacles and insights in the figure are explained in the following subsections. The last of these (corresponding to the ‘solution space’ box) covers some of the more pervasive obstacles that apply to all of the previous four HDR objectives.

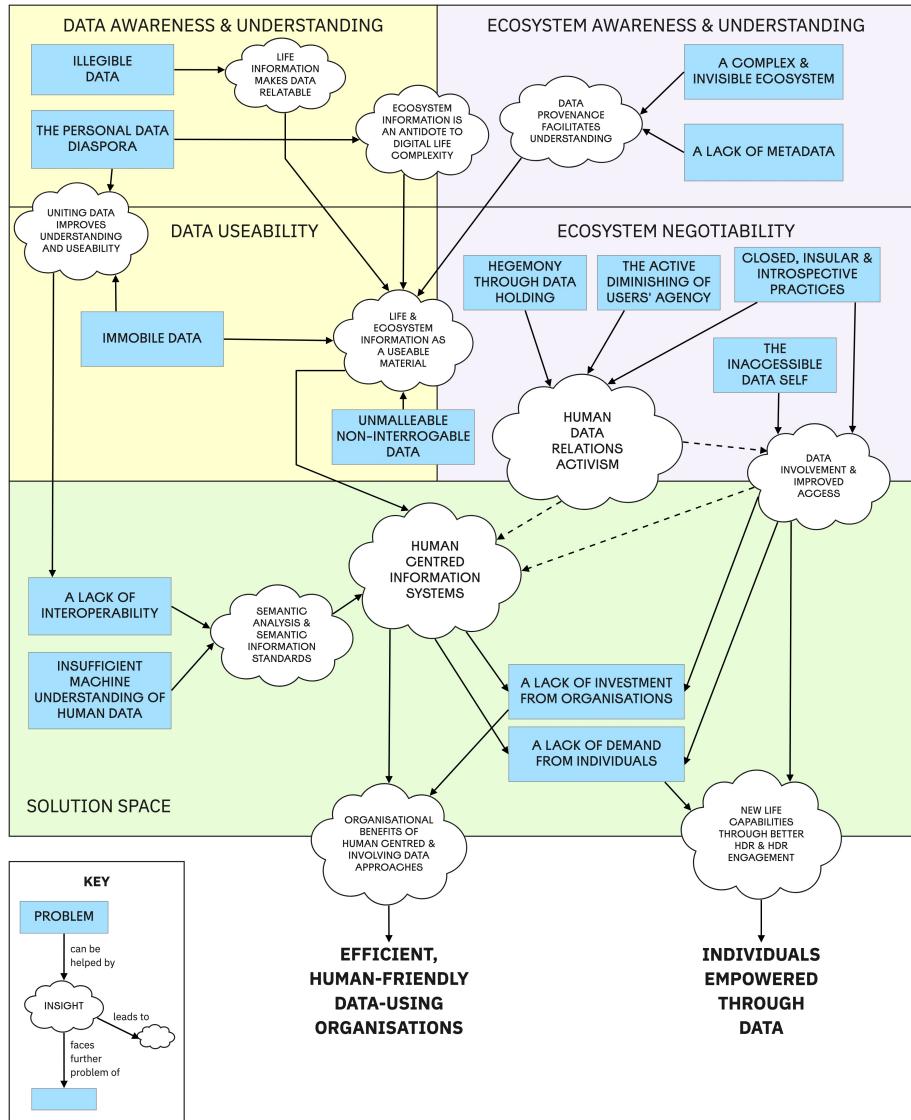


Figure 4: Figure X: Obstacles and Resulting Insights in the HDR Opportunity Landscape

### **1.3.1 Obstacles to the HDR Objective of Data Awareness & Understanding**

In pursuit of visible, understandable data [6.1.1; 6.1.2], the first obstacle encountered is that in today's complex digital landscape, **most personal data is invisible, inaccessible or unrelated**. It is trapped in service providers' databases, or on different devices or hard drives, or inaccessible due to software limitations or proprietary file formats (Abiteboul, André and Kaplan, 2015; Bowyer, 2018), or in formats. Participants of both Case Studies talked of 'not knowing' what data exists and of being 'in the dark'. As Case Study Two showed, even where data is accessible, it is not relatable ('legible' [Mortier *et al.* (2014); 2.3.2]). Thus the objective here is to tackle this obstacle and ensure that people not only have awareness of their data, but can understand ('make sense' [Gurstein (2011); 2.1.4]) of what it means.

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#### **INSIGHT 1: Life Information makes Data Relatable**

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In the pilot study and Case Study One, 'data cards' were used to represent common types of civic data [Figure 8?X]. In Case Study Two [ADD REF to Types diagram in 3.X], and in Hestia.ai's digipower investigation (7.1.1), categories of provider-held data were illustrated with examples. In my research report for BBC Cornmarket [ADD REF], the use of **relatable examples** was identified as an important way to help people understand what a piece of data represents. Recalling that to make data meaningful, we must be able to interpret it as information [2.1.1, this can be refined further: **To make data meaningful, it needs to be expressed as life information**. Tables, spreadsheets and 'big data' sound dry and (to some) dauntingly technical, but once those same datapoints are expressed as '*facts about your life*', the hurdle of relatability is overcome. The application (and effectiveness) of this principle is evident in successful online services like Netflix, Spotify and Strava, and in social media platforms like Facebook: these interfaces show understandable everyday concepts like Friends, Events, Movies, Playlists, not files, records, folders or database rows. These examples have successfully '*pushed the technology into the background*', in line with Weiser's vision (Weiser, 1991), Rogers' calm computing, and the quote that opens this chapter. While exploring this idea of mapping *life concepts* further at BBC R&D, I produced Figure X, which shows a near-exhaustive overview of the many different pieces of information in an individual's life that might be held as data by service providers:

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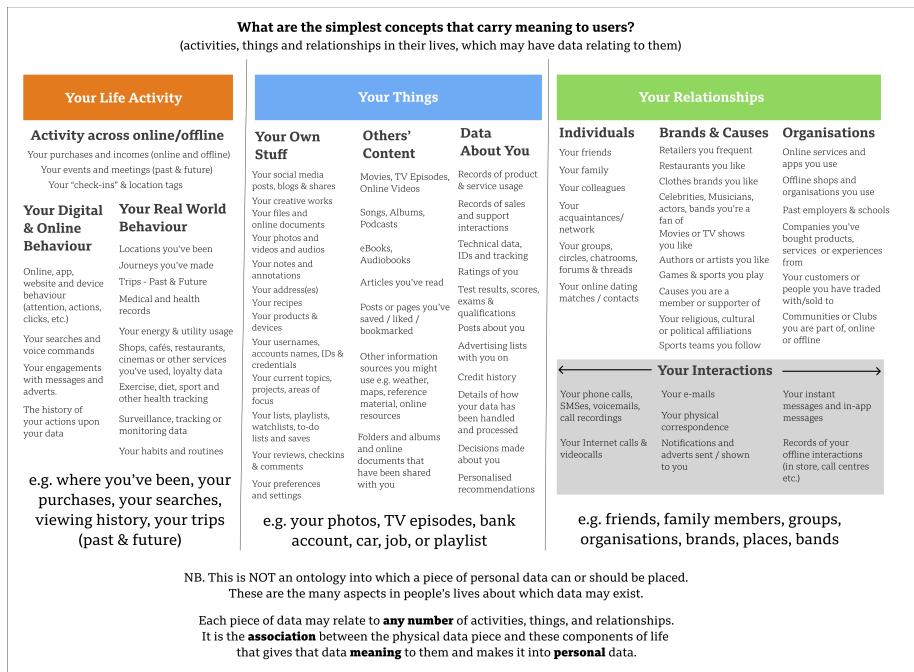


Figure 5: Figure X: Life Concept Modelling

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This diagram shows how most common personal data types handled by providers today can be mapped to more relatable life information concepts. These life concepts (illustrated with examples where possible) are the best way to make data meaningful and relatable to individuals, and to begin to help people in their search for value in their data [5.4.3.1].

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[TODO make this an inset box not a table] [TODO Fix non showing caption]

Another important obstacle to consider here is what I call the *Personal Data Diaspora*<sup>7</sup>. As illustrated by Imogen Heap's quote opening Chapter 1, an individual's personal data is typically very widely dispersed. For example, if I consider just my movement tracking data, I have over time accumulated activity logs from walking, running, cycling, and driving which are stored by Nike+, MyFitnessPal, Strava, Google Fit, Fitbit, Apple Health and Google Maps, not to mention the records remaining on my different smart watches, smartphones and hard drives. This is the problem of Integration (Li, Forlizzi and Dey, 2010) that SI enthusiasts face [2.2.3]. Even aside from the issues this creates in terms of managing one's data ecosystem [2.2.4], it means that it is impossible to view the history of my physical activity side by side, to spot patterns over time or make comparisons. To overcome this obstacle, approaches to data interfaces and life information modelling must be identified that recognise the **scattered, complex reality of each individual's personal data ecosystem** and begin to make it visible and understandable. This is explored further in 7.3.3 and 7.3.4 below.

The takeaway for this HDR objective is that data awareness and understanding is a problem of representation. Invisible data should be visibly represented, and all data should be represented in the context of its interpretation as life information.

### 1.3.2 Obstacles to the HDR Objective of Data Useability<sup>15</sup>

To consider how to improve the useability of data, we must first consider what properties of data, as it typically exists today, make it hard to use. The primary obstacles are that **most personal data is immobile, inaccessible, unmalleable and not interrogable**.

It is **immobile**, in that it is very difficult to move a dataset out of the environment where it exists: most data exists in organisations' internal databases, where it is tightly coupled to technology stacks, interfaces and business processes that use it. Separating one's data from the service that holds the data is difficult and often impossible.

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<sup>7</sup>The word '*diaspora*' is typically used with reference to populations, but is an apt term, derived from the Greek '*diaspeirein*' meaning '*scattered about*' or '*dispersed*'.

[TODO possibly move this paragraph elsewhere to avoid repetition with previous section] This setting of personal data also explains why it is **inaccessible** to individuals (in the sense of ‘effective access’ (Gurstein, 2011)). Data access requests such as GDPR are typically satisfied by creating a copy of the data, which creates problems of delay, divergence and understanding. Even then, as Case Study Two showed, this is incomplete [5.4.2.2] and much of the data is never made available. Its accessibility is also hindered by the technical nature of data. For organisational efficiency, data will often be stored in complex proprietary structures which are designed for the algorithmic efficiency of the specific operations the service provider wants to perform, rather than for general-purpose re-use.

Evident from individuals’ goals for use of their data [Table 12] is that people need to be able to ask questions of their data. This highlights the problem that data is not **interrogable**. It must stand for itself, and there is no obvious way to ask a question about the meaning of the data or about what the data says about a particular question, without either the co-operation of the data holder, or advanced technical skills in querying and data analysis. To be able to ask questions of data, it needs to be malleable - one needs the ability to break it down, look at it from different perspectives, and reconstitute it in different ways. This requires more than just an ability to produce visual representations of the data, but an ability to **interact with the data** and produce new interpretations and insights that can help to answer specific questions.

To overcome these obstacles, we need to find ways to extract data from its current constraints into environments where it can move freely and be examined and reconstituted without restriction.

To address these obstacles, the following insights could help:

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## **INSIGHT 2: Data Needs to be United and Unified**

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It is clear that better HDR involves recognising this scattered, splintered reality (Lemley, 2021) and moving beyond it. To make data useable for individuals, the diaspora must be united. This means that data from different sources must first be **united** – brought together – and then **unified**, which means making it into a collection of data about the individual and their life, rather than scattered slices of that person's life held separately in ways that are optimised for specific services. This is a multi-faceted sociotechnical problem of access, interpretation and **integration** (as recognised in self-informatics [Li, Forlizzi and Dey (2010); [2.2.3]]). The negotiability aspects are important (we can only unite data that we can access, and only those that stored information can fully explain it) but these aspects will be explored in 7.3.3 and 7.3.4 below. Setting that aspect aside and focusing on the practical, the way ahead begins with creating a space where data can be held, combined, controlled and **owned** by the individual - '*place for your personal data*' (Jones, 2011, p. [2.2.4]), forming the seed of their new human-centric personal data ecosystem. This is in line with Bergman's '*subjective classification principle*': that '*all related items should be classified together regardless of technological format*' (Bergman, Beyth-Marom and Nachmias, 2003) (We could add: '\_‘regardless of where they are held’'). This vision is embodied in the concept of **Personal Data Lockers** or Vaults (PDVs) [2.3.4]. The BBC R&D Cornmarket project [7.1.1] is one project which is examining how to build PDVs, and in section 7.4 I explore possible design approaches. At this stage, we must recognise the importance of the *concept*, though. Once data is united and unified, this enables the creation of new views of data that were not previously possible. For example, today each separate TV app, device or streaming service maintains separate records of what you have watched. Once unified in a PDV, it would be possible to present you with a unified view of all the past content you had viewed, across all channels, as this mockup I made at the BBC shows:

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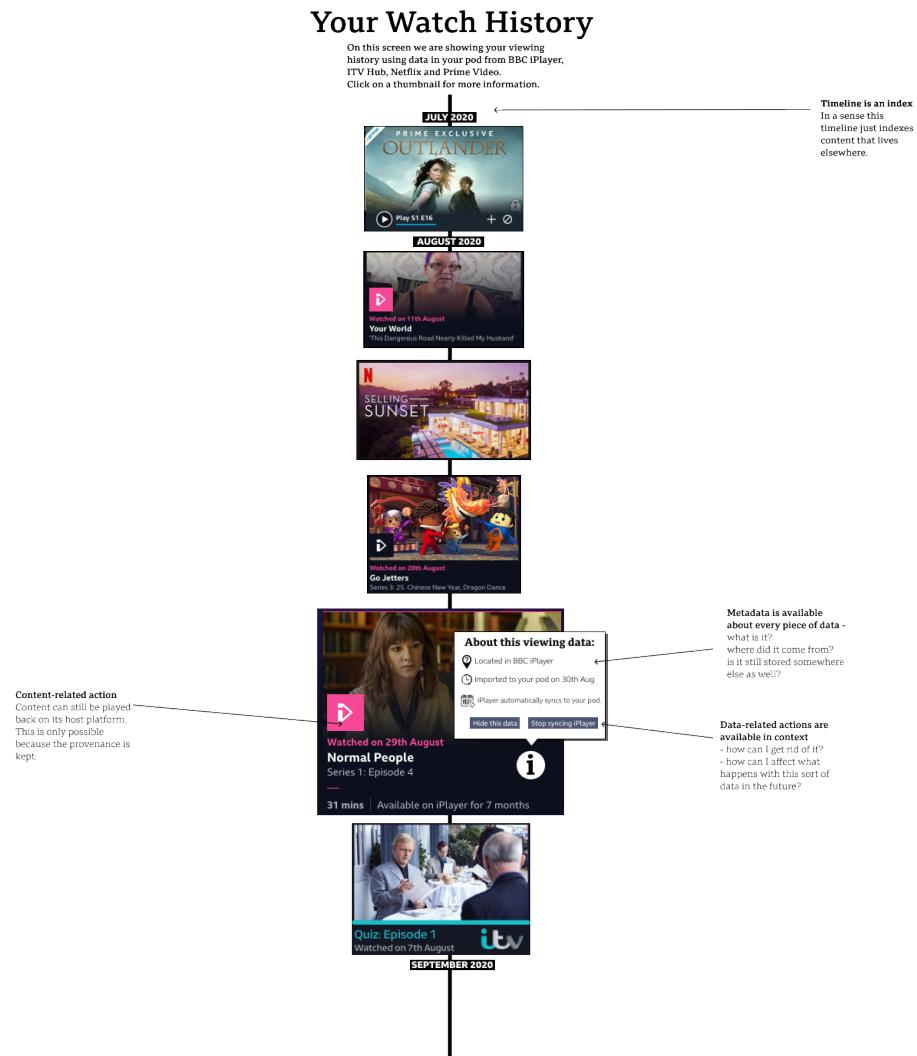


Figure 6: Figure X: A mockup of a unified TV viewing history which I created for the BBC R&D Cornmarket project

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### **INSIGHT 3: Data Must Be Transformed into a Versatile Material**

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Looking at the specific individual goals Case Study Two participants had with personal data [Table 12] (e.g. reflection, pattern-finding, goal-tracking, and creative use) - and also at the many mechanisms that innovators in the PIM space have identified [2.2.2] (e.g. associative exploration, spatial arrangement, embodied interaction for different contexts), what we can infer is that somehow, unified data must be **transformed into a versatile material**. To truly empower users to make use of their data, we need to move to a model where data - represented as facts (or assertions) about their life – can be created, deleted, moved, grouped, annotated, copied, shared, modified, labelled, organised, separated or otherwise manipulated. This idea of data being a material is new for everyone but data scientists: it is new not just to end users but for designers too. Eva Deckers, in her work on *data-enabled design*, an approach to design which also calls for data to become a material, notes that designers (and we could expand this to laypeople too) “*are in general not trained and prepared to work with data. They’re not equipped with the right tools, data manipulation is not part of the schools’ curriculum and designers [people] are rarely interested in understanding data*” (Deckers, 2018). Her work with colleagues on the ‘connected baby bottle’ illustrated how such an approach can create a space for the iterative user-centred development of new capabilities (Bogers *et al.*, 2016). Based on this thesis’s theorisation of human data relations, the best candidate for what this material should *be* is the two information concepts we have identified - life information and ecosystem information. So the goal of data usability calls for the creation of **systems that enable human information to be treated as a material**.

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So, for data to be useable, we must change its nature. We have been trained by the computers that have existed up to now that the basic units for interacting with computer systems are files - these are the material of today’s personal computers. Where we do interact with data as information instead of files, that information is typically presented in limited contexts within certain products or apps. In line with the goal to move up the DIKW pyramid [2.1], we need smarter computer systems, that move beyond files (Bowyer, 2011) - systems whose basic units of interaction are pieces of human information. **We need a human information operating system.**

#### **1.3.3 Obstacles to the HDR Objective of Ecosystem Awareness & Understanding**

As I have established in 2.2.5, 2.3, 6.2 and 7.2, human data relations cannot be made effective without a sea change in the way that individuals are able to interact with the complex ecosystem of personal data that we each inhabit. **Our personal data ecosystems are incredibly complex and largely invisible.** For example, it is very easy to allow a handful of communication and social media apps access to your address book or contact list, and before you know it you

have created a complex and unmanageable network of connections that silently sync and propagate your addresses and phone numbers across the Internet. And there are deeper layers which are not even slightly visible to users: networks of data brokers, advertisers and digital cookie companies exchange user identifiers, activity data and personal information about you while you browse or use apps (Pidoux *et al.*, 2022). As the Case Studies showed, the ability to build up a meaningful picture of your personal data ecosystem is completely absent [4.3.4.1] or severely limited, causing people to remain '*in the dark*' and leads to feelings of fear (Bowyer *et al.*, 2018), overload [2.2.4] and resignation [5.4.4.1]. Managing one's personal data ecosystem is an **overwhelming, unmanageable task** that even personal data experts are not fully able to get a handle on. We do not feel '*in control*' [Teevan (2001); 2.2.2]. The ability to provide a user with ecosystem transparency is hindered by the complexity and multiplicity of the data relationships they have been encouraged to set up, and by a lack of tools to provide a meaningful, or indeed any, view of those relationships. A further aspect to this obstacle is that in both Case Study contexts, no one individual or organisation has the ability to see the whole of a user's data ecosystem [4.3.4.3; Cornford, Baines and Wilson (2013)], and there is little commercial motive to try and solve this problem, as every provider focuses just on their own apps, websites and services. Making one's ecosystem visible, transparent and understandable is therefore an essential objective for better HDR.

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#### **INSIGHT 4: Ecosystem Information is an Antidote to Digital Life Complexity**

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Having identified that acquiring ecosystem information and understanding is a key motivator for many people (constituting 74% of participant goals in Case Study Two [Table 12]) and is an essential objective for better HDR, we can view the building of systems for **ecosystem detection** and **ecosystem information display** as ingredients to help overcome the obstacle. As a representative example to help show what this could look like, we can look to a new app called SubsCrab, pictured in Figure X.

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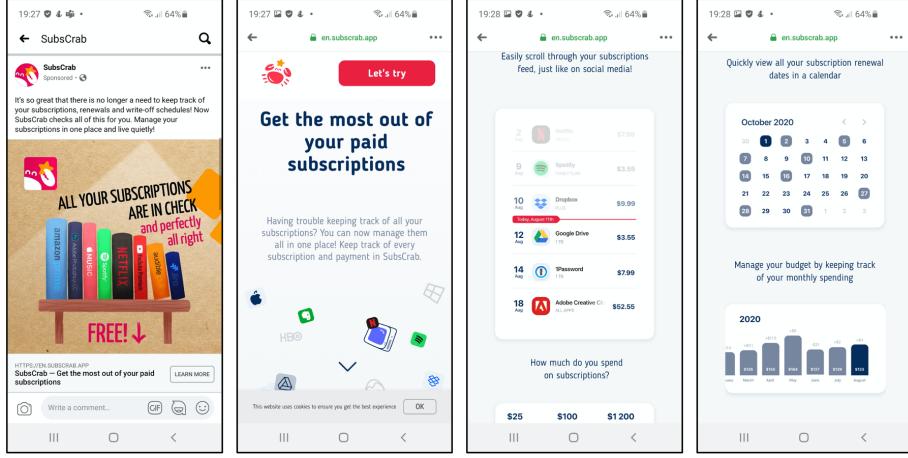


Figure 7: Figure X: SubsCrab: An example application for ecosystem detection and visualisation

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This app connects to the user's e-mail account, and searches it and monitors it for e-mails from service providers such as Netflix, Spotify, Dropbox, or Google with which the user has monthly subscriptions. In doing so, it is **detecting part of the user's ecosystem** - identifying which companies they have a payment relationship with, and parsing the e-mails to identify billing dates and payment amounts. It then **provides additional representations of that ecosystem information to the user**, so that they might get on top of their subscriptions, see what they need to pay (or cancel), and feel more 'in control' [Teevan (2001); 2.2.2] of this aspect of their digital life. Thanks to this illustration it is easy to imagine other types of ecosystem detectors, for example detecting relationships with free services and websites, identifying account numbers and e-mail addresses, password resets, addressbook syncs, OAuth logins, family identities and more. Each of these could then power new interfaces, contributing to the **simplification of the user's digital life** and **giving people more visibility and control** over their previously unmanageable data ecosystem.

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A further interpretation from this insight is that a key element of the required ‘sea change’ in approaches to human information relations mentioned above, is to challenge the current life-information-centric model that pervades in PDV and SI approaches, which all **assume that the only way to unite data is to collect it**. The difficulty in such an approach is that you can only collect that which you can extract. To address this, I drawing inspiration from a computer programming concept known as ‘*pass by reference*’ (as opposed to ‘*pass by value*’) (Ananya, 2020) where data is ‘pointed to’ rather than moved and also from productivity guru David Allen who recommends the use of ‘*placeholders*’ (Allen, 2015) to keep track of tasks you cannot otherwise bring into your planning. To be able to build a complete map of a user’s ecosystem we must **be able to keep track of accounts and data that are remote**, much like a search engine points to information on different pages around the web. We can create **proxy representations of service-provider-held or otherwise inaccessible data** (e.g. offline or restricted). These representations can become part of the manipulable material in the user interface, and could be augmented with links to visit those remote services.

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Once we begin to think about storing and representing human information in ways that go beyond simply representing the information that is encoded within the data, and into the realm of *what the data is about*, new possibilities are unlocked. We can envisage building a PDV type system that is not only a repository of personal data, but (thanks to proxy representations), a collection of ecosystem information and *contextually-situated* life information too, including information about relationships with data holders or other entities. This, however, exposes a secondary problem that any builder of such a system would face: **a lack of metadata** (as discussed in 2.2.2). Typically, much of the information stored on our hard drives lacks context about where it has come from, and how it relates to the individual in a holistic life/ecosystem sense. Where data access rights are executed (or data is shared via human means such as in 4.3.2.2), the attention is on the data itself: what it says. Case Study Two showed that some of the most desired information was not the data itself, but how it is used and shared and what is inferred from it (i.e. **metadata** [Table 9]), yet this was rarely forthcoming [Table 10]. There are many facets that can be quantified and recorded about a datapoint or dataset, as illustrated in Figure X, which I created at BBC R&D:

It is notable that many of these facets are not explicitly recorded today, or would take significant work to capture; nonetheless, this exploration can serve as a useful reference for how information can be better contextualised (supporting context-based and associative information management as described in 2.2.2). Taking a step back to view this lack of metadata at a more conceptual level, leads us to the next insight:

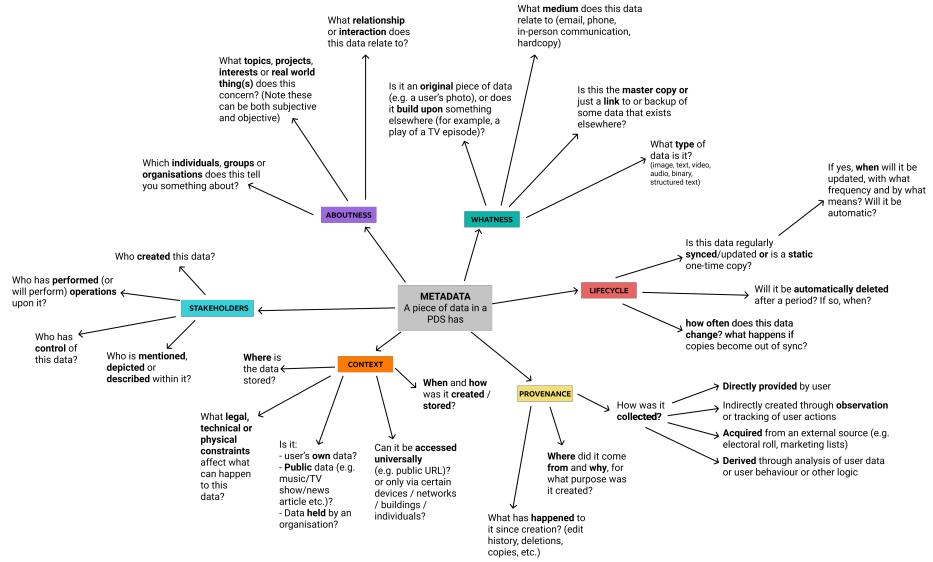


Figure 8: Figure X: Some of the many aspects of metadata that might exist about a datapoint or dataset

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## **INSIGHT 5: We Must Know Data's Provenance**

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### **INSIGHT 5: We Must Know Data's Provenance**

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Metadata is what gives information *context*, which is critical to sensemaking [2.2.3] and enables good experience-centred design [2.3.2, 2.3.3]. Without context, data loses meaning (as observed by a participant in Case Study Two [5.4.3.1]). Collecting historical data about the individual is important from an SI reflection perspective [2.2.3]), but knowing the **history of a piece of data** is vital to understanding its nature and context. Data is not neutral and in fact is inherently biased, since it was created for a specific purpose with a specific agenda in mind (Gitelman, 2013; Neff, 2013). To address this, more context is clearly needed, Significant research in this space has been undertaken by Professors Mike Martin and Rob Wilson at Northumbria University, formerly Newcastle University, who promote the idea of **data with provenance**; in other words that **data must carry with it the details of why it exists, how it came to be, and what has happened to it since its inception**, and that provenance must be communicated alongside any visualisation of the data, in order for it to be fairly assessed through full understanding of its context. Provenance is essential for data to be trusted, argues Martin, and should be quite granular: a piece of data should be attributed not just to an individual or organisation, but to the relationship between role-holding individuals in a specific context, and greater insights can be gained when **considering all actions upon data as motivated communications from one party to another**; only by capturing this information in-situ can the data be fully appreciated (Martin, 2022). This framing essentially advances the concept of history tracking into the sociotechnical, ecosystem-aware problem space this section is addressing. While everyday system designs have not approached this level of granularity, the importance of data provenance has been recognised in the PIM space: As described in 2.2.2, temporal PIM systems, from Lifestreams (Freeman and Gelernter, 1996) to activity streams (Hart-Davidson, Zachry and Spinuzzi, 2012) rely upon data provenance in some form. A study by Jensen *et al.* concluded that provenance tracking can be valuable for identifying related documents, a critical part of knowledge work today (Jensen *et al.*, 2010). Odom, Lindley and colleagues proposed the idea of file biographies, which view the lifetime of a file as something that should remain connected, and can be traversed in order to understand the context of the file at its different interaction points (Lindley *et al.*, 2018). This comes close to Martin's vision but does not capture the motivation for each interaction. While provenance capture is not a solution in its own right to the understanding of data and of ecosystems, it is clear that data with provenance is very likely to be a valuable part of any design that aims to help individuals with managing to get an overview of their complex and invisible personal data ecosystems.

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What we can see in this section is that by paying attention to Ecosystem Information, Metadata and Provenance, we can open up a new space that, at

the time of writing in 2022, almost no-one is building for. For people to manage their digital world, they need a map. This is the first step on the road to giving individuals the ability to have oversight of their personal data ecosystem and take action within it.

#### 1.3.4 Obstacles to the HDR Objective of Ecosystem Negotiability

This section explains three distinct obstacles to ecosystem negotiability: the intricate structures that give data holders power, the trend of actively diminishing user agency, and the intractable data self.

It is in the pursuit of individual oversight [6.2.2] and decision-making involvement [6.2.3] that the impact of the power imbalance between data holders and individuals [2.1.2] becomes most clear; unlike the other HDR objectives, **individuals cannot act to claim ecosystem negotiability for themselves**. Negotiability means having the power to act, and in the context of systems and interfaces owned and designed by service providers that **power can only be given**. The hegemony of data holders is therefore the greatest obstacle to this objective, so it is vital to examine the nature of that power - where does it come from?

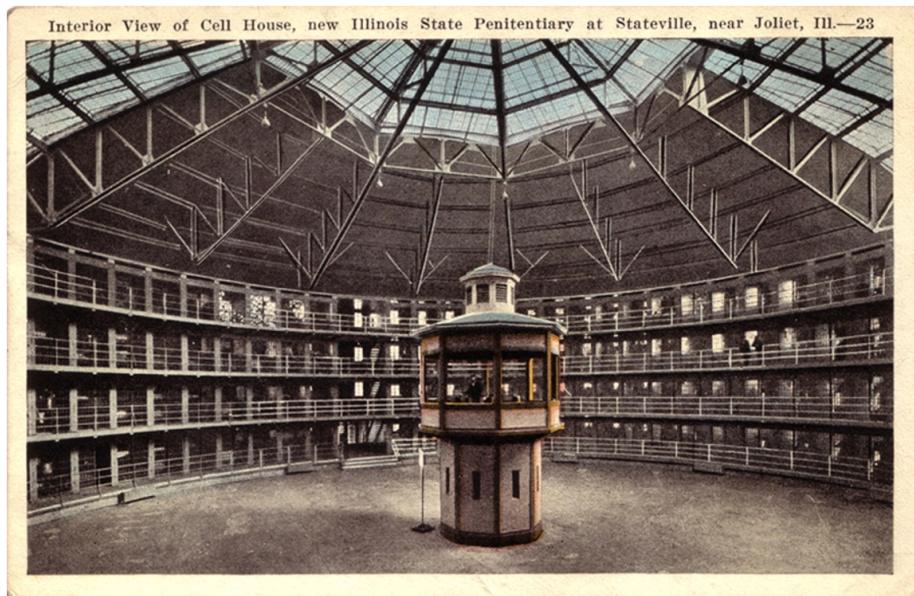


Figure 9: Figure X: The Panopticon Structure of the Illinois State Penitentiary

A helpful analogy for the relationship between provider and user can be seen in the design of Jeremy Bentham's *Panopticon* (Bentham and Bozovic, 2011), a real-world version of which is pictured in Figure X: an 18th century prison architecture design that would elevate the power of the (hidden) prison guards to observe all the prisoners easily at any time while removing prisoners' privacy

and providing no ability to observe those in power. As in Orwell's *Nineteen Eighty-Four*, individuals are unable to know when they are being watched, thus are forced into compliance. Structuralist philosopher Foucault interpreted the Panopticon as a political design, recognising that human environments can be configured to influence or regulate behaviour, in order to defend the power of the ruling class (Foucault, 1975). Such designs embody his four principles:

- **Pervasive Power:** the guards see everything all the prisoners do, all the time
- **Obscure Power:** the guards can see into any cell at any time, but the prisoners can't know when, how or why they are being observed
- **Direct Violence Made Structural:** the structure motivates the prisoners to self-regulate their behaviour without being coerced (through beating or punishment)
- **Structural Violence Made Profitable:** having been made compliant by the structure, the prisoners can be put to work for the benefit of those in power, as it is the only option available to them.

We can see at least three of these traits in modern Internet platforms such as Facebook today: these platforms monitor user behaviour (pervasive power) without their knowledge and without accountability (obscure power). Interfaces are designed to offer only those actions that benefit the platforms (for example, clicking ads, sharing content or spending more time on site (structural violence made profitable). This has happened through the processes of *platformisation* and *infrastructurisation* (Helmond, 2015; Plantin *et al.*, 2018), which have supplanted the Web 2.0-era promise of a free, open Internet that could be a great leveller and empower individuals.

Through the control of the data and of the design of the interfaces through which the data is made available – the only channel through which they can be observed – **service providers and platforms assert a structural power over the digital landscape**. Just as the design of the panopticon regulates the behaviour of the prisoners, so the configuration of the platforms, apps and service interfaces we use regulate and limits the behaviour of users. As Lessig wrote, '**Code is law.**' (Lessig, 2000). This infrastructural power is explained further in the insight below.

Looking deeper into theories of power reveals that structural power is not the only form of power which modern-day data-centric service providers hold. Jasperson *et al.*'s extensive review of types of power in the context of technology organisations (Jasperson *et al.*, 2002) identifies 23 different power paradigms, of which at least 13 can be, and are, asserted by data-centric organisations today:

- **authority:** ownership of technology or infrastructure (for example of websites, servers and code)
- **resource control:** controlling the flow of resources (in this case of information/data)
- **systems/structural power** structural manipulation of others (as detailed

above)

- **rational power:** controlling decision-making processes
- **disciplinary power:** using an influential position to affect others' mental models (for example, positioning location tracking as theft resilience)
- **zero sum power:** winning a battle for ownership/resource control at the other party's expense (e.g. losing control of your sacrificed data)
- **behavioural influence:** persuading others to carry out the desired behaviour (e.g. restricting features to motivate subscription payments)
- **interpretative influence:** determining how reality is externally represented (e.g. Facebook determining the way in which your social network is represented to you)
- **network centrality:** becoming an indispensable hub of a wider ecosystem (for example, Facebook/Google dominance in online ad-brokering)
- **processual power:** changing processes for competitive advantage (for example, platforms offering preferential APIs or rates to compliant partners)
- **socially shaped power:** influencing a wide audience to settle upon a preferred interpretation (e.g. using dominant market position to dominate debates e.g. about privacy norms)
- **interpretive power:** creating the internal representations of reality within an organisation (for example, presenting unpopular attitudes to data privacy to staff as normal/acceptable/beneficial for business)

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#### INSIGHT 6: Data Holders use Four Levers of Infrastructural Power

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Hestia.ai [7.1.1] have produced a model to explain the mechanisms by which powerful technology companies gain power and use it to shape today's digital landscape. In this model, **infrastructural power** comes from three things: **technical ability**, **organisational ability**, and **the acquisition of data about individuals and populations**. Thus, as organisations (especially platforms) collect more data, and grow in market influence or technical capability, they gain power over individuals and over other organisations. They exert power in four quadrants, using four 'levers'. Simplified and expressed in the terms of this thesis, these are:

1. **Collect & Interpret Data to Acquire Knowledge:** Data and signals are collected from individuals and interpreted in order to infer their intents and interests. For example, Google collects raw GPS and wi-fi hotspot data from mobile phones, which it then statistically analyses to infer which shops or venues you visited and what forms of transport you used, increasing Google's knowledge about individuals and populations.

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## INSIGHT 6: Data Holders use Four Levers of Infrastructural Power

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### 2. Present Content and Configure Structures to Influence Individual Behaviour:

Knowledge of individual intents and interests is exploited within user interfaces to influence desired individual actions. For example, Facebook or presents a user with a product relevant to their interests, which they are motivated to click upon, generating ad revenue. Another example might be Twitter manipulating the content of the user's feed to show more tweets from conversation topics where they can show promoted tweets, increasing ad revenue.

3. Configure Structures to Improve Knowledge Acquisition: A provider uses its dominant position is exploited to force other organisations to improve the provider's ability to acquire knowledge. For example, Google provides free analytics tools to web developers, but requires the end users of those client websites to supply visitor data back to Google, increasing their ability to acquire knowledge about individuals and populations.

4. Configure Structures to Disadvantage Others: Certain providers (typically of operating systems or popular devices) can configure the structural relationships between other parties. For example, a smartphone manufacturer could limit data exchange between other apps, while still extensively collecting data signals themselves, such as when Google was found to be collecting call history from Android's dialer app.

The precise mechanisms and techniques employed by platforms and providers when exerting their infrastructural powers, as well as the social and market consequences of these practices are explored in detail in Hestia.ai's digipower technical reports, of which I was a co-author (Bowyer *et al.*, 2022; Pidoux *et al.*, 2022).

An important aspect highlighted in the research is that providers' power is far greater than many realise: Unlike in the physical realm, providers of popular online platforms can **reconfigure the landscape to change the way that individuals perceive reality**, in line with the powers of interpretative influence, behavioural influence and socially shaped power described above (Bowyer *et al.*, 2022). Providers control the extent to which (if at all) the data stored behind the scenes, and the internal processes that use that data, are visible, and how such data and processes are represented.

The above model shows that the accumulation of data (and hence, information) is implicitly and objectively a form of power. This theory is consistent with participants' observations in 5.4.4.1 that data holding and limiting access to it is a source of power. We can therefore predict that as long as current platforms and service providers are free to collect so much personal information, the information landscape will remain imbalanced and individuals will not be able to acquire ecosystem negotiability.

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#### INSIGHT 6: Data Holders use Four Levers of Infrastructural Power

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Through this insight it is clear that the most powerful data holders exert huge influence over the digital landscape, in terms of what is knowable and what is do-able. Individuals or activists' abilities to balance the landscape are hindered by the fact that they are operating in a landscape that the incumbent platform and service providers effectively control.

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The second major obstacle to the objective of ecosystem negotiability we must recognise, is that the above processes of platformisation and power exertion are not a one-off transition, but rather an ongoing process which has not ended. There is a **continuing trend of actively diminishing individuals' agency**, especially evident in the last decade. When software was sold in a box, manufacturers competed based upon which product would let the user take home the greatest range of features and capabilities. New releases with new features drove new product sales. But in the cloud computing era, a smaller set of core features done well is sufficient to guarantee an ongoing subscription revenue from a user. Cost savings in development and support costs can be made by reducing feature sets. The relentless pursuit of increased profits and further cost saving sees products lose, not gain, features. Interfaces are reshaped to serve businesses' interests first and foremost. As described in 2.3.5, the primary concern is about making user behaviours constrained, predictable and profitable, rather than meeting their needs or providing maximal value. Plantin *et al.* describe the particular harmful influence on the ecosystem of Facebook's power exertions: “*Facebook a formidable force in a profit-motivated platformisation which is beginning to eat away at the Open Web. This entails moving away from published URIs and open HTTP transactions in favor of closed apps that undertake hidden transactions with Facebook through a Facebook-controlled API.*” (Plantin *et al.*, 2018)

Here are just a few examples of the ways in which users' agency has been, and continues to be, diminished:

- Facebook closed their RSS feeds, and later parts of their APIs, meaning that users could no longer consume their friends' posts in any other environment than the ad-filled and manipulated Facebook main feed. Later they removed features such as friend-list feeds and favorite-page feeds, removing users ability to compartmentalise their content viewing or focus on certain friends. The ‘Friends’ page on Facebook currently shows a list of recommended new friends; to access your current friend list requires an extra click. Encouraging users to grow their networks is prioritised over user convenience.
- Twitter closed the parts of its APIs that allowed realtime notifications and access to one's home feed, killing off primary functionality for a healthy ecosystem of third party Twitter clients that gave users choice (Newton,

2018). TweetDeck, a major third party Twitter client was acquired, and later shut down, as was Twitter's own desktop client. Eventually, the only option left to users was to use the web interface. (Gayomali, 2015; Hatmaker, 2018; Siegal, 2022)

- Apple has been diminishing users' agency for a long time. Users cannot open up iPhones even to change the battery without invalidating their warranty. Apple have removed disk drives, headphone ports, SD card slots and other ports. Certain parts of the hard drive on macOS devices are now read-only and unwritable by users.
- Facebook recently announced that they will no longer store users' historical location data (though they will still use location unformation) (Pegoraro, 2022). This means that users will lose the capability to access historical location records, but also this makes it harder for users to see how their location data will be used in future, as there will be no historical log to examine. This shows that data-centric companies can change their practices to limit agency and reduce accountability too.
- Online news and discussion site Reddit has removed access to content for non-logged in users, and uses deceptive techniques to present advertisements that look like posts from users and to discourage users from appearing offline. These patterns have been called '*disrespectful design*' (Regoje, 2021).
- In an example from the public sector, through my work on the SILVER project [3.4.1.1] just prior to the introduction of the GDPR in 2018, I heard whispers in at least one local authority of plans to 'shift from getting data collection consent from supported families towards simply informing them of our practices' (in other words, removing their choice). This shows that the instinct to further organisational interests over those of the individual is not limited to commercial data holders.
- In a similar vein, in 2022 TikTok announced that it would rely on legitimate interest rather than consent when it comes to using users' activity data to personalise the app experience, removing users' ability to withdraw consent to such use. This plan has subsequently been paused after warnings that this might breach GDPR (Lomas, 2022).

Unchecked, it is clear that trends to reduce users' agency and further providers' interests will continue. Therefore this trend to diminish users' agency is a particular obstacle that would need to explicitly targeted if data interfaces are to become more free-flowing (Bowyer, 2018), and if the objective of ecosystem negotiability is to be realised. Somehow, the trend needs to be halted, before it can be reversed. Judging by the TikTok example, perhaps only regulatory changes can force such a change.

The third and final obstacle I have identified to the objective of ecosystem negotiability is **the intractable data self**. As identified in the pilot study (Bowyer *et al.*, 2018), and in Case Study Two [5.4.4.1] data about individuals serves as their proxy. It serves as their data self, and if it is incomplete, inaccurate or unfair, which is highly likely given the difficulties of representing people in data

(Martin, 2007; Cornford, Baines and Wilson, 2013), this can cause harm (Bowyer *et al.*, 2018) or undermine attempts to help individuals (Cornford, Baines and Wilson, 2013). Yet currently, although some legal rights to data correction exist (Information Commissioner's Office, 2018), people lack practical abilities to modify or assert control over the most important version of themselves as far as providers are concerned: the version of them that exists in data. Even when data can be seen (such as via a support worker or GDPR data access requests) people lack the ability to exert influence over their data self [5.5.2; Cornford, Baines and Wilson (2013)]. To address this obstacle, the most likely direction would be to explore possibilities by which people could take a role in the curation of their data self, as both Case Studies have proposed [4.4.3; 5.5.2] and 6.3 have proposed.

To conclude consideration of this objective, it is noteworthy that to date, research and innovation on personal data ecosystem negotiability has been very limited. It is much easier to find business models and research funding for specific, well-defined contexts. Due to the lack of business incentive, only non-profit socially-focussed research organisations such as BBC R&D and Sitra have found themselves well-equipped to explore this problem space. Nonetheless, despite these challenges, there is an urgent societal need for researchers, designers, policymakers and innovators to explore how trends of diminishing agency can be reversed to involve people with their data. People need to be reconnected with their data selves, and given control over their digital lives, at the broadest level, rather than being excluded.

### **1.3.5 Obstacles to the HDR Objective of Effective, Commercially Viable and Desirable Systems**

In the previous four subsections, the obstacles to specific HDR objectives were considered. However, during attempts to tackle these objectives, and through observation of how the public and businesses were engaging with the growing Personal Data Economy, it became clear that there are certain obstacles that are specifically faced in this sector that affect *all* efforts to make progress towards improving HDR. The main challenge is around building such disruptive systems that are so different from the status quo: **businesses and individuals will not readily invest time and money in HDR, because it is unfamiliar**. Customers are not demanding HDR capabilities in their lives, and, all but the most socially responsible businesses do not immediately see the value in something that runs so contrary to their current business models which are based on the accumulation of data and the control of customer experiences.

Today, data is overwhelming, complex, and ‘sounds boring’. There is no denying that currently, engaging with one’s personal data economy to any degree more than that of passive consumer, is hard work. People routinely accept data sacrifice, click through T&Cs and cookie banners and are unwilling (or in some cases lack sufficient technical literacy, comprehension or skill) to do the work of asserting control over their digital lives. There is not a clear demand for

holistic and novel ways of managing your digital life and exerting agency and negotiability over it. Across both Case Studies and the PDV work at BBC R&D, it was clear that even if new **human-centric information systems** and more inclusive service interaction practices could be created, we cannot assume that people will be inclined to use them in great numbers. This can be seen as an obstacle that affects all HDR improvement approaches we see, and indeed is why many companies in the emergent PDE economy [2.3.4) struggle to find a business model - while there are clear benefits, better HDR does not appear to something that a mainstream audience would be directly be willing to pay for. But this should not deter disruptive innovation nor does it indicate that such offerings would not be useful. As automobile pioneer Henry Ford famously said, “*If I had asked people what they wanted, they would have said faster horses.*” Nonetheless, it is a clear overarching obstacle to overcome.

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**INSIGHT 7:** Human-centred Information Systems must serve Human Values, Relieve Pain and Deliver New Life Capabilities

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Through work at BBC R&D exploring how to better connect people with their data, it became clear that there is a way to combat such indifference and apathy of users. It emerges from the realisation that the way people find value in data is to connect it their lives. The more that people see relatable life information and can imagine ways to harness that information in their everyday life, the more motivated they will be. BBC R&D conducted some research (Forrester, 2021) that identified fourteen specific Human Values that people seek to satisfy in their lives, which are shown in in Figure X. These are, at the most abstract, goals that people care about in their daily existence.

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Figure 10: Figure X: Human Values, as identified in BBC R&D research funded by Nesta

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(continues...)

Given these and the earlier observation that life information is what makes data relatable, the insight I offer here is that **the way to make people care about their data is to use it to help them in their life**. By starting with a focus on a user's world, one can then focus in on their life, and then the data that represents elements of that life. Then, the individual has a vested interest.

Systems and features should be designed from this life-centric perspective. This is known as **value-centred design** (Reber and Duffy, 2005) and it has been argued that this should become the guiding design philosophy in HCI (Cockton, 2004). And to offer true individual value, all human-centric system designs must also take into account *context* [2.3.2], *environment* (Abowd, 2012) and *experience* [3.2]. In business modelling, there is a tool called the *value proposition canvas*, which identifies three ways of conceptualising value: **gain creators**, **pain relievers** and **jobs-to-be-done**. If we can use those concepts to inform our designs, we can produce better human-centric functionality - relieve an individual's pain points, help them complete their tasks, or offer them some gain over the status quo. In the HDR space, given the lack of existing tools for digital life management, we have the opportunity to create quite a unique type of gain: **new capabilities over your digital life** that you have never had before. This ability to do new things has been identified as key ingredient of user empowerment (Meschtscherjakov, Wilfinger and Tscheligi, 2014; Schneider *et al.*, 2018).

Here is an example of what this value-centric approach might look like in the HDR space: Myself and BBC R&D colleague Jasmine Cox imagined focusing on address books and contact lists as a strong relatable starting point to generate demand for a human-centric interface. This could provide people with new life capabilities while also relieving pains. Many people have address and contact information scattered far and wide, and face a complexity they cannot easily manage when it comes to the automated syncing and sharing of potentially sensitive contact information between devices, apps and providers. Developing human-centric personal information management capabilities to bring that messy situation under control would offer a clear and tangible benefit to users. In Figure X, we show how there could be a strategic path, beginning with detecting ecosystem and life information from the individual's calendar and e-mail inbox, through to building up to more holistic life-level PDV capabilities.

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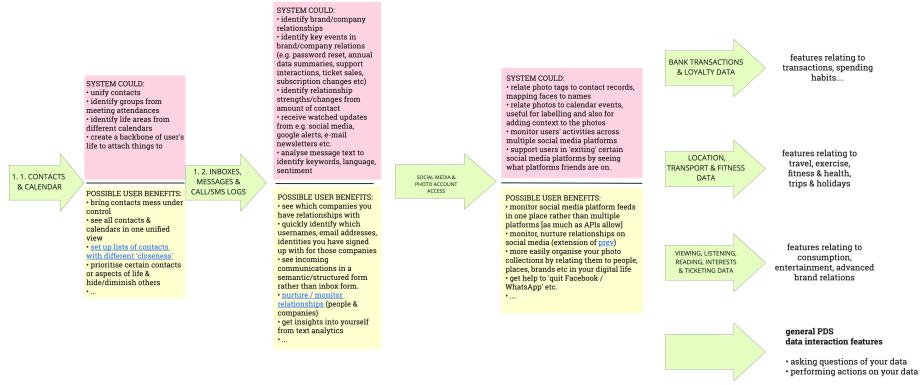
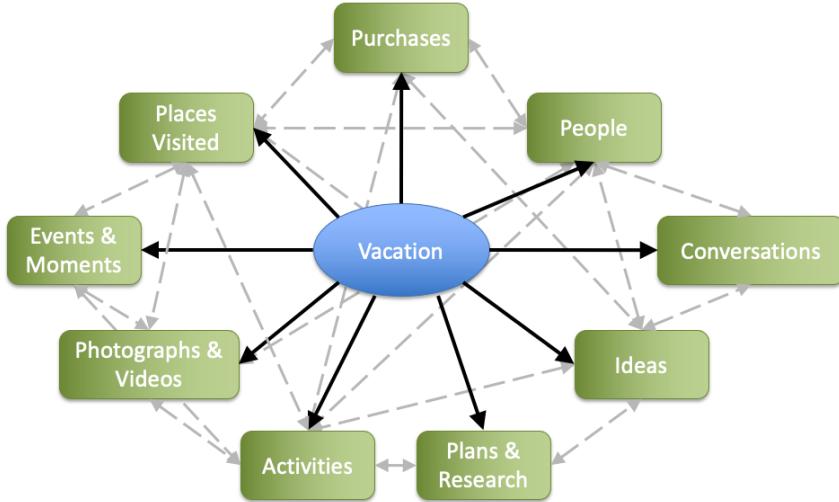


Figure 11: Figure X: A contact-and-calendar centric PDV approach

(continues...)

Another example that is helpful to consider is my the example from my 2011 article: that of a vacation, as shown in Figure X (Bowyer, 2011). Today, all the information around such a holiday is scattered into multiple systems - emails, online provider bookings, chat logs, cloud synced photos, web browser bookmarks, smartphone location logs, etc. It is not hard to imagine that a system that was able to bring all related information about that vacation together in one central interface (mockup in Figure X) could deliver huge value to users and be very compelling. Such context-targeted human-centric offerings can have a much greater chance of generating interest and impact than offerings that merely allow you to 'organise your data' or some other abstract phrasing.



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The kind of life-spanning, unifying interfaces described in the insight above are nothing like the interfaces that are built today, as they span across different providers' data and services. This highlights the secondary obstacle that all HDR system builders will face, whichever objective they wish to target: **closed, self-interested organisations with a lack of interoperability**. Building an HDR system will necessarily involve connecting to systems of different providers that have different touchpoints into an individual's life and world. Yet most companies act in closed, introspective and non-cooperative ways to further their own interest. Companies like Apple, Amazon, Microsoft, Facebook and Google (the so-called 'big five') build **proprietary, incompatible silos** or 'walled

gardens' – sub-Internets that pretend that the alternatives do not even exist, in order to encourage a flow of money and attention to their own products and services. Commercial motives encourage them to get users to spend time in their own proprietary spaces (so that resultant ad revenue can be captured) and in order to maintain subscription revenues it is in providers' interests to make it hard for individuals to leave or switch providers. In effect, providers build for a world that does not exist, where **every individual is imagined to only interact with that single company's interfaces**. I would argue, for example, that Google's venture into social networking with Google+ did not succeed because it failed to build for a reality where most people and their friends were already on Facebook. But one can understand their motives; there is little incentive to open up the ecosystem when the free flow of information and of users might result in loss of income for the company in question. Users with negotiability would be more able to leave. And this also encourages keeping users in the dark [5.4.2]. The less agency and negotiability that users have, the more freedom the provider has to do exactly what they want with their data. In this context, users are '*pathetic dots*' (Lessig, 2000) or '*docile bodies*' (Foucault, 1975).

The tendency of organisations to work in closed, introspective practices and to be resistant to opening up data or services is not solely motivated by commercial reasons: the public sector has a vastly complex, closed and fragmented ecosystem [Pollock (2011); Copeland (2015); 4.1.2]. Efforts to build a system to share health data with support workers for the SILVER project [7.1.1] proved hugely challenging. Sometimes the challenge was a more technical one - incompatible data formats that are hard to reconcile, or data being stored in legacy systems with no public API that would allow programmatic access to that data, or issues around licensing. Data sharing agreements must be established, especially in the public sector which is by its nature more liable to scrutiny and accountability. But more than these technical or procedural issues there was resistance to change in data processes and an unwillingness to share data between agencies, often motivated by a fear of legal repercussions. **Data-centricism encourages insular thinking:** it encourages organisations to codify the world into their own systems, processes and formats for their own use.

And yet, for effective HDR, **data needs to be separable from services**. The more users data is tightly coupled to specific services, the less agency users have and **the harder it is to build life-centric systems**. On BBC R&D's Cornmarket project, attempts to build an interface for users to import data from multiple popular Internet services proved to be a hugely complicated endeavour, requiring access to many different APIs or manual exports and imports of data by users. There needs to be greater interoperability and **greater establishment and adoption of standard formats for exchanging human information** (as distinct from establishing standards for data or service-specific APIs). As mentioned above, platformisation breaks the Open Web (Plantin *et al.*, 2018). To overcome this, companies must be persuaded that human-centric thinking, interoperability and transparency has not just social benefits, but business

benefits too.

But at an abstract level the technical obstacle, the problem is one that has always faced the tech industry, which is that there often is no universally agreed way to represent important concepts - in this case human-centric information concepts such as events, social media posts, website visits, location history information, app activity, etc. And any entity that does create a standard then faces the challenge of trying to persuade others that their standard is the best one to use. In general, standards work best when established by non-commercial industrial standards bodies (for example the World Wide Web Consortium (W3C) or International Organisation for Standardization (ISO) and then mandated through policy such as European Union law. Such standards must be established with input from industry experts.

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#### INSIGHT 8: We Need to Teach Computers To Understand Human Information

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In order to move towards standardised ways to store and unify personal data from multiple sources, computer systems must be taught to understand the information within the data, and how it relates to an individual and the world. This moves beyond just capturing data provenance: put simply, **computers need to understand human information**. They need to move beyond files (Bowyer, 2011) and databases, and begin to perform operations on human informational concepts, and to associate those concepts according to what they mean - i.e. ***semantically***. This is a preliminary step that will enable the building of systems and interfaces that are able to deal in human concepts and represent the elements of everyday life.

We need to store **semantic context and semantic associations**, i.e the meaning of things, not just raw bundles of data. This is advocated by the Web's inventor Tim Berners-Lee in his vision of a Semantic Web (Berners-Lee, Hendler and Lassila, 2001) and by proponents of *networked* and *semantic* PIM systems, as detailed in 2.2.2. There is a need to develop standard ways to digitally model facts and assertions about users' lives, so that those disparate pieces of data can be unified, connected, correlated and compared. Some standards are already developing, such as *data shapes* ('ShapeRepo: Make your apps interoperable', 2022). And the extraction of meaning from data is a problem domain all of its own. Sizable industries have built up around Content Analytics and Enterprise Content Management. But to consider the problem at its simplest level, I offer this insight: Through **the capture of metadata** at the point of data recording, and through **subsequent programmatic analysis** of stored data, as illustrated in Figure X, we can begin to teach computers what the data we store represent.

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Machine learning technologies and Artificial Intelligence have pushed machine understanding of human words, images and content to impressive levels in recent

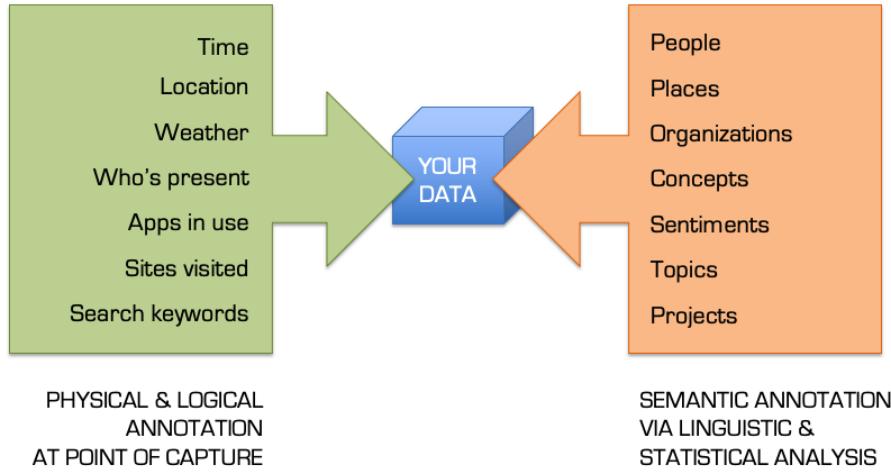


Figure 12: Figure X: Annotating Data with Semantic Context

years and such technologies can certainly be helpful, but in fact at the core what we are talking about here is something much simpler than AI; It is simply about labelling datapoints in as many different ways as possible so that those datapoints can be associatively retrieved from many different angles, and providing humans with ways to amend incorrect labels and to reclassify data or apply new semantic associations. Issues of interoperability for PDV systems are being actively explored and developed in the 'Solid' community (Bansal, 2018; Berners-Lee, 2022) in pursuit of a decentralised web (Verborgh, 2017).

Such approaches are in their infancy, and have not yet been adopted extensively in commercial settings. Even after addressing the obstacles of end-user buy-in and the technical complexities of building human-centric systems, data-driven corporations, motivated as they are by profit and business success (and smaller online organisations too) need to be persuaded of the business value of transparency, interoperability and human-centrality. This is explored further in 7.4.5.

In summary, whichever of the above four HDR objectives are targeted, all HDR reformers involved in building HDR systems must:

1. create, adopt and co-ordinate around **new standards** for human information storage and management
2. invest in systems that elevate computers from data-processing machines to **human-information-processing machines**, and
3. make a persuasive case to both businesses and individuals that the new approach offers **tangible, previously unavailable value**.

## 1.4 The landscape of opportunity: Four approaches to improving Human Data Relations

In this section, I will present four different ‘flavours’ of activity, that we can pursue as HDR reformers. These are represented diagrammatically as trajectories of change through the ToC space [[7.1.3]], and could be supported or pursued in many different ways, which may appeal to different readers: prototyping and creating proofs of concepts; fundraising or investment; design activities; market research, participatory research or usability research; ‘early adopter’ testing and quality assurance of PDE offerings; promotion, advocacy and journalism of HDR issues; critical audits of provider practices; policy design; political pressure on governments; participation in open data, PDE or MyData communities; or even self-experimentation with HDR tools, rights and capabilities.

### 1.4.1 Approach 1 to Improving HDR: Discovery-Driven Activism

[DIAGRAM PLAN - TODO ADD DIAGRAM] [individuals informing/powering collectives Collectives helping individuals Using Data to Demand Change in Practice => which in turn enables individuals with stronger capabilities and better transparency & insights also data access & understanding services helping collectives and individuals info pulling from the bottom right and top left into bottom left, then pushing up into top two.]

The approach to HDR reform presented in this section embraces the *activist* aspect of being a recursive public [7.2.5], as well as the idea of reconfiguring one’s world. This approach focuses on the realities of the current data-centric provider ecosystem, and is focused upon deeply understanding it so that it can be challenged from a grounded position of strength. The approach, which would be applied typically to a single service provider, app or platform (which could also be a public sector service) is fourfold:

1. **Gather Evidence:** Using all available means, gather personal data and information from the target organisation.
2. **Determine Current Practice:** Analyse the gathered data and information, using targeted approaches to dig deeper where needed, to establish facts about how the target organisation stores and handles personal data.
3. **Identify Desired Change:** By consideration of the specific practices observed from the analysis, specific problematic practices, gaps or areas where improvement or change is needed are identified.
4. **Appeal for, or Compel, Others to Act:** Using all available means, directly or indirectly persuade or force the target organisation to execute the desired change.

I describe this approach as **Discovery-Driven Activism**. The discovery phase, which aims simply to establish facts about the past or current data practices of the target organisation, can be broad (*‘let’s see what we find’*, as in the digipower investigation [7.1.1]), or highly targeted, such as when The Citizens (a non-profit pressure group in the UK who *‘use impact journalism to hold government and big*

*tech to account*' ('The citizens - about us', 2020)) used Subject Access Requests to investigate a breach of personal data by the Labour Party in the UK (Colbert, 2022).

**Subject Access Requests** and **Data Portability Requests** (Information Commissioner's Office, 2018) are two of the most powerful tools for this kind of investigation. Similarly to Freedom of Information Requests which have used to obtain otherwise hidden data and information from governments and public sector organisations ('More than 400,000 freedom of information requests made since 2005', 2014), so these new data access rights are beginning to be used to force commercial organisations to release personal data or information about data processing. There are challenges in non-compliance, as discussed in 5.4.2.2 and 5.5.1, but the ability for the individual to ask very broad or very precisely targeted questions and to be able to threaten a complaint to a Data Protection Authority if that question is not answered, is a significant new power that HDR reformers can exploit.

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INSIGHT 9: Individual GDPR requests can compel companies to change data practices.

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In this inset box, I will show, using a mini case-study from my own direct personal experience, how one person can apply the discovery-driven activist approach to compel a multi-billion dollar international data-centric organisation to improve their HDR.

As an avid user for several years of the music streaming service Spotify who has built up a large library of playlists, I have made a number of GDPR requests to get copies of my personal data. When I was first given a copy of my personal data, I was returned a basic ZIP file including 12 JSON files containing playlists, search queries, account information, my last 12 months of track play history, and inferences about my musical tastes. Spotify also make an extended data download available, including technical log data, and extended play history (which covers the lifetime of my account). I requested this extended download and received a much larger dataset with 175 JSON files, including granular details of when I had used different interface features and the precise details of every song I had ever played. Thinking that I would like to use this data to build a view of my listening history that was not tied to the Spotify platform (in line with the idea of increasing agency by separating one's data from the service that holds it [7.3]), I examined the streaming history and playlist data with this purpose in mind. What I found was that individual songs were identified only by textual strings of the title, artist and album name. This information is insufficient for a programmer's use - there is no unique identifier or Uniform Resource Indicator (URI) to uniquely identify the specific version and release of a track played. Also without such an identifier, it would not be possible to generate a thumbnail image of the track, or build functionality such as a clickable link to 'play this track in Spotify'.

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INSIGHT 9: Individual GDPR requests can compel companies to change data practices.

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This highlights a common issue that occurs with data access requests, as highlighted in 5.4.3.2 - there is ambiguity over whether providers should identify data in a machine-readable way (useful for programming), or in a human-readable way (to optimise understanding). In my case, I needed both. I e-mailed Spotify back and was provided with an alternative fileset which contained only Spotify Track URIs, such as `spotify:track:5CKqyYTZqp6Nb4b3kJjUL5`. These met the programmer need to uniquely identify the track, but not the human need - I had no idea which artist or track each of these URIs corresponded to, as there was no human-readable text accompanying each entry. So, I e-mailed Spotify back, making the case that my GDPR rights had not been fully satisfied, because I needed *for each play history entry*, both machine-readable ID and human-readable track title and artist name. I sent Spotify over 30 e-mails on this matter between October 2020 and May 2021. There is little continuity of conversation between support agents, and hard to be escalated to the correct staff with the technical or legal expertise to assist with such nuanced questions. However, by persistently and politely repeating my questions and not accepting No for an answer, I was able to achieve a notable outcome, Spotify **changed the format of their data returns**, not just for me but **for all future customers**. Now, each item in the playback history data you get back from Spotify, every item includes textual track and artist details AND a Spotify track URI. The data can now be understood by both human and machine. The likely interpretation here is that I successfully able to persuade their Data Protection Officers (who handle GDPR requests) the importance of returning data that is both machine-readable and human-understandable. Perhaps they also recognised the amount of work they had invested in supporting my query, and wanted to **avoid having to do such work ever again** should I or any other customer make the same request in future. This was a tiny impact, but a lasting one, and it shows that the discovery-driven activism / civic hacking approach can have an effect in improving HDR with a target organisation.

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INSIGHT 9: Individual GDPR requests can compel companies to change data practices.

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A larger scale example of individuals forcing giant corporations to change is seen in the case of Facebook. In the early 2010s, Austrian lawyer Max Schrems began to pressure Facebook to disclose more personal data to their users. He created a tool to enable people to make their own data access requests, which over 40,000 people used. Faced with an overwhelming volume of work and massive liability of future data access requests, Facebook was forced to launch the self-service ‘Download Your Information’ (DYI) download tool, increasing transparency for all Facebook users worldwide (Solon, 2012). Facebook was forced to increase its transparency further when Paul-Olivier Dehaye (now CEO of Hestia.ai [7.1.1]) made a GDPR request (later backed by legal action) to force Facebook to disclose more information about which advertisers Facebook had enabled to target him using the Facebook Custom Audiences feature. Apparently in order to avoid being embarrassed in court, Facebook updated DYI so that your downloaded information includes a list of advertisers who have added you to a Custom Audience (Dehaye, 2017). Dehaye and Schrems both continue to act as HDR reformers and civic hackers following the discovery-driven activism approach, through their organisations Hestia.ai [7.1.1] and privacy rights organisation noyb.eu ('none of your business') (Schrems, 2017) respectively.

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Facebook’s DYI tool, mentioned in the insight above, represents another powerful tool in the arsenal of the activist HDR reformer. Along with Google Takeout, it is one of number of '**data download portals**' that allow users to download their own data. Since GDPR’s introduction in 2018, an increasing number of large online platforms including Facebook, Google, Apple, Netflix, Twitter, Spotify, Uber, Instagram and Strava, faced with the need to reduce the cost impact of GDPR request handling for their large userbases, have developed and augmented online self-service portals available where users can download a copy of their personal data. This has some advantages over Subject Access Requests in that data can usually be obtained within minutes or hours rather than taking up to 30 days, but have some disadvantages in that the data returned is a voluntary offering by the company, that may not cover the data that the individual is seeking and does not provide any ability to ask follow-up questions. This technique was sometimes used as a fallback means to obtain data in Case Study Two, and was used more strategically in the digipower project, where its merits and limitations are discussed [7.1.1; Bowyer *et al.* (2022)]

Both access requests and download portals rely on the organisation in question to be transparent, accurate and thorough in their provision of information, but an alternative technique of **data flow auditing** allows individuals to investigate and collect data on the *actual* behaviour of a target organisation. This was used effectively in the digipower project [7.1.1]. Using an Android app called TrackerControl (Kollnig, 2021), a service provider’s app can be monitored while the user is using it normally, to see which servers or domains that app

is contacting (and one can imply, exchanging data with). Apple has recently introduced an equivalent function on iOS known as App Activity Reports (Apple, 2022), providing iPhone users with the same ability as part of the phone's operating system. This has limitations in that the content of the data exchanges is not known, but can serve as a valuable tool to verify claims made in privacy policies or GDPR responses, and also as a means to *generate questions* for further investigation, for example by identifying third parties such as data brokers which the target organisation may be sharing personal data with. This technique is described further in (Bowyer *et al.*, 2022), along with a comparison of the different techniques of data flow auditing, data download portals and data access requests.

In general, what the discovery-driven activism approach highlights is that there is a role for pro-active citizens to play in challenging the power of data-holding organisations by treating those organisations as a subject of investigation, both in research (Walby and Larsen, 2012) and in the pursuit of improving civic society (Schrock, 2016).

Once information has been obtained, the HDR reformer activist can use a variety of means to try to bring about the desired change. If a target organisation fails to comply with a data access request, or a demand to erase or correct data, they can be **reported to the Data Protection Authority**. In some cases even the threat of this (which can carry a large fine) can be enough to compel the organisation to change. If a breach of law is found, the target organisation could be **taken to court**, as seen in the Schrems case above, which resulted in new legislation that Facebook had to comply with (Kuchler, 2018). As well as individual cases, this also often happens in the form of class action lawsuits, as with Facebook and Cambridge Analytica (Bowcott and Hern, 2018). Increasingly, unethical or illegal data practices are being challenged. In some cases, such extreme measures are not needed. Simply **making data available to the public** can be empowering to society at large. This approach has been demonstrated by the UK website TheyWorkForYou, which increases democratic accountability of MPs by making MP's votes and public statements more readily accessible (mySociety, 2004). As well as structured '*impact journalism*' such as that conducted by The Citizens as mentioned above, another technique available to individual activists is *public shaming of misbehaving organisations*, especially on Twitter. While the ethics of this are complex and it does not always succeed, the technique has been used effectively to force organisations to change, in order that they might avoid further bad publicity (Silver, 2014; Braw, 2022).

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INSIGHT 10: Collectives can compare and unify their data and use their pooled knowledge to demand change.

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Increasingly, the Internet experience that individuals experience is not the same as anyone else's. Thanks to recommendations, targeted ads and social media feeds personalised to your interests, no two people will see the same digital reality. This means it is very difficult for regulators or individuals to hold digital service providers to account. In recent years, many activists have embraced **the power of collectives**, and realised that together, they can discover far more than they can alone.

An example of this is the WhoTargetsMe project, launched in 2017 (Jeffers and Webb, 2017). The objective of this project was to monitor political advertising in the UK. Recognising (as larger studies have shown (Bakshy, Messing and Adamic, 2015)) that everyone was seeing different advertisements, the goal was to have each individual report what adverts they see on Facebook, so that these can be pooled and compared with others. Over 50,000 people participated, building up an otherwise unavailable clear picture of the ways in which different political demographics were being targeted. This is a powerful mechanism available to collectives in this space: the ability to **have individuals obtain their own datapoints and then compare them**.

Another example is seen in the Worker Info Exchange ('Worker info exchange', 2022), a collective that helps gig economy workers such as Uber drivers and Deliveroo riders to make data requests. Using the pooled data, they conduct investigations to understand algorithmic inequalities and identify unfair treatment of worker by employers. They then help those workers to fight for better working conditions, much **like a traditional trade union, but powered by collectively-sourced data**. This resulted in Uber being taken to court, and some gains being made for drivers (Lomas, 2021; Foucault-Dumas, 2021).

As the aforementioned case with Max Schrems showed Insight 9, collectives can be particularly powerful when **exerting their data access rights *en masse***, and this can improve HDR and force greater transparency. René Mahieu and Jef Ausloos have published an exhaustive list of collective actions taken using GDPR rights, addressing issues such as discrimination by US colleges, corporate surveillance of climate activists, identifying gaps in data disclosures, and manipulation of users on dating apps (R. Mahieu and Ausloos, 2020). The authors identify that the GDPR provides an '**architecture of empowerment**' and have called for better enforcement and for European authorities to provide better support for the ability for collectives to make data access requests together (R. L. P. Mahieu and Ausloos, 2020). Hestia.ai's digipower investigation concluded that data-discovery driven collectives are a vital step on the road to a more digitally empowered society (Pidoux *et al.*, 2022, p. 70). It is clear that organised collectives exploiting data access rights represents a powerful vector for impactful discovery-driven activism.

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Having identified that there is a clear trajectory where individuals and collectives can obtain data to empower them, it is clear that this complex work can be supported. We see the emergence of '***data access & understanding services***', with entrepreneurs and activist enthusiasts:

- creating **tools to help people get their data back** from organisations, such as Tap My Data ('Tap my data', 2022), AccessMyInfo ('Access my info', 2022) and My Data Done Right ('Privacy salon & my data done right', 2022);
- creating **tools to help people understand their personal data**, such as Ethi (Jelly, 2021) and HestiaLabs (Dehaye, 2021); and
- helping collectives and journalists with **training, workshops and skills development** to take advantage of their data rights and **understand data ecosystems**, like Hestia.ai (Dehaye, 2019).

If such emergent endeavours can be supported and enabled to flourish, that could make HDR reformers using the discovery-driven activism approach more successful by ensuring that a lack of legal, technical or investigative skill does not become a barrier to any HDR reformer wanting to use this approach.

This approach shows that there is a role for independent actors and organisations to carry out discovery-driven activism - access requests, complaints, legal challenges, public campaigns and more. Discovery-driven activism can empower individuals and collectives to incrementally work towards building the world of better HDR that this thesis outlines.

#### **1.4.2 Approach 2 to Improving HDR: Building the Human-Centric Future**

The approach to HDR reform presented in this section focuses on the gaps in individual data interaction capability that exist today. The objective here is to design and build proofs of concept for novel human-centric information systems that can deliver people new capabilities over their data. In this approach, the focus is more introspective than Approach 1, it is about how the individual can improve their relationship with data in the context of their own digital life. The bulk of this section describes specific design ideas developed by myself and colleagues at BBC R&D during my 2020-2021 research internship on the Cornmarket project, which sought to develop a personal data store proof of concept [2.3.4]. As established in Insight 2, one of the most promising models for giving people a new and improved relationship with their data is to create a place where one's personal data can be stored and aggregated in one place.

and insight 3

MAIN POINT: Design Ideas for a Human Centric Information System, illustrated with diagrams BBCREF A central home for your personal data BBCREF modelling data as life information BBCREF Happenings Diagram Time as unifier (LITREF TIME C2). What data IS to people (ref lenses) BBCREF (backref life

concepts, then: Simplified model of presenting information to users) BBCREF Dashboard example SUBPOINT Capabilities BBCREF diagram What can users do (properties) Asking questions (THESISREF C5) BBCREF taxonomy diagram BBCREF Browsing by areas of life.. leads to: SUBPOINT Mental Models > Life- level systems, life partitioning teevan. conceptual anchors 2.2.2 BBCREF cluedo rooms LITREF Lenses etc C2

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INSIGHT 11: Automating the identification of Entities can enhance machine understanding and unburden information management system users

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Approaches by automatically finding entities ref back to semantics etc. (two arrows diagram back ref'd, and the Insight about semantic understanding) (can callback the subscrab example from above here too) Extraction and Learning systems BBC REF flows for entity identification BACKREF digital agents. like an assistant. [POSSIBLY CUT?] SUBPOINT Digital Self Curation & Inclusive Data Flows Litref VRM OUTREF BBC Wired article the potential of inclusive flows (build on provenance, rivers of data, LITREF streams) FRAME AS DIAGRAM Building new designs (reaching into understanding, LITREF data enabled design and Human values) Delivering new structural capabilities. Enabling new individual and collective perspectives. ENDING: Individuals Empowered with new Life / Ecosystem Information Capabilities.

#### **1.4.3 Approach 3 to Improving HDR: Defending Autonomy and Nurturing the Information Landscape**

MAIN POINT: That it is not just about Positive Change, there must also be Defensive Action, in the face of the active erosion of user autonomy (backref above diminishing agency). That this is an avenue of activist and grassroots work in its own right. some kinda visual? LITREF guard rails for the status quo

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INSIGHT 12: The ‘Seams’ of Digital Services need to be identified, exploited and protected.

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By identifying, exploiting and protecting the seams of digital services and devices, user autonomy and the viability of data-unification efforts can be protected.

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[TODO make this an inset box not a table]

Black Box diagram LITREF Storni magical design An unseen battle for the free flow of information is ongoing. (data separation from services) DERC REF Seams, JustEat etc. Facebook example. That guy who got banned from Facebook for letting people read their Facebook feed in a different way AND the

blocking of accessibility readers and Chrome getting reinvented List of bullets  
DERCREF the opportunity of scrapers & webaug

seam hacking example: <https://www.theverge.com/2016/2/1/10872792/facebook-interests-ranked-preferred-audience-size>

LITREF right to repair SUBPOINT Surface Information Injustices. REAL-WORLD REF Frances Augen, Snowden, Assange.whistleblowers. but also can do this within interfaces. Build the features that should be there with a big “we can’t do this because X won’t let us” SUBPOINT promoting and developing standards, and better regulations OUTREF guidelines [GDPR guidelines I fed back on] OUTREF new European laws, DSA etc, to regulate the landscape ref back to end of C5, for policymakers FRAME AS DIAGRAM taking external *protective* action as collectives, surfacing, challenging, pushing for better enforcement of existing regulation ENDING: Seizing and holding the powers we are given and never giving them up. The price of freedom is eternal vigilance OUTWORLD ref cars OUTWORLD REF Apple OUTREF Ad blockers > Brave > facebook containers.

#### **1.4.4 Approach 4 to Improving HDR: Winning Hearts and Minds: Teaching, Championing and Selling the Vision**

MAIN POINT: That the nature of pursuing Human Data Relations causes for a radical reconfiguration of today’s data world. We need new systems (which means not only there need to be business drivers for those systems but also that existing organisations much choose or be compelled to invest in them), and people need to understand, use and see value in those systems. Therefore, there needs to be specific investment: SUBPOINT in Education, and Data Literacy SUBPOINT in Systems Building (just ee above) SUBPOINT in standards, information uniting the diaspora SUBPOINT in Researching New Business Models and Demonstrating Value of transparency and human centricity

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INSIGHT 13: It is possible to demonstrate business benefits of Transparency and Human-centricity

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As outlined in 7.3.5 and in this section, it is essential that work is done to persuade data-holding organisations of the benefits of moving towards the new paradigms outlined in this thesis. The following avenues for possible future research and advocacy toward data holding organisations have been identified:

- **Trust & Reputation:** In line with the third aspect of HDR [[7.2]] as well as the recommendations in [4.3.4], [4.4.1], [5.5.2] and [6.2.1], displaying a more inclusive, open and supportive attitude to data handling could strengthen the service relationship and increase customer loyalty and trust. Organisations that are seen to have good human data relations are preferred.

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INSIGHT 13: It is possible to demonstrate business benefits of Transparency and Human-centricity

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- **Consent:** In the wake of the GDPR, ensuring consent is becoming an increasing concern to organisations, and the risks of legal consequences for mistakes are high. It makes sense that a more dynamic [Bowyer *et al.* (2018); 4.4.1; 5.5.2; 6.2.2] consent approach that involves individuals [6.2.3] and keeps them in the loop, will enable individuals to speak up much earlier and express consent wishes that might otherwise go undetected.
  - **Accuracy:** The best placed person to spot errors in data's accuracy or fairness is the individual about whom the data is concerned. Therefore, increasing their involvement is likely to improve the quality of the data, especially if additional data is contributed or curated by the service user [4.3.3.4, 6.2.3]
  - **Liability:** In an increasingly litigious society, storage of personal data, especially health or financial data, is a significant liability for businesses, especially if something goes wrong. Investment in human-centered personal ecosystems would outsource the storage of sensitive data to data trusts or PDV providers, reducing liability for the service business. By ensuring that data is accessed only in ways that are centralised outside of the business and remaining in the user's control – such as PDV company digi.me's Private Sharing model (digi.me, 2019)– organisations can ensure that have negligible risk of mishandling customer data.
  - **Better Customer Targeting** The most radical, but perhaps the most persuasive, business model relating to better HDR, is the Vendor Relationship Management approach [2.3.4], where individuals express their own service or product desires explicitly, which vendors then respond to. This turns traditional models inside out, and would empower users more, but due to the inherently improved accuracy of a self-declared interest, might also give businesses a greater confidence that their investment in converting those customers to a sale would be worthwhile. It is important to remember that the current drive towards collecting more data that drives the platformisation trend is in order to improve ad targeting, so that businesses can get a better return on their investment. A VRM approach, or any other approach where the individual contributes improved data to their data self, is in line with that current business objective.
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[TODO make this an inset box, not a table]

SUBPOINT in supporting Data Understanding Industry. empowering individuals as investigators. Tools to map their own ecosystems and unite their own personal data diaspora. FRAME AS DIAGRAM Structural work in upper right - standards Selling work in top level - show value to individuals Selling work in top level - show value to organisations Structural work in bottom right - systems Individual work in top left - empower and educate individuals all leading to new action of individuals in top right ENDING: that this is not just a technical problem, and not just a case of building new things. It's about

beginning and catalysing a cycle of constant feedback, of data enabled design and action research / iterative software and business model development - finding what works, championing it, selling it.

## 1.5 Thesis Conclusion

- recap HDR field as contribution
- recap the findings of the thesis and the map of the landscape
- recap the obstacles, insights and opportunities
- reiterate the answer to the main RQ
- highlight future value/societal implications of the work
- we have defined HDR. who the recursive public are (roles). what they might do... what the field is... etc
- [TODO add stuff from here]

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