

# Understanding and Improving Human Data Relations

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## 1 Discussion - An Understanding of What People Want in Data Relations

*“For a participatory system to work, you need: a plausible promise, an effective tool, and an acceptable bargain.”* —Clay Shirky (author and journalist focused on the social and economic effects of Internet technologies)

It will be already evident to the reader that there are significant overlaps and parallels to be drawn across the findings and discursive insights in Case Study One (CS1) and Case Study Two (CS2). In this first discussion chapter, I will draw on both Chapter 4 and Chapter 5 to produce a unified summary of findings and insights in terms of the first two research subquestions RQ1 and RQ2. To recap on the research objectives expressed in 3.3, these two RQs are:

- **RQ1: “What is the human experience of personal data, and what do people want from their data?”**
- **RQ2: “What role does data play in people’s service relationships and how could relationships involving data be improved?”**

The answers to these research questions are best expressed as an understanding of individual *wants* relating to data. The word ‘want’ is used here in a broader sense than its everyday meaning, referring to the *lack of something that would be beneficial* (which may or may not be accompanied by conscious desire). Framing the accumulated understandings from the Case Studies in this way, both exposes both the problem (the things that individuals do not have or cannot do) and also provides clear goals that any imagined solutions or improvements to the status quo would need to address. It logically follows that any solution that better delivers on individual *data wants* will lead to improved relations between individuals and their data. These wants also allow us to understand what ‘better’ means, serving as a yardstick against which progress can be measured. The concept of *data relations* will be developed further in Part Two, but for now can be understood as two kinds of relationship people have with their data:

- ***direct interaction*** (such as through an interface in an app or website) and
- ***indirect interaction*** (through interacting with services, providers or individual representatives who themselves have access to personal data about the individual).

RQ1 [3.3.1] and RQ2 [3.3.2] map cleanly onto these two types of data relations. To answer RQ1 we must identify what people want from direct data relations—which is the focus of 6.1. To answer RQ2 we must understand what people want from indirect data relations—which is the focus of 6.2. Once those two questions are answered, these new understandings can then be contextualised [6.3] as an answer to the overall research question and a conclusion to the academic inquiry part of this thesis.

## 1.1 Answering RQ1: What do people want in *direct* data relations?

By comparing and grouping elements of the findings from CS1 (see 4.3) and from CS2 (see 5.4), three distinct data wants are evident when considering *direct* data relations. All data about individuals should be:

- 1) **Visible:** People want to have knowledge of data about them and an ability to see it and effectively access it;
- 2) **Understandable:** People want to be able to interpret this data to extract meaningful information from it (and about it), including through visualisations and summaries; and
- 3) **Useable:** People want to be able to act upon this data, including exploring it, asking questions of it, using it to serve their own goals, and gaining personal value from it.

These wants are detailed in the following subsections.

### 1.1.1 Visible Data

**Data matters to every individual now, in a way that previously it did not.** As described in 2.1.2, the role of data in our everyday lives has changed; data has become a material used by businesses to shape our world. In 2.2.2 and 2.2.4 I outlined how this change has practically manifested itself in people’s lives. Where once data was viewed as *ours* for our personal reference and use, the emergence of complex multi-party data ecosystems has meant that personal data management has become a sociotechnical & societal problem, not a practical individual one. In the past, when businesses were more local, more personal and less data-centric, the data they held about us was minimal and much less significant to our lives than the human relationships we had with them. Businesses grew and data began to be considered as a resource to be processed at scale for customer insight and marketing exploitation. Though we didn’t realise it, our need to understand those processes to protect one’s own interests began to grow. In the past, you didn’t need to become aware of data storage and use, because it had little effect. Now, data has become a substitute for direct communication with the individual being served, as my research in both public sector [PS; 4.3.3] and the private sector [5.4.3] has shown. In both domains, people do not have awareness, let alone access, to the extent of data that exists about them. In 5.4.4 we saw individuals feeling that companies forced them to hand over data in exchange for service access, and then subsequently maintaining power over them through holding that data, using it to make decisions, and denying them access to that data or even be clear about what data is held.

**Data sacrifice is now required for many services, putting individuals at risk.** Be it the personal financial, health and lifestyle data collected on an Early Help (EH) assessment form when a family signs up for EH support [4.1.2], or the contact details, payment information and preferences provided when individuals register with commercial service providers such as insurance providers or streaming media platforms [5.4.4], supplying your personal data is required to access services. Consent to hold and use this data is enforced upon signup, through waiver forms or Terms & Conditions agreements. Service providers in both sectors see the acquisition of more personal data as beneficial to their operations, be it support workers wanting to gain more data about families’ lives [4.2.3; 4.2.6], or commercial providers using trackers to gain more insight about users that they can exploit for advertising (Binns, 2022). In both domains, this sacrifice is seen to have an emotional effect on people, ranging from curiosity to fear and distrust [PS; 5.4.4]. Such fears are well-founded, with mistreatment through incorrect data known in both settings [4.2.2; 5.4.4]. While data holders almost certainly do not *intend* to cause harm, data *can* be ‘used against you’ (P2’s quote in 5.4.4) (Kröger, Miceli and Müller, 2021; Strohmayer *et al.*, 2021). In providers’ eyes, people are now represented through data [2.1.2]. Despite the fact that data is never truly objective (Gitelman, 2013; Taylor *et al.*,

2015) and a recognition (at least on the public sector side) that a data record can never tell the full story [4.2.6; PS], the data record becomes the object to be administered, rather than the individual (Cornford, Baines and Wilson, 2013; Zuboff, 2019), and this in itself creates risk - through mishandling or inaccuracy. Given the data record is seen as a source of truth [4.1.2; 5.5.3], it is vital that such information remains *fair*, and *accurate*; this is especially important in the commercial sector, where people are only just beginning to become aware of data misuses and data exploitations that are actually happening (Chang, 2018; McNamee, 2019; Zuckerman, 2021; ‘Data Brokers: Everything You Need to Know’, 2022). Ensuring fairness and accuracy of held data cannot be verified without individuals’ awareness of data held about them.

**Once data has been sacrificed, it enters a closed and opaque ecosystem, where the individual loses access and becomes unaware** of that data’s storage and use (Luger and Rodden’s ‘point of severance’ (Luger and Rodden, 2013)). What was previously available for individuals to see becomes inaccessible and invisible. In the EH context, this manifested as families having a lack of awareness or direct access to data held about them and having to rely on support workers as gatekeepers to choose to inform or show them aspects of their data [4.1.1; 4.5]. In the commercial context, the situation is perhaps even worse, as not only is there rarely any kind of data viewing interface, there is not even a gatekeeper who might make people aware of their data and its use (given DPOs rarely engage individually). Even if someone becomes motivated to gain awareness, the GDPR leaves them in the dark; in 62% of cases, the data that companies own privacy policies stated they collect, was not returned, and data that was returned was complete in only 22% of cases [5.3.2]. In both contexts, no awareness is gained unless the information is actively sought. This means that the vast majority of people, busy and unaware, remain so. This is problematic, because people cannot judge data accuracy or protect themselves from risk, because they may not even be aware of certain data’s existence and use, or be able to access it even when they are.

**People want to see data which is hidden from them.** In the SILVER project [3.4.1; 4.2.2], PS, and in CS1 [4.2.6; 4.3.2; 4.4.2], families wanted to see what data was held about them (*‘what they’ve got on me’*). They wanted to be actively kept informed and to have the ability to see if data was fair and accurate. In the commercial context, the same feelings were found; participants expressed a great desire to see and know what companies are storing about them, especially data collected or inferred about them without their involvement. This is not just a desire, but a need, given that data can have impact on their daily lives as it is used to inform decisions on how content is presented and recommended to them, and what services they are advertised, offered or can access [5.5.3]. We also see from CS2 that awareness is not a binary. It includes having an appreciation of why the existence and use of certain data is significant and what its implications might be. Article 13.2.f of the GDPR (‘Article 13: Information to be provided where personal data are collected from the data subject’, 2020) states that, at least in the case of automated decision making, people are entitled

to meaningful information about the significance of the processing of their data, yet such explanations were typically not given to participants in CS2.

**Effective access to held data is required for visibility.** Having gained awareness of data held and of the significance of it, people want that to be accompanied by meaningful access to the data itself. In CS1 [4.3.2; 4.4.2], we saw families and support workers recognise the need to accommodate the differences in families’ digital literacy, mental and physical handicaps, and technology skills while providing them access to the data held about them. This mirrors Gurstein’s call for ‘*effective access for everyone*’ (Gurstein, 2011). Four aspects in particular are relevant here: the content and formatting of the data (which should support different levels of linguistic and computer literacy), the capabilities made available in terms of software, hardware and Internet access (sufficiently powerful, sufficiently available and affordable), and skills (ensuring that individuals are able to interpret the data). In CS2, we saw several participants feeling that data was delivered in too-technical formats [5.4.3], or that they lacked the skill to properly interpret the data [5.4.3]. Effective access and interpreting data goes beyond visibility of data and includes understandability, which is explored in the next section.

**Visibility of, and access to, data must be timely, and ongoing.** Given the ever-changing nature of data (and indeed of the lives of the people it represents), occasional or one-off access is not sufficient. In HDI theory, this concept is described as having *negotiability* (Mortier *et al.*, 2013, 2014): the ability to re-evaluate data and associated decisions as contexts change externally. It is also mentioned by Gurstein, who points out that time-limited access to data would not be effective (Gurstein, 2011). In the EH context, families wanted access to their data outside of support meetings; this implies the availability of self-service interfaces that you can use *in your own time*, rather than being reliant on the support worker as gatekeeper. People wanted to see all data about them directly, through a personal interface, as reflected in their workshop designs [4.3.2]. This echoed PS findings that continuing rights and visibility of data over time are needed in order enable vigilance over keeping data accurate and meaningful as life changes. Timeliness also implies that access to an up-to-date view of the data does not require special and ongoing effort by the individual, it is always available. Both support workers and supported families saw value in notification feeds about changes to data records [4.3.3], so that changes are discovered and can be acted upon without having to wait for the next support meeting. In the commercial context, we can see that GDPR provides a form of access that is not at all timely. The 30-day delay on request processing guarantees that data will be out of date by the time it is viewed, and individuals must repeatedly make GDPR requests to maintain an up-to-date view (and in doing so, they risk the imposition of charges as GDPR states that requests should not be excessive and that fees can be levied for additional copies). This lack of timeliness in the design of GDPR data access motivates my third suggestion to policymakers in 5.5.1, that they should offer ongoing access rather than the one-off delivery of data packages.

**For held data to become visible, systemic support is needed, including governance, advocacy and assistance.** Offering access to data is not solvable at a purely technical level. Even a well-built data interface with 24/7 access would not provide the depth and breadth of visibility people want. As observed in CS2, even those companies that provide instant data access portals such as Google and Facebook did not provide participants with all the data they desired, nor all the answers they sought [5.4.2], and most companies offered negligible follow-up support after data had been delivered [5.3.3]. Further investigations into data access conducted as part of the *digipower* investigation [ARI-7.2] confirmed CS2's findings that SAR requests and data portals rarely provide insight into some of the most desired types of data including derived and acquired data and data transfers. Effective access and visibility also requires advocacy (Gurstein, 2011): people require support and training to make use of their data. Furthermore, given the insufficient breadth of returned data from companies [5.3.3; 5.4.2] and near-total lack of access to data on the public sector side [4.3.2;4.3.2], it is clear that external governance (Gurstein, 2011) to ensure effective access is needed. Without the sort of pressure on data-holders that only policymakers can exert, organisations will not be compelled to provide richer responses or better information-access support [5.4.2; 5.5.1], and while small improvements can be achieved through individual action, people generally lack the means to effectively *demand* the increased visibility required [5.5.3]. The impact of this lack of governance is most keenly felt in the PDE/MyData space [2.3.4], where emergent actors seek to encourage data-holding organisations to enable greater information access so that they might build better data access tools for individuals, but are hampered by a lack of top-down governance supporting their requests as well as a lack of funding and investment by data-holders in data advocacy.

**If data is not visible, this can lead to subjection, alienation and exclusion.** Throughout both Case Studies, we have seen the negative psychological effects of people not being able to see their data. Families in both my earlier work with families [the pilot study (Bowyer *et al.*, 2018), hereafter 'PS'] and CS1 were caused significant worries by not being able to see their data. People do not want to be treated like *subjects* (in either sense of one being subjugated [PS], or as a topic being discussed) and reducing people to a set of assertions in data causes them to become, in effect 'objects to be administered', which is harmful and disempowering [4.2.3; 4.3.4; Cornford, Baines and Wilson (2013)]. Supported families felt helpless and resigned to being judged through data and sometimes suspicious of those holding or using that data [4.3.4]. This led in some cases to withholding of information or distrust of support workers, harming the effectiveness of a relationship that is designed to empower [4.4.1]. In that same section (and in (Bowyer *et al.*, 2018, p. 7)) I outlined how ongoing individual access to data has the potential to transform attitudes, remove dependence and a feeling of being a subject, and could empower families to help themselves. Such fears and worries about unseen data were echoed in CS2, with participants exhibiting great unawareness of held data [Table 5.4, 5.3.3], and concerns over

data being held out of their sight for long periods of time [5.4.3] as well as similar feelings of resignation or lack of choice [5.4.4; 5.6]. Denying access to held data was seen as a key source of holding power over individuals [5.4.4], and visibility of data is a key part of assessing ‘*to what extent the bargain*’ (of data sacrifice for value as described above) ‘*is fair*’ [2.1.4; 5.5.3; Larsson (2018)]. It is an inherent consequence of representing people through data and then using that data to make decisions [2.1.2; Cornford, Baines and Wilson (2013); PS] that individuals become sidelined and excluded [2.3.3; Crabtree and Mortier (2016)]. Without visibility of data, consent is not meaningful, and individual needs are more easily ignored or overlooked.

### 1.1.2 Understandable Data

**Visibility and access to see data is not enough, people need to be able to interpret it.** Data is only valuable in so much as it enables us to access the information which it encodes [2.1.1]. People need to be able to make sense of it. When humans look at data, we inevitably attempt to interpret it to see what it can tell them; in EH, support workers try to learn more about people’s lives by examining data about them [4.2.3; 4.3.3]. In doing so they apply their own knowledge and expectations in an attempt to extract facts. Similarly in the context of everyday digital life data, individuals search for value and meaning in that data, they reflect upon it and try to relate it to their own lives [5.4.3]. While EH staff receive training on how to understand families’ data, individuals struggle to understand their data without sufficient support, as discussed above. Returned data from GDPR requests is often dry and technical. It may contain codes, internal notations or abbreviations that a layperson cannot understand [5.4.3]. Raw data is rarely sufficient to provide clear, unambiguous and unbiased information to the reader (Gitelman, 2013; Neff, 2013). In line with one of the three core principles of HDI, *legibility*, data should be understandable by those it concerns (Mortier *et al.*, 2014). In both Case Studies (and my prior work), individuals shared a desire to not just be aware of, but to *understand* what data was held about them and how it was used [PS; 4.3.2; 5.4.2]. People are only just beginning to understand the significance of a data-centric world that uses data to make decisions that affect their lives [2.1.2; 2.1.4; 5.5.3].

**People need understandable summaries of information content and context.** It was very clear from the findings of both Case Studies that all humans looking at data need *summaries* to help them digest and locate key information. In CS2 participants were often overwhelmed or ‘*drowning*’ (P1) at the volume or technical complexity of the data returned from access requests, ‘*so much of it that’s impossible to know what it all means*’ (P4) [5.4.3]. These feelings were mirrored in CS1, by support workers who feared the liability of having to ‘*trawl through*’ large volumes of data and know all the relevant and important facts about a family so that they do not make mistakes [4.3.2]. Participants on both sides talked of needing help to see the whole picture, something that is hard to achieve from individual datapoints or sets of files. In both cases, summaries

of data would help comprehension. However, the task of creating a summary is not straightforward and places power in the hands of the summary-maker, who can decide what is relevant, how the data is framed and what is omitted from the summary. People look at information for different reasons, to answer different questions, so the question of who decides what is relevant or most important within a body of data is a critical one. Different summaries would be needed for different audiences. As Mortier reminds us, effective legibility requires a recognition that individuals’ viewpoints of data can and should differ (Mortier *et al.*, 2014). There is a question about who decides what the viewer of a summary ‘needs to know’ [4.3.3; 4.3.4]. This is further complicated by the fact that the data itself is not neutral (Gitelman, 2013); in the EH context it was clear that opinions as well as facts are recorded ((Bowyer *et al.*, 2018, p. p6) and from SILVER project), and a focus on the recording of data most helpful to the support worker. Commercial data holders record data in ways that are optimised for their existing systems and processes, as seen through the presence of internal codes, system screenshots and filenames in returned data [5.4.3]. In CS2 most participants’ comments on returned data indicated that it had not been not presented in a way optimised for understanding [5.4.3], failing to support *sensemaking*;

*“Information presentation should be as clear as possible so that people can interpret their data and extract meaningful information from it.”—Gurstein (2011)*

**Rather than raw data, people need information and visualisations, arranged and optimised for understanding.** Data, by itself, is not meaningful. In order to be able to answer questions and acquire knowledge, people need information [2.1.1]. Access to raw data files or database records or spreadsheets does not satisfy this, and prior research in the civic data context states that this would be inadequate and limiting (Cornford, Baines and Wilson, 2013). To comprehend the meaning of data, visualisations and explanations can help [4.4.2]; as one support worker in CS1 observed, some families might find data tables too technical, *‘I think sometimes it’s easier to do it in pictures’* [4.3.2]. Participant-designed interfaces in CS1 included pie charts, graphs, spider diagrams and timelines, all designed to convey information more intuitively [4.3.2]. In CS2 and prior GDPR requests, it was often the case that companies often returned data not in understandable forms that were less useful than the apps or websites those service providers offer. For example, run-tracking apps such as Nike+ and Strava return route log information in XML-based TCX files which are meaningless without some analysis tool or visualisation. JSON files, a commonly returned data format, often use a timestamp format that is just a long number, not understandable by humans without extra work. Data was often returned in formats that were more a reflection of internal systems (e.g. screenshots, table dumps or exports) than being optimised for understanding [5.4.3], which some participants found useless. As P5 observed, *‘It’s like being given the bricks to a house... It doesn’t really mean anything when it’s just bricks, if you don’t know how to put it together’* [5.4.3]. It is clear that visualisations are key to accelerating



understanding (and are also subject to the same challenges of selection and bias as summaries). Furthermore, visualisations of data can function as powerful *boundary objects* and *things to think with* [PS; Brandt and Messeter (2004); 3.5.2; 4.4.2]. In the care context the use of data representations as a focal point or evidence for was thought to be more productive and empowering [4.3.2; 4.4.1].

**Information becomes most meaningful when it is recognisable and relatable and can be mapped back to life experiences.** Across both case studies, there was a clear search for meaning in data, which manifested as a desire to use that data to build a fuller picture of the individual (or family)’s life. In CS1 and in SILVER, it was evident that support workers seek a broader view into supported families’ lives by reviewing data about them [4.3.2; 4.3.3]. Both supported families and staff saw value in seeing all the data about each individual in a common place - in other words, structuring the information around the individual’s life, rather than the information silos of different agencies [4.3.2]. In CS2, where participants were asked about the value they saw in the data companies held about them [5.3.3], it was clear that data was most valuable to participants when it was recognisable and relatable to events in their lives. This is particularly important for data that participants have never seen before such as derived, acquired or metadata - without a way to connect it to one’s own life, it is impossible to relate to [5.3.3]. Echoing goals surfaced in personal informatics literature (Li, Forlizzi and Dey, 2010), participants sought insights about themselves in data, and so valued data that spanned a longer time period such that they might use it to spot patterns in relation to events in their lives [5.4.3]. They valued the opportunity to use data as ‘*a window into the past*’ [P11 in 5.4.3]. Long term data was seen as a liability [5.4.3], and when it came to considering attitudes to providers, participants were most concerned about data collection by the larger data companies like Google and Facebook who, through their myriad apps, websites, devices and other means, had many touchpoints into their lives and thus had a broader picture of their life activity [5.4.3; 5.4.4]. It is clear that to transform dry, technical data into meaningful information, it should be contextualised in relation to events in the life of the individual it describes.

**In practice, ongoing human support is needed to facilitate the understanding of data.** In both case studies, participants felt that they had questions to ask of data holders, especially when the data was difficult to understand but also more generally when the answer to a given question could not be found in the data. In PS and CS1, participants emphasised the ability to talk to someone about their data [4.3.2], and included such features in their designs - both to understand and receive help in understanding, but also to feedback and provide additional information, explanation or context so that they might be better understood [4.3.3]. In some cases, families needed additional support for reasons of accessibility or technical literacy. Human communication channels for data support need to be available at convenient times too; in CS1 individuals felt constrained by needing to wait until their next meeting with a support worker, and wanted a communication channel they could use in their own time. In CS2,

participants were regularly frustrated by data they could not fully understand and could not ask about: sometimes literally, when internal codes were not explained or technical formats were used, and sometimes when they could not understand how the information had been derived, such as insurer’s driving scores [5.4.3] or Instagram’s inferred interests. The general pattern of GDPR handling by organisations was to deliver data, often handled by a back-end team with no customer face or means to ask follow-up questions. Where questions were asked, they were typically hindered by delays and middlemen preventing an effective conversation [5.3.3]. Considering the systemic changes toward data-centricity that the world has undergone, as described in 2.1.2 and 2.2.4, it is no surprise that human support has reduced. Across both studies we see the cost of that shift toward dealing with data instead of dealing with people; individuals get left behind, without the means to understand or ask about their data.

**If data is not understandable, distrust can arise.** In both Case Studies, the costs of individuals not being able to understand their data and being left in an unsatisfactory position of being unable to resolve concerns or ask questions is evident: Without understanding, comes distrust. In CS1, participants were concerned when they saw assertions on their records that they disputed or could not identify the source of. In CS2, privacy policies that were too vague in their explanations of data (such as Google’s) caused participant distrust because they seemed broad and lacked tangible examples, and large volumes of technical data caused suspicion. It is clear that understandable information about what is represented in data, and about the context and use of that data, can help individuals to trust the data holder. In the minority of cases in CS2 where the GDPR had a positive impact, the reasons given included understandable data and helpful human responses, for example P10 cited Niantic’s detailed data and positive attitude, while P6 described Sunderland AFC as upfront, and said that their data *‘just made sense’*. P7 specifically distrusted LinkedIn because she felt they had not bothered to adequately engage with her [5.4.4]. The importance of trust will be discussed in more detail in [6.2.1] below.

### 1.1.3 Useable<sup>1</sup> Data

**People need to be able to explore and interrogate data to ask questions of it.** In both case studies, many participants showed they are aware that their personal data contains insights and value they cannot access. In CS1 and PS this manifested as concern over what unseen incriminating judgements might be storied in their records, and an awareness that the only data supported families

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<sup>1</sup>The words *‘usability’* and *‘usable’* (spelt without an ‘e’) most commonly refer to a judgement of the degree to which a website or user interface is easy to use (Nielsen, 2012). Throughout this thesis, I deliberately use the alternative word spellings of *‘useability’* and *‘useable’* (Collins English Dictionary, no date a, no date b) respectively, to clearly distinguish from this ease-of-use concept and to denote that I am referring a different meaning: the more literal definition, i.e. *‘the quality or state of being convenient and practicable for use’* (Merriam-Webster Dictionary, no date a, no date b). Any usages without an ‘e’ can be taken to refer to the interface ease-of-use concept.

can actually see is whatever subset of data their support worker chooses to share with them [4.3.4]. In CS2, this manifested as feelings of not having the technical skills necessary to explore their returned data [5.6] and that without better tools individuals were not getting the same view of data that service provider staff have [P2 in 5.4.3]. What we can see from these observations is that even visible, understandable data is not enough to meet people’s needs. People need to be able to interact with their data, in order to explore it, gain insights or answer questions. There is a need for tools not only to access data, but to help people make sense of (often technically formatted) data [5.4.3], and explore it in different ways to answer questions - which implies the need for operations such as filtering, searching, comparing and orienteering (see 2.1.4 for others), in order to understand history, context and patterns in the data, as suggested in self informatics (SI) literature [2.2.3]. Several participants in CS2 hoped to receive data in formats they could visualise, ‘*mash up*’ and play with, but did not get this - not only was data not optimally formatted for such use, it lacked sufficient explanation to enable individuals to pursue such goals for themselves [5.4.3].

**Data needs to be useable - correctly formatted and explained in a portable and standardised form.** As discussed in 5.6 and 5.4.3, people have multiple needs around data: For understanding, people need *understandable information*, both the facts and assertions encoded within the data, but also information about the data itself - its context, history, use, and significance. But there is a distinct need for *useable data*, which is somewhat orthogonal to this. A PDF containing a screenshot from an internal system might potentially be sufficient for understanding, but is useless for exploration or visualisation-building. Similarly a technical log file might contain rich data that can be queried and visualised given the right tools, but without those tools or an informational summary, is of no immediate value [5.4.3]. This dilemma was alluded to by P4 in CS2 thus: ‘*If you want to view the data they have about you, it’s quite useable. If you want to do something [analytical], then it’s not*’ [5.4.3]. This dichotomy of needs is discussed in 5.5.1, where the introduction of standard formats is proposed as a means to catalyse the building of data insight interfaces. As P1 stated, ‘*it would be nice if these companies had a standardised model of how this information is presented to people*’ [5.4.3].

**People need to be able to interact with data, which means interfaces are needed.** By themselves, even standardised files as described above are not practically useable. As discussed in 4.4.2 and consistent with effective access (Gurstein, 2011) participant data designs in CS2 remind us that simply providing data is not sufficient: to be meaningfully able to act upon data requires some form of interface not only for visualisation and interrogation as mentioned above, but also so that any physical, cognitive or accessibility needs can be met. In CS2, some participants wanted not just for data access, but for tools to help them find insights from their data [5.5.3; 5.6]. While several companies are starting to create interfaces for data access, most of these are still focussed upon file delivery, with the notable exception of Google Timeline and Google My Activity, which provide a glimpse how an interface to explore data could be more useful

than providing a bundle of files. Both of these examples also re-iterate the value of unifying data around an individual’s life, as discussed in 4.3.2 and above in 6.1.2 above.

**Data needs to be explorable from a temporal perspective.** Another aspect of useable data that goes beyond what a data file can offer is the ability to view it over time. The importance of this temporal capability, as identified in literature cited in 2.1.4 (practical information access) and 2.2.2 (temporal PIM systems), and my prior writing (Bowyer, 2011), was evident in both Case Studies. In SILVER and in CS1, being able to access historical data for a full picture regularly surfaced as a desire in discussions - even though the exact bounds and mechanisms for achieving this were contentious [4.2.6; 4.3.2; 4.3.3]. In CS2, as Table 5.4 shows, 26% of participant goals related to SI-type reflection [2.2.3] on one’s past to enable self-insights, nostalgia and creative uses of data. No participant was able to achieve this, and this was in large part due to the lack of temporal data exploration capability, meaning that significant potential value (the value of a long-term dataset as described above) remained locked away and inaccessible [5.3; 5.6]. CS2 also suggested a lack of thought to this temporal perspective from data holders, who delivered data as a one-off snapshot that was already out-of-date when delivered. Indeed the GDPR explicitly discourages excessive data requests, rendering an ongoing view of data as proposed in 5.5.1 near impossible. Having better temporal data exploration capabilities would enable people to understand themselves and their data ecosystems better, informing both personal self-improvement goals and better decisions about personal data practices and provider choices [5.6]. Other exploration perspectives that could be powerful include location-based views or person/company/relationship-based views.

**People need to be able to access the valuable knowledge locked within their data.** People need to see the complete picture of their data in order that they might access at least glean as much value and insight from it as data holders do [5.4.3]. For self-improvement and improving one’s situation (a key goal of EH), access to metrics visible in data are extremely important, so that one might measure progress [4.3.2]. While support workers do endeavour to provide this and sometime show data extracts, this can never be as empowering as having full capabilities to explore that data *‘in your own time, at your own pace’* [PS; 4.3.2]. In commercial service provider relationships, data interfaces present data in ways that are configured to reflect the profit motives of the organisation (explored further in my work with Goffe *et al.* (Goffe *et al.*, 2021)), and so accessing a relevant view of one’s own data and having the means to access the knowledge within it is similarly difficult. Participants in CS2 found returned data unuseable [5.4.3], and wanted visualisations that would allow them to discover patterns and insights, and tools to explore their data [5.4.3; 5.5.3]. If data holders can make data not just visible but useable, individuals can learn about the valuable knowledge that data holders are currently extracting from their data, and hopefully how to access that knowledge for themselves.

**If holders do not make data useable, this is a barrier to individual agency and power.** In Human-Data Interaction terms, people need not just legibility, but *agency* - the ability to act upon one’s data (Mortier *et al.*, 2014). Personal data contains valuable and actionable information about individuals and their lives [5.5.3]. The SI field has identified that there are already many practical barriers to working with one’s personal data effectively, including not just access but challenges in integration, sensemaking and goal-tracking—the ‘barriers cascade’ (Li, Forlizzi and Dey, 2010)—which hinder the ability to use one’s data for personal benefit. As observed in CS2, an inability to access the value in your own data can lead to feelings of resignation, concern, suspicion or distrust [5.6]. Even if one can see and understand one’s data, an inability to act upon it can reinforce feelings of being passive and uninvolved; without this, any opportunity to feel engaged and motivated is lost (Bowyer *et al.*, 2018, p.8). Being able to use data for one’s own purposes is a critical ingredient of empowerment and rebalancing power (Hoffman, 2014a). Without data usability, individuals are in effect digitally impaired, leading a less functional society where innovation and growth is limited [Abiteboul, André and Kaplan (2015); 2.1.4].

## 1.2 Answering RQ2: What do people want in *indirect* data relations?

By comparing and grouping elements of the findings from CS1 [4.3] and from CS2 [5.4], especially in the context of individual relationships with care providers and digital service providers respectively, three distinct data wants are evident when considering *indirect* data relations:

- 1) **Process Transparency:** People need to know what data is being collected or held, and critically how it is being used, for accountability and safety and in order to have trust in data holders;
- 2) **Individual Oversight:** People need the ability to affect what data is held and how it is used, including reacting to changing circumstances, deleting data or withdrawing consent for certain uses; and
- 3) **Involvement in Decision Making:** People need to be invited and involved in decision making based upon their data, so that they are not misrepresented and their needs are not overlooked. This can be aided by collaborative use of data, giving individuals a human point of contact, and consulting the person not just the record.

These wants are detailed in the following sections:

### 1.2.1 Process Transparency

**People need a window into how their data is used; this means transparency of processes not just of data.** It is well-established that there is currently extensive use of personal data by service providers and other parties that is beyond an individual’s view (Hoffman, 2011), forming an ecosystem of data use based upon one’s data, which is currently not centred on or visible

to the individual concerned [2.3.4]. Decisions made based upon personal data directly affect people’s lives through policy decisions (in the care context) or business/functionality decisions (in the commercial context). People need to understand the value created by the use of their data and how (if at all) they are compensated for this (Hoffman, 2011). Even with full data access, understanding and useability, individuals cannot see into this opaque world of data use; the data is just an artefact produced and shaped by unseen processes. Like an archaeologist trying to infer the customs of lost civilisations through ancient relics, observation of the data can only reveal so much. Andrew Cormack, writing before GDPR, observed that *‘it is more important to know how information is processed than the actual values involved’* (Cormack, 2016). The SILVER project found that families had very little awareness or understanding how their data was used, and that consent was therefore not meaningful because consent had been given without processual understanding [4.2.2]. In CS1 participants agreed that people need rights to see how their data is used [4.2.6]. CS2 revealed a clear desire for awareness of how data is used, how decisions are made, and how this might affect them [5.4.2], with over 74% of goals in pursuing GDPR requests relating to wanting greater insight into personal data use practices [5.3.2]. 70% of participants wanted to understand what providers infer from their data and this was unmet in 73% of cases and fully met in only 7% of cases [5.3.2].

**Process transparency is required to enable accountability.** In CS2, participants recognised that organisations had collected data about them which could be exploited, and wanted to understand the extent of that capability [5.4.3]. Data access can provide a window into collection capability, but only process transparency can reveal the extent of data use capability. Many participants expressed a desire to assess the trustworthiness of their service providers; they had curiosity, suspicion and unanswered questions that only transparency could address [5.3.2] and sought to judge whether data use practices were “appropriate” [5.2.4]. In the EH context, all data processing is hidden from individual view and no access or questioning capability except through their support worker (functioning as a selective gatekeeper) [4.1.1; 4.2.1; 4.4.1]. Returning to CS2, there was evidently some transparency available in the form of the ability to make a GDPR request, but many participants found GDPR responses inadequate for holding providers accountable [5.2.4]. Nonetheless, data access request handling is itself a data process, and so in this sense, the GDPR process did offer some ability to judge the trustworthiness and integrity of providers in data handling, in part informed by the breadth and quality of data returns [Table ARI5.1] but perhaps more by the experience of the GDPR process. Many participants formed or revise their perceptions of companies, with perceptions of providers having a lack of care and making access difficult, or of providers being helpful and open having a strong impact on participants’ attitudes toward them [5.4.4].

**There is no accountability, processes are not transparent, and thus power remains imbalanced.** Across both case studies, the lack of process transparency is clear. EH services have no obligation to describe or share their data use practices with supported families, and apparently only even attempt to

do so at the point of initial onboarding and consent collection [PS; 4.2]. This equates in practice to a complete lack of accountability over data practice [4.4.1; 4.5]. Meanwhile in the commercial context, some companies failed to respond at all to GDPR, which is a barrier to accountability service providers. Many routinely failed to adequately meet the transparency rights stated by GDPR, without repercussion or consequence [5.4.2]. In both sectors, data holders' freedom to collect and use data without adequate transparency or ability to be held to account can be seen as an exertion of power over individuals. The power imbalance (Hoffman (2011), Hoffman (2014a)) and the dominance of data holders over the individuals about whom data is held, is reinforced by a lack of transparency.

**People face an incomplete picture of their data ecosystem, even after using all available means to achieve transparency.** In SILVER and PS, supported families expressed concern that data could not adequately represent the complexity of their lives, a view supported by literature (Cornford, Baines and Wilson (2013); Gitelman (2013)) and sustained by support workers & staff in CS1 [4.2.6; 4.3.3]. Therefore, transparency is vital in order to ensure data is fair and accurate to them, yet it is not available [4.3.4] so they have no means to ensure this. Similarly in CS2, the most popular GDPR goals around understanding inferences made from data about people [5.3.3] remained unmet. Data was incomplete, delayed, or inaccessible [5.3.2] and the potentially most informative type of data when it comes to understanding processing—metadata, derived and acquired data—were typically absent. Apparently broad responses were discovered to be very limited when viewed through the lens of privacy policy commitments and GDPR transparency rights [5.3.4].

**Trust in data holders is needed, and gaps in transparency create distrust and a risk of broken expectations, harming relations.** Individuals need a functional understanding of their data and its handling, and this is crucial to trust. Good explanations (as were often found lacking in CS2 [5.4.3] can deliver some of this needed understanding and subsequently increase trust (Glavic *et al.*, 2021), as observed in a minority of cases (14%) where a good GDPR response led to the participant's trust in their provider increasing. Conversely we found that incomplete data (or a general lack of transparency/difficulties of access [5.4.4; 5.6]) can harm trust, as in the majority of cases (52%) can harm trust [5.3.4], leading to thoughts such as 'what are they hiding?' [5.4.4]. Privacy policies that contradicted expectations or lacked sufficient explanations also led to distrust [5.3.4]. Trust in the independence and integrity of data holders is essential (Dijck, 2014), and this was often a concern in the EH context, where trust between support worker and supported family is especially critical in order for the support relationship to be effective. Earlier work found that families wanted to be confident that their data would be handled sensitively and fairly only by those with a need to know, and believed that greater visibility of data processing would allow them to trust that that was the case [4.2.2; PS]. When families felt alienated from their data, trust was absent [4.4.1], and a lack of transparency and accountability makes it hard for families to maintain trust

in the system [4.5]. These issues of transparency and trust are inherent in a data-centric operating model:

*“A crisis of trust is developing, stemming from the use of personal data in ways that are inconsistent with individuals’ preferences or expectations.”*—World Economic Forum (Hoffman, 2014b)

**Information facilitates trust; transparency therefore offers an opportunity to earn trust & improve relations.** In both studies, the findings indicated that increased transparency from data holders / service providers would improve trust; in CS1 support workers and organisations were recommended to be as open as possible about data handling and sharing [4.3.4]. CS2 highlighted the potential benefits of increased consumer loyalty that greater transparency might bring [5.5.2], as well as the need for policymakers to legislate in favour of increasing individuals’ understanding of data practices [5.5.1]. This is a level of transparency that goes beyond current GDPR practice, and even beyond current GDPR policy. In order to redistribute power, GDPR needs to deliver meaningful transparency, not just the *‘box ticking’* delivery of unhelpful files that our participants sometimes observed [5.5.1]. Crabtree describes meaningful transparency by saying that it cannot be a *‘one-way street’* that reduces individuals to *‘being spectators’* on how their data is used; he says that it involves *‘making the whole ecosystem transparent, not just the front end’* (Crabtree and Mortier, 2016). Access to good information about practices is the most effective way to earn trust [5.4.4], and both studies’ findings suggest that a proactive attitude can do just that [4.4.1; 4.3.4; 5.5.2; 5.6].

**Initially, transparency may cause distrust, but only where practice is problematic; this is accountability becoming real and catalysing better data practices.** It is important to note that in CS2 we saw the transparency of GDPR cause elevated distrust [5.3.4], however this does not mean it should be avoided. The reasons cited for distrust arising were invariably due to the discovery of practices that participants did not approve of. This is a clear illustration of the link between transparency and accountability; the transparency reveals the non-consensual or unsatisfactory practices that providers must change if they wish to maintain trust and loyalty, such as unclear data practices, data over-use or data sharing that the individual would not have consented to had they been asked. This shows that in some cases trust is fragile, where unfavourable practices are hidden and only the individual’s unawareness is keeping the relationship intact [5.4.4]. Data holders should not only be transparent, but should follow this up by acting upon subsequent feedback, improving practices that individuals discover and challenge [5.4.4]. By shining a light, accountability becomes real and change for the better can occur. Ultimately, increasing transparency can help providers uncover exactly what they need to do to earn greater trust [5.6].

**Without transparency of data and processes, individual action is blocked and power remains imbalanced.** Across the two studies, a clear pattern emerges: transparency can increase trust, enable accountability, empower individuals, and (provided organisations respond favourably) actually tilt the



power balance back toward an equitable and fair relationship where data is collected and used in clear sight of the individuals it concerns, where they might hold those organisations to account and immediately challenge any unsatisfactory practice, unauthorised processing/sharing or inaccurate data. Thanks to GDPR, individuals are now able to take direct action to educate themselves and pursue greater transparency, and utilise their rights to motivate incremental changes from data holders [5.5.3]. Without transparency, data holders will continue to hold the balance of power, and individuals will lack agency and accountability.

### 1.2.2 Individual Oversight

**Data visibility and process transparency naturally leads to a desire for individual oversight.** If you see something that is ‘not right’, you are motivated to want to fix it. And therefore, people want something more than data and process transparency, the natural next step is the ability to make decisions about what happens to their data. Participants’ goals in CS2 included curiosity, suspicion and a desire to shed light on specific incidents [5.3.3], mirroring the desires families in PS exhibited to be able to know and see what data was held and used about them. In both cases, individuals wanted to have a say over what happens. Current models of informed consent have been found to be inadequate, with the initial handover of data acting as a *point of severance* (Luger and Rodden, 2013). This was echoed in the experiences of families in the EH context, who gave consent at the point of initial onboarding, but lost all ability to influence what happens to their data thereafter [PS; 4.2.2]. GDPR aims to adhere more to a *dynamic consent* model (Kaye *et al.*, 2015; Williams *et al.*, 2015) by giving people an ongoing set of rights, including the right to be informed about the use of your data, the right to object to certain data uses, and the right to get your data corrected or deleted (Information Commissioner’s Office, 2018). In line with the *accountability principle* (Article 29 Data Protection Working Party, 2010; Crabtree and Mortier, 2016), this in effect would allow people to act as overseers or regulators over their own data: watching how it is used, and demanding action or change to practice when they see data use that goes against their wishes.

**People need agency and negotiability over held data about them, in order to ensure fairness and accuracy and reduce risk.** As PS showed, there is a strong desire to ensure data is *fair* and *accurate*, because that data is used to inform judgements and make decisions that can directly affect the individuals concerned. Data in CS2 showed a clear problem with the accuracy of unseen data: while in 92% of cases volunteered data (which by definition, has been seen by the individual) was found accurate, derived and acquired data (previously unseen by the individual) was found inaccurate in 50% and 80% of cases respectively [5.3.2]. Being able to ensure fair and accurate data goes beyond being able to see and understand the data, but requires also *agency* (the ability to act within a data system, such as to delete or correct data, or withdraw consent) and *negotiability* (the ability to continue to have a voice

and make changes as circumstances change) (Mortier *et al.*, 2014). People need a relationship with their data [2.1.5]. In both CSs and in PS, individuals perceived tangible risks both of data being held beyond their reach, but also of potentially inaccurate data being used to make decisions. Risk factors identified in the EH context included facilitating or encouraging crime, causing social and psychological harm, and enabling medical mismanagement or welfare support failures. In CS2, participants felt that held data about them that is not visible or controllable was a liability that might lead to privacy violations, commercial exploitation, and an increased risk of data leaks [5.4.3]. Clearly people feel that for their data to be safe, they must be able to see and verify its storage and use for themselves and enforce action when something is not right. As early as 1980, when the world was less data-centric, it was already recognised that individuals would need the ability to challenge data use, as the OECD observed in their guidelines:

*“The right of individuals to access and challenge personal data is generally regarded as perhaps the most important privacy protection safeguard.”*—Organisation for Economic Co-operation and Development (1980)

**Individual oversight capabilities must be supported by governance, so that individuals can effect desired changes.** As Gurstein notes, a key element of effective data access is governance, that is, mandating data holders to support individuals in accessing their data and respecting their wishes over what should happen to that data (Gurstein, 2011). Individuals need to be able to give instructions, make changes and express permissions that have weight; they need to be listened to, so that they can meaningfully effect change [4.4.2]. Bakardjieva, examining the use of data about others in a different context (research), identified that individuals whose data is used need the ability to influence not only the data about them, but the actual decision making that occurs based on that data: both the data *and* the decision making should become objects that the individual subject can manipulate (Bakardjieva and Feenberg, 2001). At the time of writing (August 2022), much of the focus on GDPR has been about access to data, perhaps because this is more tangible, and very little about GDPR’s other rights that can influence decision-making [5.1.2]. This was backed up by participant experiences in CS2, where desires to influence or change practices or delete data were either not actionable or ineffective [5.4.3]. Governance over individual data rights has two elements. First, to support individuals in complaints or challenges, which are currently unevenly enforced [5.5.1]. But more importantly than this, given the extensive use of data by organisations and the great potential for misuse or harm, individuals need to be able to trust that systems are in place that mandate the behaviour of data holders to be trustworthy; to compel organisations to maintain good data practices such as data security and dynamic consent in the first place [5.4.4]. In the GDPR context bodies that can do this already exist—the Data Protection Authorities. In the public sector/care context, the picture is less clear. Participants identified a need for oversight bodies to compel good practice, identify appropriate access rules, and to provide

independent oversight in contentious cases [4.3.4]; this is particularly difficult given that no organisation can see the full picture of an individual's civic data.

**Individual oversight would bring individuals back to the centre of their personal data ecosystem as an active participant.** As outlined in 2.3.4, the ideal has been established that individuals need to be at the centre of their own personal data ecosystem, overseeing and controlling their data selves as easily as their physical selves. This aligns with the concept of *individual self-determination*, which is gaining ground in PDE circles (Fisch, 2015). Currently, as seen in both contexts, data functions as a proxy for their direct involvement [PS; 5.4.4]. Decision makers consult data first, as the primary source of truth [4.1.2; 2.1.2], and the individual second (if at all). For transparency to be meaningful, data flows need to open up to include individuals as part of the loop, changing them from passive spectators to *active participants* (Hoffman, 2014a; Crabtree and Mortier, 2016) in the processing of their data. Examples of specific oversight abilities desired in CS1 were the ability to explain or annotate datapoints [4.3.3], to be able to check data together with support workers, with the record of that check becoming part of the data [4.3.3], or to have granular access controls over precisely which data could be seen by whom [4.3.3]. In CS2, a clear picture emerged that what participants want is the ability to make *choices*. They want control over the data they are forced to sacrifice to companies [5.4.4]. To avoid the *point of severance*, data sacrifice should be a loan or sublicense, not a taking-possession-of.

**Given the changing and complex nature of human life, data is inadequate and consent is never complete, so longitudinal participation and oversight is needed.** Too often, data is treated as a static source of truth (see above). Attempting to represent people as data in order to require less human contact is a reasonable goal from an organisational efficiency or cost-saving perspective, but any representation will never be complete or adequate [Cornford, Baines and Wilson (2013); PS]. In CS1, the findings showed the need for numerous efforts to augment data in order to combat its inherent inadequacy, such as support workers seeking to understand the people behind the records [4.3.3] and maintaining a constant attitude of seeking to understand more deeply than the data record can allow [4.3.4]. Even if a data record can be corrected or completed, it will still be inadequate, because human lives change continuously: people move, start and end relationships and jobs, marry, divorce, have children, pursue new interests, become incapacitated, or die. The passage of time can radically change the context or relevance of data [PS]. A one-time informed consent upon data collection is inadequate in this ever-changing context [4.2.2; 4.2.6; 4.3.3]. If consent needs to be ongoing (and in order for it to be meaningful) this means that engagement with the individual concerned, and that individual having a view of their data and its use, need to be ongoing too. In order to avoid storing or using data beyond its need, ongoing data access is needed, in order to enable ongoing individual oversight [4.2.2; 4.3.2]. Systems and processes must treat data as dynamic [4.3.3], as something that will become inaccurate without sustained engagement. CS2 noted that GDPR data access is currently based

upon viewing a one-time snapshot of your data, and does not take this need for negotiability (Mortier *et al.*, 2014) into account at all [5.5.1] (though some companies now offer download dashboards that come closer to providing ongoing access). Ongoing access, consent and participation do carry cost implications for providers, and effort implications for individuals - but these can be improved over time: the former through automation, standards and education, and the latter through holistic approaches to personal data ecosystems; these mitigations will be explored further in Part Two.

**There is scant individual oversight available today. Governance is lacking. If people cannot make choices about their data, they will remain powerless.** Participants in both contexts faced an inability to see the full picture of how their data is processed and used. Families in CS1 workshops spent time designing interfaces for seeing and correcting their data and changing permissions [3.5.3; 4.3.2; 4.3.2], but no such interfaces exist. The entirety of their data access and influence is limited to what can be achieved verbally with their support workers [4.2.4; 4.4.3]. Without transparency and dynamic consent mechanisms, those families lack accountability. They are excluded with no ability to oversee or participate in the life of their data. In CS2, of the 41% of participant goals that concerned gaining insight into and control over the use of their data, 66% were unmet. Participants saw no clear pathway to use their rights to control over data. Only 1 of the 10 cases where a participant wanted to delete their data was successful [5.3.3]. At the time of writing, only one company (Apple) has a privacy hub that offers clear routes to access data rights other than access. Participants also reported in some cases being unable to check the accuracy of their data, or to investigate specific incidents where they had concerns [5.3.3]. The general view was one of widespread disappointment, that despite the promise of GDPR it did not confer any power to the individual to influence data use [5.2.4], leading in some cases to a reluctance to submit GDPR requests in future. Access requests were also rarely seen as useful in the care context. They typically only occur in the case of complaints. In the GDPR context, the inability to restrict data use or delete data was seen as a lack of control, and the retaining of data against their wishes as a liability [5.4.3]. Ultimately oversight means having choices, which is essential in the data-centric world. The Case Studies' findings show that, in general, participants felt they had been forced to sacrifice data to access services, and offered *no* practical choices or control over that data. Without individual oversight, there is no choice and people remain powerless.

### 1.2.3 Involvement in Decision Making

**Data represents people. But people are more than can be encapsulated in records. There is a need to engage the human behind the data, as people can never be fully represented in data.** Intrinsic in the move towards data-centricity has been a move away from human involvement. In the commercial sector this is due to cost-saving (call centres and web portals being

cheaper than individual customer interactions) [2.1.2]. In the care context it is similar but there is also a desire to create a society that functions at large without individuals requiring special handling and support [3.4.1]. Both case studies’ findings, consistent with literature (Abiteboul, André and Kaplan, 2015; Crabtree and Mortier, 2016), reveal myriad problems created by the exclusion [PS] of people from matters that affect them - from feelings of alienation or disengagement [5.4.4] to actual harms caused by erroneous or unfair judgements [4.2.2]. Service providers holding data need to contextualise data as an incomplete view into the complex human world, and seek greater understanding [4.3.4] while looking for positives in data [4.3.4]. It is interesting to note that the Troubled Families programme was created help find the human situations of people slipping through the cracks of the system. This highlights the inadequacy of purely data-based decision making [3.4.1].

**Consent to access and use data needs to be dynamic and meaningful, which can only happen through ongoing involvement.** As established in 4.4.1 and 6.2.2, ongoing data consent is essential, and this is especially important where that data is used to make decisions [4.4.3]. One-time consent is ineffective and meaningless [4.5]. Asking individuals for consent and subsequently less involved in decision making reinforces a hierarchical, rather than an equitable, power relationship (Bakardjieva and Feenberg, 2001). Without ongoing consent, the power imbalance is amplified [4.5]. In the commercial context, companies view data as their asset to exploit (Hoffman, 2011; Toonders, 2014), and the simple fact of having the ability to collect or access to data about people has proved in practice, sufficient to enable a variety of practices which would be likely to be refused consent if made visible to users (Melendez and Pasternack, 2019; Evans, 2021; Claburn, 2021). Individuals feel forced into a one-sided arrangement of sacrificing data in exchange for service benefits; with no choice upfront on signup, and minimal practical choices afterwards, their only choice is Hobson’s choice (‘Hobson’s Choice’, no date). Consent has become commoditised, and from a corporate perspective the focus has become constructing a *legal justification* for using an individual’s data rather than practically engaging with them and verifying if they approve (Woods, 2022). This can only happen when the individual about which data is held is excluded from data handling processes.

**A human channel for conversation is wanted, to enable explanations, questions, and consultation.** In PS and CS1, all participants viewed that individuals should be able to talk to someone about their data [4.2.6; 4.3.2], in order to ask questions or explain datapoints. In CS2, participants had questions about their data that they wanted to answer [5.3.3], yet these questions remained unanswered [5.4.2]. Participants regularly experienced painful and ineffective processes when trying to answer their questions, found that GDPR responses, often unhelpful, provided no backchannel for follow-up questions or further communication [5.4.2]. They were left *‘in the dark’*. This highlights the need for a human support channel, which is not mandated by GDPR, not just to better understand the data itself [6.1.2], but to enable ongoing consent negotiation within the relationship with data holders.

**Individuals should be consulted in decision making. This improves accuracy, perspective, and fairness and reduces consent liability.** A common theme in the findings of both PS and CS1 was the idea that data is more likely to be fair and accurate if in the individual has the opportunity to express their perspective on it. Families advocated checking data together to identify gaps [4.3.3], valued the prospect of making their own contributions to the data to ‘*tell their own story*’ [4.3.3] and wanted a ‘*right to explain*’ or annotate their data [PS]. Support workers recognised the need to work with families to understand their situation better [4.3.2]. These findings show it is important to give the human data subject a role in data creation or checking, and that if they are involved, to ensure a fairer and more complete view can be obtained than the limited view presented by the data record [4.3.3]. Without involvement, agency (Mortier *et al.*, 2014) will always be limited. Data is not neutral (Gitelman, 2013; Neff, 2013), and this means all stakeholders should be given a role (Bowker, 2005) in order to avoid errors, harm or disempowerment [4.4.1]. Involvement is negligible in the care context (being limited to the TAF and the support worker relationship). In the commercial context, there is no such involvement, and the results of this can be seen in the low accuracy of previously unseen data [5.3.3] and in the low trust ratings [5.3.4] given to many providers after seeing data returns. It seems that data and knowledge would become more accurate when it is closer the data is to the individuals concerned [4.4.3; 4.5]. Data created and handled far from the family would intuitively be less accurate and less likely to have been considered from their perspective [4.2.2]. Organisations on both sides value data accuracy [4.2.3; 2.1.2] so greater involvement could help achieve this. Data holders would also benefit from involving individuals because responsibility for consent would become shared, resulting in a higher ‘buy-in’ from individuals and a reduced liability. Provided communication is effective and without barriers, involved individuals would be inclined to speak up if they see something they do not agree with [4.4.1]. Of course, this call for involvement in decision making is not absolute. Businesses need to be free to exercise their expertise. Patients are not best placed to decide what medicines they need, and over-involvement of users in product design can result in mediocre products that suffer from *design by committee*. In fact, the attitude conveyed toward the individual is critical. This was borne out in CS2 findings [5.4.4; 5.4.4]. Edwards and Elwyn, in their paper on shared decision making, argue that *feeling* involved is actually more important than actually contributing to decisions (Edwards and Elwyn, 2006).

**Effective collaboration can be achieved by coming together around the data, using it as evidence (of facts or of opinions) and as a boundary object.** Workshop C in CS1 specifically explored the prospects of shared data interaction, which had emerged from SILVER and phase 1 (Workshop A/B [4.2.5]) findings as a possible way to meet the needs of both supported families and support workers. Shared values were identified [4.2.6] and a model for shared data interaction builds upon the findings [4.4.3]. Central to this is the idea that evidence-based decision making can be more effective (both from a rapport-building perspective but also in terms of the quality of decision made)

as guidance has advised [OFSTED (2015); Department for Education (2018); 4.1.2] and as seen in the findings [4.3.2; 4.3.3; 4.4.1]. Families and staff saw potential benefits from checking data together [4.3.3], using specific datapoints in discussions as evidence [4.3.2], or to help families open up [4.4.2], on top of the simple benefits of making all evidence equally visible [4.3.2; 6.1.1]. Throughout such shared data interactions, representations of data perform an important function as a boundary object (Star, 2010; Bowker *et al.*, 2015); it provides a common focus to discussions that is relatable to both parties, *things to think with* (Papert, 1980; Brandt and Messeter, 2004). This helps improve legibility by surfacing the (perfectly valid) differences in different parties' perspectives (6.1.2, Mortier *et al.*, 2014). In PS I observed that gathering around data representations facilitated a less confrontational interaction than an across-the-table interview would.

**Being involved means being able to learn and take action at any time, including on one's own and away from official contact or interactions with service representatives.** Both Case Studies reveal that people want an ongoing window into their data and its use. Limiting data access and process transparency to specific times spent with a gatekeeper, as in the EH case [4.1.1], or to a process that only provides a one-time snapshot of data [5.5.1] reinforces the hierarchical power imbalance. Giving access to data and abilities to explore and ask questions '*in your own time*' [4.3.2] can unlock new individual benefits from data [5.4.3; 6.1.3] and provide more immediate feedback that can help people measure their progress towards improvement goals [2.2.3; 4.4.2; 4.4.3], as well as enabling ongoing individual oversight [4.4.2] and dynamic consent [4.3.4]. In the face of providers making decisions based on unseen data using processes that cannot be observed, people feel excluded and powerless [5.4.4; 6.1.1]. To ensure effective access (Gurstein, 2011), accountability and trust, there must be ongoing involvement, data access and transparency [5.5.1; 6.2.2].

**Indirect data use enforces an uneasy trust; services that use data need a human face or point of contact, in order to grow understanding, earn trust and improve relations.** There is a coldness to data. Facts, judgments and mistakes appear in print with equal weight, without explanation or context, seemingly a complete set of objective facts. In both studies, the value of human contact accompanying data access was evident; in CS2 participants valued the GDPR responses that felt most human [5.4.4] and lamented the inability to discuss data or resolve questions [5.3.3; 5.4.2]. In PS participants wanted '*to have a conversation*' about their data and in CS1 participant data interface designs included buttons to chat to their support worker or ask questions [4.3.2]. People do not want to be severed or alienated from their data, yet they feel they have no choice but to relinquish access and involvement [4.4.2; 5.4.4]. Ideally, all data-using organisations would have a human face or point of contact that individuals can address questions to and in whom their trust of the organisation can be embodied [4.4.2].

**Without involvement, people cannot take a full and equitable role**

**in processes that affect their life.** When data is used by organisations, this inherently serves as a proxy for their involvement [PS; 5.4.4]. People have consequently lost control and agency (Crabtree and Mortier, 2016), creating a crisis of trust and a power imbalance (Hoffman, 2014a, 2014b). Exclusion from data handling and decision making inevitably reinforces a hierarchy, with the individual destined to have less say and influence over services that affect their daily lives. Taken together, an ongoing involvement with the data held by service providers and the processes that use that data would change indirect data interaction [6.2] into direct data interaction [6.1] and transform the individual experience of service use. Of course such a shift is difficult and costly to offer, for both small and large companies—the data-centric world emerged in part as a means to reduce costly human interactions and facilitate large-scale scaling up to serve larger user bases—but what we see suggests that the balance has tipped too far towards exclusion of individuals, and that giving them even a limited role in reviewing data, consenting and contributing to decisions, and just being informed, could carry significant benefits for both individual empowerment and organisational reputation, and trust.

### 1.3 Summation: Empowering Individuals with Better Data Relations

In this chapter, the separate Case Study findings and insights from Chapters 4 and 5 have been synthesised to identify six specific capabilities that people need in their relationship with their personal data - both from the direct perspective of RQ1 [3.3.1], where people want for **visible, understandable and useable** data, and from the indirect perspective of RQ2 [3.3.2], where people want for **process transparency, individual oversight and decision-making involvement**.

#### 1.3.1 Empowerment

In line with the pragmatist, individualist outlook of this thesis [3.1], these six wants amount to **a desire for empowerment**, motivated by a desire to pursue one’s own happiness and self-interest. Empowerment is defined as *‘the process of gaining freedom and power to do what you want or to control what happens to you’* (Cambridge Dictionary, no date). In essence, empowerment is achieved when the individual, in consideration of the question *‘what can I do?’*, judges that they can do more. Power, it transpires, is a double-edged concept. The power imbalance over personal data [2.1.2] encompasses both *power to* but also the concept of *power over*. These are best considered as two sides of the same coin or two perspectives on the same set of facts: organisations have *social power* over individuals, that affects what both parties can do. An organisation having social power does not imply a desire to dominate. Impacts on the individual’s agency are merely material effects of the power holder’s attempts to influence the behaviour of individuals in pursuit of the power holder’s own desired outcomes (Pansardi, 2012). Concepts of power are explored further in 8.4.1.



### 1.3.2 Disempowerment

Not only do these six wants lead to individual empowerment, there is a clear correlation. **The more that the six data wants can be addressed, the more empowering it is to individuals.** From the Case Studies it is clear that the status quo of the data-centric world [2.1] is that the lack of these six capabilities reduces individual capacity to act, individuals are **disempowered**. People are treated indirectly through data (Cornford, Baines and Wilson, 2013). They are excluded and not involved [4.5; 5.4.2; 5.4.3; 5.4.4]. In both Case Studies many of the findings are based on the opinions of participants as to what they believe *would* be desirable, preferable or more successful. In the case of data visibility [6.1.3] and process transparency [6.2.1], however, there is clear evidence that these *do* have an impact on individual’s subjective assessment of their own empowerment: In CS2, 45% of cases saw people experience a change in power after examining privacy policies and scrutinising GDPR responses. 29% felt a decrease in power, and 17% an increase. Data visibility and process transparency seem to be key first steps towards empowerment, as they allow a more accurate assessment of one’s own capability. In 52% of cases, CS2 participants felt more distrustful, having discovered unsatisfactory exertions of power by providers [5.3.4]. Once visibility and transparency have been achieved, it is clear that this should be followed soon after with understanding [6.1.1], agency [6.1.3; 6.2.2] and involvement [6.2.3]. Any one of the six wants can improve data relations for the individual, but the combination of all six is likely to produce more than the sum of its parts—an empowered digital citizen.

### 1.3.3 Towards A Better Society

Considering the societal level, these six wants show **how society should be reconfigured to improve data relations**. Giving people a role in influencing the life of their own data is a key ingredient in and of more progressive digital citizenship (Bridle, 2016). Shifting data interaction interfaces and processes to a more human-centric [2.3] model where people are controllers at the centre of their own personal data ecosystem [2.3.4] would be progressive and transformative, and not without cost, education, deployment and uptake challenges. Nonetheless, participants in both Studies could easily imagine more human-centric interfaces and more empowering service interactions, and demanded those improvements. And it is possible. Just as some human-centric practices were beginning to emerge among support services in CS1 [4.3.1], so some companies targeted in CS2 are already beginning to move in this direction. Some offer privacy hubs and explanations of data practices, while others offer interfaces solely for accessing data and exerting data rights [5.1.1]. In both Case Studies, there was a clear demand for these initial forays by service providers to be expanded: be it through more pro-active data practices in the care context [4.3.4], or through new models of data involvement in the commercial context [5.5.2]. If the locus of decision making [4.4.3] could be shifted towards individuals through such reconfigurations of existing practices, this would give them a role to play as

*agents in the life of their own data.* This would allow them to curate their own data self, the representation of them used in decision making, so that it is fair, accurate and representative [PS; 4.4.3]. The principles of involvement, effective access and shared data interaction could be applied in many domains - education, health, democracy and commerce, and an emphasis on individual sociotechnical capabilities is a useful mindset to apply to both business process design and data interface design.

**Empowering individuals with better data relations should lead to a better future.** Taken together, the pursuit of the six data wants allow us to envisage a new, data-empowered future for individuals, who would reap the benefits of being able to gain insights and feedback from their own data in real time, while also co-operating with service providers in the stewardship of their data and involved in decisions. They would have agency, influence and negotiability in an ongoing manner. In this future, there are opportunities for organisations to reimagine customer relations and the role of data in service provision, leading to increased accuracy and consent, reduced liability, greater trust and loyalty [5.5.2], and potentially to capitalise on new demands for data insight tools [5.5.3]. The ideal is that individuals would have a *‘permanently open two-way communication channel [with data holders], allowing a dialogue to take place’* (Bakardjieva and Feenberg, 2001), delivering dynamic consent and ongoing involvement. Such a change in thinking, away from legal box-ticking (be it capturing informed consent [4.1.2], or satisfying GDPR requests [5.5.1]) and towards delivering an ongoing understanding of the collection and use of one’s data and a voice in what happens to it, would empower individuals and begin to move us towards that idealised future. In such a society, the positive impacts of transparency would be evident. The general principle that transparency allows trust to be earned (which can in turn benefit organisations themselves) could be applied in a wide range of service endeavours that are currently very closed. This would allow innovation in data access and process involvement to flourish.

The vision of these new empowered individuals, given new inclusive roles in the lives of their data, therefore, is the ultimate answer to the research question [2.4] Part One of this thesis set out to answer: This data-empowered and process-involved future is what better data relations would look like.

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