

Understanding and Designing Human Data Relations

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- [4 Case Study One: Accessing and Using Civic Data in Early Help](#)
 - [4.1 Context: Data Use in Early Help](#)
 - [4.1.1 Data-centric Family Intervention in UK Social Care](#)
 - [4.1.2 Current Practice: Early Help Case Records as a Source of Truth](#)
 - [4.1.3 Rethinking the Role of Data in Early Help Support Relationships](#)
 - [4.2 Preliminary Explorations of Family Civic Data: Families' and Support Workers' Perspectives](#)
 - [4.2.1 What is Family Civic Data?](#)
 - [4.2.2 What is the Family Perspective on Their Civic Data and its Use?](#)
 - [4.2.3 What is the Staff Perspective on Family Civic Data and its Use?](#)
 - [4.2.4 Seeking an Equitable and Mutually Beneficial Data Use Model: Shared Data Interaction](#)
 - [4.2.5 The Workshops](#)
 - [4.2.6 Sensitising Participants and Discovering Shared Values](#)
 - [4.3 Thematic Findings](#)
 - [4.3.1 Themes & Subthemes](#)
 - [4.3.2 Theme 1: Meaningful Data Interaction for families](#)
 - [4.3.3 Theme 2: Giving a Voice to the family](#)
 - [4.3.4 Theme 3: Earning Trust through Data and Process Transparency](#)
 - [4.4 Discussion](#)
 - [4.4.1 The Value of Involving People With Their Data](#)
 - [4.4.2 Effective Data Access Requires Human Interaction](#)
 - [4.4.3 The Benefits and Implications of shifting the Locus of Decision-making](#)
 - [4.5 Summation](#)
- [Bibliography](#)

4 Case Study One: Accessing and Using Civic Data in Early Help

In this chapter, I describe the first major case study of this PhD, in which I ran three 2 hour participatory co-design workshops involving local authority support workers and parents and children from supported families that had recently participated in Early Help programmes. The purpose of the research was to build upon prior explorations to gain deeper understanding of family and staff attitudes to civic data holding (in pursuit of RQ1) and to move beyond this and explore the role of data within the support relationship (in pursuit of RQ2). A particular area that I explored was to consider the possibility of shared data interaction, where supported families and their support workers would interact with data together and in person as part of the support engagement.

In section 4.1, I will provide background on the Early Help context in England. In 4.2[CHECK], I will review

the prior findings from my own preliminary studies as well as that of others including Connected Health Cities, and show how these findings were used to establish a common ground within the sensitisation activities at the start of each workshop. In 4.3, I will describe the three themes discovered through qualitative analysis: that families want to be given a voice (4.3.1), that trust can be earned through data and process transparency (4.3.2), and introduce the concept of meaningful data interaction for families (4.3.3). In section 4.4, I will discuss these findings in the context of prior literature, drawing insights into the value of involving people with their data (4.4.1), the need for human interaction to make data interaction effective (4.4.2), and the pros and cons of the shifting of the locus of decision-making towards the family that shared data interaction would bring about. In 4.5, I will summarise the case study in terms of how these insights expand our understanding of the research questions and their wider significance.

4.1 Context: Data Use in Early Help

4.1.1 Data-centric Family Intervention in UK Social Care

In the UK, the social care system has been shaped by a history of efforts, initially under the *Every Child Matters* policy programme [REF], to improve the lives of children, especially those suffering the most. The *Contact Point* and *Common Assessment Framework (CAF)* programmes, were established with the aim to create universal digital tools to support co-ordination at a local level across public sector services, centred around children and young people [REF Wilson et al 2011, Cornford et al 2013], later expanding to include their families [REF Malomo and Sena, 2017]. A change of government in 2010 saw many of the policies around children and families moved from a basis of universal access to a targeted provision. Programmes such as *Think Family* [REF Cornford et al 2013, Crossley XX] introduced a focus on *family intervention* as a primary approach; social workers learn about and get directly involved with the lives of targeted young people and their families in order to understand problems and to help empower them to overcome specific difficulties they face. The Troubled Families Programme (TFP), created in 2012 for England, was built upon a claim that £9 billion of civic spending was due to just 120,000 families and that a net saving of £11,000 could be achieved for each family that could be “turned around”. Local municipalities were required to work with partner agencies to identify *troubled families*¹ – those ‘at risk’ families experiencing multiple issues from a list including unemployment, overcrowded housing, poor education, mental health issues, disability, low income, poverty, truancy, crime and domestic violence – and to work with such families to reduce these risk factors for them (Bate and Bellis, 2018). The TFP was set up in such a way that local authorities could claim central government funding for each family they had provably ‘turned around’, and as such encouraged extensive collection and use of data about each supported family to track and demonstrate progress and impact. This shift towards using data mirrors the societal rise of data-centrism described in section 2.1, but was also being seen across the public sector; under increasing pressure to demonstrate performance and deliver measurable, consistent results, all human services (including social care, health care and education) have become adept in the collection and use of data about their clients or service users. The use of data by the state as a means to represent and think about families is considered problematic (REF Cornford et al., 2013, Neves and Casimira 2018). For instance, from the perspective of the state, such data may include both objective facts from families’ lives such as address or family inter-relationships, as well as potentially more subjective information such as practitioners’ observations or numerically-quantified measurements of risk. The risk of inaccurate data or unfair judgement is compounded by the fact that the clients of such services typically have limited access to this data. Although in theory families retain the ability to interact with services (and have access rights to data) the practitioners and the organisations for which they work become de-facto *gatekeepers* to the data about a family (REF). This is then played out in a policy context where data-driven approaches to family care are encouraged through policy and reports about improving quality of the sector (Bate and Bellis, 2018; Department for Education, 2018; Field, 2010; OFSTED, 2015).

4.1.2 Current Practice: Early Help Case Records as a Source of Truth

Over the last decade, *Early Help* programmes have become a key social care offering from almost all local authorities. These programmes seek to pre-emptively help individual residents voluntarily before statutory

intervention is needed. Early Help was quickly identified as a suitable setting to explore the use of *family civic data* (a term I introduce in (Bowyer *et al.*, 2018)) and its impact on individuals in this data-centric policy context. Connected Health Cities' SILVER project, a Department of Health and Social Care funded project working across five local authority areas in North East England, aimed to improve Early Help support through improved use of family civic data. Through my embedded collaboration within this project, existing use of families' civic data by early help practitioners and front-line support workers was possible.

The need to produce data for use as evidence for schemes like the TFP led local authorities to update their Early Help processes; support workers would now carry out an 'early help assessment' (a guided enrolment questionnaire) to create an 'early help record' (EHR) for each supported individual and their family, which is then stored in a case management system such as CareFirst, LiquidLogic or eCAF. To help form a holistic perspective of a supported family's situation, a process of information gathering and family-centric inter-agency collaboration is adopted. The EHR is supplemented by data from other agencies reporting on an ad hoc or periodic basis (e.g. via emailed spreadsheets, phone conversations, and in-person meetings, such as the *Team Around the Family* (TAF) – a bespoke grouping with representatives from other agencies such as police, schools or housing agencies. This data is used to evaluate that family's situation and progress against the 'Common Assessment Framework' (REF). Support workers are encouraged to use data as evidence at all stages.

An Ofsted report into UK early help in 2015 found that early help services across the UK were too inconsistent and recommended that greater standardisation in assessment and evidence-based practice were needed. Consequently, Early Help schemes continue to seek more data about 'at risk' individuals to use as evidence and to inform their care. Support workers, if provided with better data, can in theory make better decisions as part of the care they provide, and this belief that the best evidence is data is baked into national policies: "IT systems are most valuable when practitioners use the shared [between agencies] data to make more informed decisions about how to support and safeguard a child." (Department for Education, 2018). Such central policies highlight that in the UK, early help work is a data-driven service.

Despite this policy goal, the technical reality has been far more complex. Many different IT systems are used for social care, even within the same local authority; teams work in isolation using different systems and applications. The information ecosystem that the care services fit within is vastly complex (Copeland, 2015) with each part of the system having its own ICT systems and limited arrangements being in place to facilitate information sharing across the different data-holding authorities (which sometimes include local charities with their own ICT systems to which care functions are sometimes outsourced). The existence of different administrative boundaries for different authorities and agencies further complicates the situation. This fragmented ecosystem has proliferated due to each local authority being responsible for procuring their own IT systems in the absence (despite recommendations (Harbird, 2006)) of any centralised systems or information sharing standards.

The reality of information sharing in this context today is that many barriers exist – for example care workers can rarely access health data from GPs and have to rely on school nurses, health visitors, specialists or the individual's own account. Where such information is shared, it is often in the form of emailed spreadsheets or reports, telephone conversations or committee discussions, and not supported by technical integration. No one team, agency or authority can have a full picture of an individual's data (Malomo and Sena, 2017). Different operating policies, consent agreements, privacy regulations, technical access levels, system functions and staff competences result in different interpretations and limitations about what data can be shared (Malomo and Sena, 2017). Data should flow freely through the system in the service of individual care, but it does not, the public sector has a closed and fragmented ecosystem (Pollock, 2011).

Processes such as TAF meetings and the attempt to unify all information onto a single EHR can be seen as a recognition of this failure in the system to produce a single source of truth or understanding of individuals from a 'whole life' perspective. In attempting to create and expand the EHR as a central representation of truth about the family in order to inform care decision making, we can see data-centric solutionism [REF]

being applied to try and solve a problem that was created by a data-centric approach in the first place.

4.1.3 Rethinking the Role of Data in Early Help Support Relationships

While support workers often refer to data from the EHR, the families they are supporting have no access to the data records and are only aware of those aspects that support workers or TAF professionals choose to share with them; often such data is reported only in verbal form and would rarely be shown in its entirety. Critiques suggest more data may only consolidate more power in practitioners' hands and further undermine the families they are meant to be supporting (Neff, 2013; White and Wastell, Crossely). The scattering of data across so many different systems and organisations, combined with informal processes for sharing, provide a serious opportunity for privacy breaches or mishandling of people's personal data. At the most basic level, this might be a violation of consent – the passing of some data, collected for a specific purpose, to another authority for some new purpose without the data subject's explicit consent for such use. The creation of the EHR as a source of truth carries significant risk of disempowering families further and countering the empowerment goals of the programme itself: The possibility of errors in the personal data that goes into the EHR is high, and might result in prejudice or unfair decisions being made. In more serious cases, individual privacy may be violated, or individuals put at risk, if a domestic abuser or criminal gained access to the record. The failure of such case record systems to properly represent families (REF Cornford) produces further risk; information shared by one individual in confidence could be seen by another family member, and this could have extreme psychological consequences, such as an adopted child finding out they are adopted.

Data is not neutral (Gitelman, 2013; Neff, 2013), and collecting data within the context of the delivery of a specific service or intervention rather than as an objective collection of facts undermines local professionals' discretion and organisational agility to deliver the care that is needed ((Cornford et al., 2013); Lowe and Wilson 2018). This means that rather than improving the situation of a family the collection and use of data may be instead reinforcing the existing asymmetries of power that exist between data-holding organisations, the practitioners and the supported families (Cornford et al., 2013).

This context therefore provides an ideal opportunity to study the dynamics of data use and its impact upon service relationships, in service of RQ2. Following preliminary sensitisation research with both families and support staff (summarised in 4.3 below), a study was designed with the objective of investigating the role of data within the Early Help support relationship, from both the individual perspective of both parties (in so doing deepening our understanding of RQ1), but looking at the power balance and effectiveness of the relationship as a whole, remembering that the ultimate goal of Early Help is to empower families to build better lives for themselves and get them to a point where they no longer need support. A further objective in exploring RQ2 is to explore possible alternative models for the use of data within Early Help relationships, and to explore the viability and potential benefits of such models with participants in pursuit of better and more effective support relationships and more empowered citizens. The approach taken to this objective is to conduct participatory research separately with supported families and with support workers to understand their separate perspectives, concerns and needs, and then to identify common goals and bring both parties together in further participatory work to explore and design solutions that would improve the relationship effectiveness for all in pursuit of those common goals.

4.2 Preliminary Explorations of Family Civic Data: Families' and Support Workers' Perspectives

4.2.1 What is Family Civic Data?

As outlined in section 3.5.1, the first step in designing a study like this is to sensitise oneself as researcher to the study context. In this case, there were three things to familiarise myself with - the type of data being stored, the family perspective on the storage and use of that data, and the support workers' perspective on the same. Importantly, I needed to understand how families and support workers understood and talked about this data, so that I could represent and refer to it in ways that made sense to them. To do this, I

collaborated with colleagues in the SILVER project and at local authorities to see anonymised examples of what data was used by TAF/Early Help teams or mentioned by support workers as being of interest. I adopted the term *Family Civic Data* to refer to these types of data (further detailed in (Bowyer *et al.*, [2018](#))) and organised these into different groupings and categories to create a taxonomy. I then created a taxonomic model of these data types, as shown in table 3:

Table 3. Example Categories of Family Civic Data.

Category	Type of data	Examples/Details
Family	Personal details	Date of birth, address, telephone number.
	Relationships	Marital status, ex's, step-parents, living arrangements.
	Children	Parentage, adoption, fostering, childcare.
Education	School Records	Attendance (truancy), special needs.
	Academic Results	SATs, reports, exam failures, training courses.
Welfare	Social Support	Social worker visits & notes, details of family crises, interventions, allegations.
	Welfare Benefits	Jobseeker's Allowance, child support, Disability Living Allowance, tax credits
Money/Work	Family Finances	Salary, savings, credit cards, spending, debt
	Employment	Job history, periods of unemployment, performance at work, NI, PAYE, pensions.
Civil	Housing data	Council house provision, eligibility criteria.
	Legal documents	Birth/marriage/death certificates, citizenship/immigration status, work permits.
Crime	Criminal records	Arrests, cautions, offenders' registers, prison time, speeding tickets, spent convictions.
	Court orders	Restraining orders, lawsuits, custody, ASBOs.
	Domestic Violence	Allegations made, medical records, social/legal interventions, victim support.
Medical	GP records	GP's notes, prescriptions, tests, referrals.
	Hospital records	Operations, hospital stays, emergency care.

Category	Type of data	Examples/Details
	Medical conditions	Diagnoses, diseases, allergies, blood type.
	Mental health	PTSD, breakdowns, depression, sectioning.
	Addictions	Substance abuse, gambling, rehab, crime.
Leisure ²	Library Usage	Books/CDs borrowed, computer access.
	Sports & Health	Gym usage, class attendance.
	Shopping Habits	Loyalty cards, store & online purchases.
	Transport Data	Buses used, ANPR tracking, walking patterns.

Early research recruitment attempts revealed that data is seen as an abstract concept in people's daily lives; a dry, technical topic that many families feel unqualified to talk about. We needed to make these data concepts relatable. Drawing on the work of Brandt and Messeter (Brandt and Messeter, [2004](#)) in creating *design games*, which observes that game pieces can be used to create common ground and as “things-to-think-with” (Papert, [1980](#); Brandt and Messeter, [2004](#)), I created a set of data cards (shown in Figure 8 in the previous chapter), that would serve as a visual and tangible representation of Family Civic Data. By using these as boundary objects (Star, [2010](#); Bowker *et al.*, [2015](#)) the aim was to bring researcher and participants' worlds closer together and to approach the concepts of data by directly starting with individual life experiences. A Data Card was created for each category in Table 3, including a summary and meaningful examples, so that the cards would be easy to digest, yet still contain sufficient detail to stimulate thinking. Keeping child-friendliness in mind, bright colors were a key element of the design. The cards were printed on high-quality, thick card with a glossy finish using a business card printing service to make them appealing and fun.

These cards were then used as research stimuli (see 3.5.2) within a preliminary study in which I met with four families in their homes³ and conducted a variety of participatory design activities and design games in order to explore family attitudes to family civic data. This study has been published at CHI (Bowyer *et al.*, [2018](#)) where its full findings are detailed, and these findings serve as researcher sensitisation to inform the main Case Study One. We found that once families had understood data as “stored information about their lives” they were able to very effectively engage and talk about it. The use of the games and the cards was very successful, keeping a light and playful environment and making the topic relatable. The topics on the cards served as a focal point that allowed families to talk freely about their own lives and views without feeling personally interrogated, as they were dissociated from the participants' lives.

4.2.2 What is the Family Perspective on Their Civic Data and its Use?

The families we spoke to did care very much about what happened to their civic data, contrary to the expectations of some of our peers, and perceived a variety of risks due to data mishandling including identity fraud, criminal targeting and psychological harm. Families felt that data could easily misrepresent them through errors, prolonged storage of data beyond its need, or the recording of unfair judgements and opinions. Families wanted to view the data stored about them. They wanted a set of basic rights - to be informed, involved and accurately represented, with the ability to see, explain and correct their data to

ensure it is fair and accurate. They wanted to know that their data will be handled sensitively and only by those that need to know, and they believe that having these capabilities would help them to be able to work together with representatives of the state in a more positive relationship.

As well as the need for families to be given such rights, other implications we were able to draw from these findings were that family civic data is currently used as a proxy for them in decision making, which cuts families out of the loop, and that families should be given the opportunity to have a relationship with their data and also the opportunity to co-operate and have agency in the stewardship of their data. Further findings and insights are published in (Bowyer *et al.*, 2018).

Through my embedded involvement with the SILVER project (see 3.4.1.1) I was able to complement my understanding of the family perspective on civic data use in Early Help, but also was able to acquire an understanding and sensitisation to the staff/local authority perspective on that same data use. SILVER conducted qualitative interviews with supported families, and the findings from these reinforced this need for greater inclusion of families in data handling, having identified that while families were willing to consent to their information being shared in order to improve their care, they had very little understanding of how it was used and could not be deemed to have given informed consent to the way their data is currently used.

4.2.3 What is the Staff Perspective on Family Civic Data and its Use?

SILVER conducted a series of “Amy’s Page” (Wilson, Wilson and Martin (2020)) focus groups/workshops with support workers and other local authority representatives, through which I learned that staff had a desire for greater access to health information, particularly mental health indicators. These staff revealed a desire to gather as much data as possible about the families they were working with. The workers viewed the collection of data as a useful raw material that enabled them to do their job better.

Collectively the findings from my own research and from SILVER showed a conflict between the desires from families and support workers – with families wanting more involvement and less reduction to data but support workers wanting to amass more and better data. In part due to its solutionist framing, the SILVER project gave priority to the support worker perspective and continued to pursue the building of a richer data interface for support workers. This was the point at which my research objectives and those of the SILVER project diverged, as I was not ready to ‘take sides’ and wanted to explore whether it might be possible to satisfy the needs of both parties.

4.2.4 Seeking an Equitable and Mutually Beneficial Data Use Model: Shared Data Interaction

In searching for an approach to civic data use in Early Help that might help both families and support workers that could meet both parties’ needs while also addressing our research focus of increased data interaction within Early Help, I began to explore the idea of shared data interaction; instead of the support worker being the gatekeeper controlling and limiting the family’s access to data, and accessing data ‘behind the scenes’ at their offices, what if data could be looked at, examined, and updated together, during the face-to-face encounters between families and their support workers? This could potentially bring all the benefits of human-data interaction (increased agency, negotiability and legibility) (Mortier *et al.*, 2014) to families (and also to workers), while also serving as a boundary object that might improve the relationship itself (Bowker *et al.*, 2015). In theory it would allow families to gain some access to currently inaccessible data while also making it easier for support workers to ‘fill in the gaps’ in the data they already have by simply asking questions.

This concept formed the basis for the main research engagement within this study, so that we would not only exploring RQ1 and especially RQ2 in the context of current practice, but also ask participant to imagine a different set of practices that might potentially serve their needs better and in doing so, assess whether the proposed model of shared data interaction might address both groups’ needs and whether or not it would be perceived to benefit the early help support relationship as a whole. Regardless of whether this particular model was a preferred solution, such an exploration would put participants in a speculative, co-

design mindset that would elicit deeper insights about how civic data *should* be used, not just opinions on how it was used currently.

4.2.5 The Workshops

Table 4 - Case Study One Group Design Workshops.

Workshop	Engagement	Phase	Number of Participants	Activities
Workshop A	Design Workshop for Families	1	8 adults and 9 children from 5 supported families	<ul style="list-style-type: none"> - Data Card Sorting - Sentence Ranking - Ideation Grids - Poster Design - Scenario Discussion
Workshop B (2 instances)	Design Workshop for Staff	1	36 support workers & related staff	<ul style="list-style-type: none"> - Data Card Sorting - Sentence Ranking - Ideation Grids - Poster Design - Scenario Discussion - Interface Discussion
Workshop C	Combined Staff and Parents' Design Workshop	2	3 support workers and 4 parents from supported families	<ul style="list-style-type: none"> - Sentence Ranking - Storyboarding Practice - Scenario-based Storyboarding

During the summer of 2018, we conducted four two-hour co-design workshops, with two phases, as detailed in Table 4. In phase 1, the initial objective was reconfirm the findings of early work and gain a deeper understanding of both parties' (families and staff) perspectives on data within the support relationship, by working with each group separately. A further objective was to learn about existing data practices and whether they work, or need improving (and where they do, to identify what the issues were). In phase 2, the objective was to work collectively with representatives from both groups to design imagined data practices and interactions for the shared data interaction model and to understand how *in practice* staff and families would imagine themselves using data together in the support relationship. Across both phases, a variety of participatory methods were used to explore these topics, as described in section 3.5.2 and 3.5.3. All workshops were audio recorded and transcribed. These transcripts were then analysed thematically, and in some cases quantitatively, as described in section 3.5.5. Refer to section 4.3 below for the major themes discovered.

4.2.6 Sensitising Participants and Discovering Shared Values

Prior to the main exploratory activities, it was important to ensure that all participants arrived at a common understanding which they would use to approach their 'design brief'. Also, there was a need to validate whether prior findings about the perspectives of staff and families held true for these participants too. To address both of these goals, a sensitisation (see section 3.5.1) and data-gathering activity called 'Sentence Ranking' was conducted, where participants were asked to consider a number of 'opinion statements' and rank them according to (a) whether they agreed, disagreed or were neutral on that statement and (b) whether or not they felt that statement was important. These statements, such as "*Families should always be able to talk to someone about their data*" (more examples in Figure 21 below) were collated from family and staff perspectives observed during the above preliminary study, from the SILVER projects own research findings, and from my own observations through interacting with local authorities as part of my embedded role within the SILVER project. In discussing and reaching consensus on these opinions,

families and staff would be in effect 'agreeing requirements' that could inform their thinking during design activities. By conducting this same activity across all participant groups and across both phases, this would also allow comparison between the different groups to identify differences and find shared values.

Within each workshop, groups of participants sat at tables of 4 to 6 people, and each table provided its own sentence rankings. This produced numerical ranking data which was analysed as follows:

1. Sentence rankings were encoded on two scales. Sentences which contained a negative statement were inverted so that disagreement with them could be considered as agreement with a positive statement.
 - a. *Agreement*: neutral (0) -> agree (+1.0)
 - b. *Importance*: not important (0.0) -> important (+1.0)
2. Rankings from different groups within workshops were aggregated, using mean averaging, with a weighting to ensure each workshop contributes equally regardless of attendance.
3. This gave four values for each sentence, for each participant group (families only, staff only, and combined). *Variance* can be understood as 'unanimity of opinion': i.e. variance 0.0 indicates total agreement and 1.0 would indicate disagreement.
 - a. *Mean agreement*
 - b. *Variance of agreement*
 - c. *Mean importance*
 - d. *Variance of importance*.
4. Prioritising variance in agreement over variance of importance, the four dimensions were reduced to three to allow a visualisation to be produced.

The data table for this analysis is shown in [INSERT REFERENCE TO APPENDIX]. The visualisation of these findings on shared values is shown in Figure 21. As the figure shows, there was universal agreement that:

- families should be able discuss their data with someone from the authorities,
- public sector officials cannot make good judgements solely by looking at families' data,
- data cannot adequately represent a family,
- families should be treated as more than just what their database record says,
- information stored about them must be fair and accurate,
- families must have rights to see it and how it is used, and
- support workers really need to know mental health details of family members.

Participants felt it important to address that current consent practices were inadequate. There was also strong agreement that families did not want to be responsible for looking after their own data, though this was felt to be an unimportant matter.

Participants showed considerable contention over whether or not support workers should be able to access historical family records, about how families would feel about the collection of data about them and about having responsibility to managing access to it. Most other sentences received moderate agreement.

<p>AGREE & NOT IMPORTANT</p> <p>STRONG AGREEMENT</p> <p>"Families don't want to be responsible for looking after their data."</p>	<p>AGREE</p> <p>UNANIMOUS</p> <p>"Families should always be able to talk to someone from the authorities about their data."</p> <p>"Public sector officials can <u>not</u> make good judgements just by looking at families' data."</p> <p>MODERATE AGREEMENT</p> <p>"Support workers make better decisions if they have more data about a family."</p> <p>"Support workers should be able to see family medical records."</p> <p>"A family's data should not be joined up and looked at together."</p> <p>"Labels like 'domestic abuse' are damaging to families and hard to shake off."</p> <p>"Numerical scores are <u>not</u> a good way to compare the progress families have made."</p> <p>"Families will be willing to spend time checking their data is correct."</p>	<p>AGREE & IMPORTANT</p> <p>UNANIMOUS</p> <p>"Councils should treat families like people, not records in a database."</p> <p>"Families should have a right to see their data and how it is used"</p> <p>"Information stored about families must be fair and accurate."</p> <p>"Just looking at data doesn't tell you everything about a family."</p> <p>"It is important for support workers to know mental health details."</p> <p>STRONG AGREEMENT</p> <p>"Asking families for consent to share data just once at the start is <u>not</u> enough."</p> <p>MODERATE AGREEMENT</p> <p>"Families' data should be private unless they say it can be shared."</p>
<p>NOT IMPORTANT</p>	<p>CONTENTIOUS</p> <p>LOW AGREEMENT</p> <p>"Families find setting privacy preferences to be annoying and tedious."</p> <p>"Families won't mind lots of data being collected about them if they can see it."</p> <p>"Officials should be able to see historical records about families."</p>	<p>IMPORTANT</p>
<p>NEUTRAL & NOT IMPORTANT</p> <p>MODERATE AGREEMENT</p> <p>"The police should be able to see all of a family's data."</p>	<p>NEUTRAL</p> <p>MODERATE AGREEMENT</p> <p>"Any personal information from more than 5 years ago should be hidden from staff."</p>	<p>NEUTRAL & IMPORTANT</p>

[TODO: update the diagram to indicate (e.g. via a family symbol and a "support worker symbol" together with either a + or - sign and coloring in green/red) disagreement / agreement by the different stakeholder parties] [TODO: update the diagram so it doesn't look like rows 2 and 3 are in the wrong order]

Having completed the sentence ranking sensitisation activity, participants went on carry out the other co-design activities as detailed in Table 4. Findings from the analysis of these activities' transcripts is presented in the next section.

4.3 Thematic Findings

[Target 5,000 words]

4.3.1 Themes & Subthemes

[Target 500 words]

Within our four themes, the phenomena detailed above can be crystallised into 38 practices concerning ways in which early help services could or should use family data, which we understand from participants to be current, emerging or imagined. These are detailed in Table 4:

Table 4: Summary of identified current and envisioned data practices for Early Help services [TODO MAKE THIS INTO A TABLE AND ADD POWER QUOTES] [First, explain what the key themes are. Then for each, tell the reader what the theme and its subcomponents are and how they will be represented. This is the 'Tell' part. Then include a 'data structure' table - picking 'power quotes', the strongest quote for each subtheme. This is the 'Show' part.]

4.3.1.1 Giving a Voice to the Family

Review family data before contact. Treat people like family, not records.

Avoid judgements based solely on data. Record data visibly and get family sign-off. Explicitly involving families in processing their data.

Annotate own data with new information. Create or contribute own data. Regular reviews of data and consent with family. Workers and families checking data together (for accuracy). Make a 'feed' of family data changes available to both parties. Systems and processes support change. Families can initiate conversations about their data at any time. Enable families to manage access controls to their data. Families can get their data changed/corrected.

4.3.1.2 Earning Trust Through Data and Process Transparency

Explain how data will be used and shared. Respect family and individual privacy. Avoid data mishandling and unexpected uses. Use a strength-based approach when referencing families' data.

Ensure that consent is never assumed. Show and maintain deep understanding of families' lives, not just their data. Always seek a more complete picture.

Be as open as possible with families about their data. Independent oversight of data handling for contentious issues. Promote an open data-sharing culture.

4.3.1.3 Meaningful Data Interaction for Families

No existing

Actively inform families about their data. Make reference to data while talking to families. Make data summaries available to both parties. Use visualisations when presenting data to families. Address data at different levels (family, individual, community).

Use families' data together with them in a planning conversation. Proactively counter the knowledge imbalance. Make clear information available and support families in understanding it. Allow families to directly view their own current data. Provide individuals with personal data interface. Enable families to question data records. Single place for all family data access by all parties.

4.3.2 Theme 1: Meaningful Data Interaction for families

[Target 1,500 words] [Then (perhaps including saved back longer quotes that were too big for the table) explain each subtheme, similar to in past papers you've done, with reference to the table - what is this subtheme, why is it important, why did I include it, analyse what it shows. This is the 'Explain' part.]

Our next key finding is that families need meaningful interaction with their data. Most discussions focussed not upon the mechanics of data interaction (screen layout etc), but upon the wider sociotechnical system around the data, including the interpersonal interactions and whether or not the individuals were able to access their data in a meaningful way. This helped us to clarify that considerations around data interaction need to focus on capability and intra-party perspectives. Meaningful data interaction can be key to addressing knowledge imbalances between care provider and client. Our thematic analysis identified four ways in which data interaction can be meaningful – families must (1) be kept aware and informed, they must (2) have effective access to understandable information, not just raw data, they must (3) be involved in direct data use, and they must (4) be able to freely interact with data at a time that suits them. These ingredients of meaningful interaction are explained and evidenced in the following paragraphs: Currently, much of the data stored about families is invisible to them. "Families really only see the data that we want to present." [Worker, SQ37] Regardless of legal rights to request copies of data, our understanding is that this right is rarely used [SQ38], and typically only around filing complaints. This may be due to a lack of awareness of what data exists and who holds it [SQ39]. Lack of awareness can not only cause suspicion

[SQ17], but also incorrect assumptions that support workers 'already know everything'. The amassing of large volumes of historical data is expected, and families expect (though are not happy about it [FQ6]) that any aspect of their past life may be 'findable': "We go to them and say, 'We're aware that you've got these issues going on' [...] and not one family I've ever met has said, 'How on earth have you got that information?'" [Worker, SQ42]. Managing expectations can be problematic [SQ40] and some workers mentioned this as a reason why they should not be given greater data access, fearing greater liability to 'trawl through data' so that they know everything. In current practice, consent is seen as a one-off formality at the start of the support process. Workers could easily imagine explaining data in greater detail than they currently do [SQ41] and clearly there is a need for proactive action by workers to counter the inherent knowledge imbalance of data being collected into systems that they are gatekeepers for. However, workers lack control over the quality, coverage and timeliness of the family data and see this as a systemic issue they would not always be able to address. From our collaboration with multiple local authority early help services through the SILVER project (Connected Health Cities, 2017) it became clear that while support workers can see more data than most, they have far from the complete picture; in fact, there is no one organisation or individual with visibility of the entire family-information ecosystem. Following information on what data is stored about individuals, its form must be considered. It is not sufficient to simply open up public sector databases to allow individual record access, it needs to be understandable. There is a need for 'effective data use for everyone' (Gurstein, 2011) – not just the opportunity, but the technology, skills, formatting, interpretation and sensemaking to make the access effective. Some individuals may lack "proper access to a computer." [Parent, CQ9]. Data interfaces may not be helpful, and may need to be supported by visualisations and conversation: "Some families might not understand [a data viewing interface]. They might not be technical... I think sometimes it's easier to do it in pictures to discuss the data." [Worker, SQ43] Design suggestions and comments from participants indicate that pie charts, graphs, spider diagrams or timelines could particularly support understanding [SQ30, SQ3Q1]. Accessibility also arose as an important consideration. One group imagined an audio interface to allow visually impaired to understand their data [SQ45]. As a form of human support, verbal explanations should accompany data access [CQ11], with language and vocabulary adjusted to individual literacy [SQ46] or age [SQ47]: "No matter which [presentation of data we think is the best for a family data interface], you'd have verbal context for it as well, wouldn't you? You wouldn't just go, 'There's your app' or 'There's your piece of paper' and leave them. You'd just talk it through with them anyway." [Worker, SQ49] All participants agreed that 'Families should be able to talk to someone about their data' [S7]. Written summaries of information were independently considered to be critical for both parents [SQ44] and support workers [SQ40]. These could also be used as a mechanism to protect privacy, by keeping sensitive details hidden: "In that example, depression, ten year ago, that shouldn't be on there for the support worker. All they should get is if Social Services have been involved and it should just be, 'Please contact for more information.' [...] [The system should stop workers from] getting a list of all the kids who have ever missed dental appointments or when you were depressed ten years ago. [...] There needs to be a thing where it's, sort of, keywords [...] key trigger words, where if the word comes up a lot of times, it spots the patterns. Whereas, if [a problem] is mentioned once, it should only be at the highest level." [Parent, CQ10] Notably, it is not clear who could or should do the skilled knowledge work of creating accurate and representative summaries that are relevant to a particular purpose. In exploring shared data interaction we saw that directly using data together within a support conversation is seen as a key element of making data interaction meaningful for families. For support workers, the use of data can form "a way in" or conversation starter: "[Showing the data could be] an ice breaker [with] a new case. So, 'We've got this information; can you tell me more about it?' That opens it up, like a can of worms and it all just comes out; you know what I mean? Then you're able to have that open and honest conversation with them to see what level of support that they need." [Worker, SQ28] Participants particularly recognise the value of referencing data points over time (such as a record of welfare scores that support workers have previously given them), for example as a means to track progress: "You could have a table... you'd look at where they are and where they could be. [You could say] 'This is where you are now but if you do whatever, even though you've got a criminal record, you can progress to this level.'" [Worker, SQ29] This can have motivational reinforcement effects through clearly illustrating progress [SQ6] and relating behaviours to consequences [SQ32] – essentially facilitating data-

based decision making. Participants also noted how historical data review can be more tangible, making it easier to spot errors: “Whenever you go through stuff like that [verbally], especially historic stuff, they can be quite remote so [having the data in front of you] would be good for that.” [Worker, SQ33]. Linking these considerations to earlier ones on handing data to family members for accuracy checks [SQ34], others noted that this would require support by workers, not just to leaving families with their raw data [SQ49, CQ11]. The final aspect of meaningful interaction that we identified is that access must be timely. Currently any interaction with data can only occur within the support interaction, through the support workers as a gatekeeper, and therefore opportunities for data interaction are limited both in time and coverage. Family members would like to access data “in their own time, at their own pace” [Parent, CQ12]. This would be particularly important because it would allow families to reflect upon facts in a way they cannot currently do: “[If conflict occurs,] I [the worker] would need to go away and seek some advice on what can happen next, but it could be useful for the family, to spend that period of time, perhaps looking at all the information and identifying what it is that they feel they’re being judged on.” [Worker, CQ13] Access to data in their own time could also be very empowering, as families could then monitor themselves and track their own progress, enabling them to make plans outside of the support relationship, reducing dependency on support and making them more able to prepare for the future – which is a designated goal of the support engagement: “If we were working with a family about school attendance, could we then link that in to this app [that the family would have] so parents [would be] aware of what their attendance looks like at this point in time and they can manage it and they [could] monitor it themselves and take accountability.” [Worker, SQ49] Key to meaningful involvement is the ability to start a conversation. Groups imagined families being able to send a message [SQ51] or record audio to raise an issue for discussion: “If we had this audio thing going on, [families] could also access it and come back [in their own time], leave a message saying, ‘I don’t actually agree with that point. I’ve made a change.’ So [being able to be part of a dialogue about their data] is empowering them about what’s put on [their] information.” [Worker, SQ60] This theme of the family taking an empowered role in their information ecosystem is the focus of the next section.

4.3.3 Theme 2: Giving a Voice to the family

[Target 1,500 words] [Then (perhaps including saved back longer quotes that were too big for the table) explain each subtheme, similar to in past papers you’ve done, with reference to the table - what is this subtheme, why is it important, why did I include it, analyse what it shows. This is the ‘Explain’ part.]

The purpose of an early help intervention is to obtain more information for a better understanding of the family’s situation and to make evidence-based plans and decisions to improve the situation, so seeking objective truth is clearly central. Reading the data and talking to the family form two possible sources of information. We uncovered benefits and dangers of relying solely on either source, as the following findings illustrate. It is clear that families’ civic data can provide support workers with information that enhances their understanding; over 80 comments from workers support the idea that reviewing a family’s data prior to meeting that family in person (the current practice) is beneficial, because the information provides useful background that will help them identify support needs. For example [FQ1A] and:

“I had a family where trying to unpick what had happened, over ten years, to the child, was really difficult. So, I went away, got the information and came back and if you have [...] that picture of how the family works [when you meet them], [that helps].” [Worker, SQ1]

Additional benefits identified included safeguarding workers by identifying risks in advance [SQ3] or giving them an ability to ‘check the family’s claims’ so that they might constructively challenge individuals [SQ4]. Benefits to family members included ‘not having to repeat your story’ [SQ5]. One of the key things that support workers are in a unique position to do is to correlate data from different sources to spot patterns, as illustrated by this participant who imagined a data interface to support this: “[This imagined interface] would provide individual histories but you could also pull them all together so you can prepare, so for instance if mum was having some significant issues with mental health, you might be able to correlate the [child’s] school attendance alongside that and find out why that’s happening.” [Worker, SQ8] Both families and support workers were aware that the use of data can be problematic. Data is relative, and does not

represent absolute truth (Gitelman, 2013). In line with this and our prior findings (Bowyer et al., 2018), we are again reminded that data can be subjective, biased and misleading, as observed by parents [FQ11A] and by workers: A: [discussing a scenario] “For [this] family, the situation they’re in, information that’s there on their family, it’s just showing you how shit they are.” [...] B: “Yes, the way it’s being presented.” A: “It’s not showing them as good parents, it’s all negative.” [Workers, SQ59] There is a delicate balance with historical data: while it can provide essential understanding to a worker [FQ11B], historical information may no longer apply, and it could mislead the worker to a prejudiced viewpoint: “[There’s] this perception of something sticking with you even after you’ve potentially reformed. [...] That’s something that happened a long time ago and that judgement is still there but [you’d be wondering] ‘Okay, is it [true]?’” [Worker, SQ61] This is especially true where labels are used; many agreed, and no-one disagreed, with the sentence “Labels like ‘domestic abuse’ are damaging to families and hard to shake off” [SQ62], and participants discussing this thought of examples where labels could be misleading [SQ9]. There was agreement among participants that ‘relevant’ information needs to be available, but this is a highly subjective judgement. Some participants suggested a cut-off period before which workers should have no right to look [CQ15]. Incomplete data can mislead. For example, a lack of mental health information could make an individual look like a poor parent [SQ12]. Families may be less willing to ‘open up’ if they feel they may be judged unfairly [SQ14]. Therefore, developing a strong relationship between worker and all family members is key to understanding the full picture [FQ1]; to ensure fairness, data must be current and complete [SQ13], but this state can only be achieved with the family’s cooperation. Looking at data will never provide support workers with a complete understanding. Yet, workers often ‘tend to just trust that everything that has been put down is right’ [CQ1], allowing the data perspective to dominate. Such assumptions should be avoided [SQ10]; processes must recognise maintaining human face-to-face dialogue as a priority. Data should only provide only supplementary insight: “You should never make a judgement on data... that data could be wrong. It takes individuality, working with that person as well, doesn’t it?” [SQ11]. All participants presented with the sentence “Public sector officials can make good decisions just by looking at a family’s data” disagreed with it. One reason for reviewing historical data and for requiring dialogue with the family to gain an up-to-date picture, is that the truth changes over time. People are not static, and families’ lives are always changing given marriages, divorce, birth, death, house moves, etc... Inaction will cause data to become out-of-date, as it is inherently static – data does not change, but people do [SQ61, SQ63]. Accordingly, it is not just the content of the data, but the family’s consent over what happens to that data that needs to be reviewed regularly: A: “If [consent] has to be all or nothing I can’t see that is ever going to work [...] most people will have something they don’t want anyone else to know.” B: “So, you might agree [to data sharing] as a family now but after a break-up, what happens?” A: “Yes, or the kids reach a certain age and they might say, ‘Hang on a minute, I don’t want you looking at all my medical records.’” [Worker & Researcher, CQ16] This is important to prevent unwelcome surprises about how family data is handled [CQ2, CQ17], which can damage trust and hinder co-operation. It is clear that the support worker must always be seeking to form a complete and more up-to-date picture of the family. Several participants imagined ways how technology could support this, with the databases issuing notifications or update feeds for families and support workers showing significant events or data updates. Support workers currently get notified of police incidents, safeguarding concerns and hospital admissions, but including data across the care ecosystem could provide useful triggers for reviews or discussions [SQ64, SQ65]. Many participants envisaged that rather than solely relying on dialogue with families, families might provide new data more directly, e.g. through a ‘family network app’ for information contributions, which could also increase their sense of data ownership: “It would [ask them] who they could name outside of their family to create a network. [...] But it would collect more than that, [...] it would allow the family to be accountable for their data collection and making sure that it’s accurate [...] because we often go away and record it all on [our existing database] and it’s our story rather than their story of how the events occurred.” [Worker, SQ36] Some participants noted that families are better placed than anyone else to identify inaccuracies or gaps in their civic data, and that more accurate data could be obtained through families providing corrections. This does not mean free editing of records (as, for example, fears and/or self-interest could lead to families misrepresenting themselves in data (Bowyer et al., 2018)) but rather taking a role in reviewing, annotating, explaining, filling gaps [SQ57, SQ58] or requesting changes. This was imagined as a collaboration between

workers and family members: “[There would be an] individual view where each person within the family would have their own section [...] you could sit with them [...] and go through the data that we have got which would enable them to change anything that they want taken out.” [Worker, SQ66] With new ways for self-expression, families could add context for support workers [FQ9, SQ55], unlocking new support topics [SQ56]. Another option arose at the intersection of relying on dialogue and having families contribute data, suggesting workers visibly recording data in front of families on a tablet or 2-in-1 digital device and then asking them to ‘approve’ the accuracy [FQ12, SQ67]. Participants believed this would help to build trust between the support workers and families. The overriding sense from both groups is that families having the ability to annotate or explain their data would allow them to hold authorities to account, and empower them to tell their story and ‘show the real me’: A: “If you read information or anything about me, you wouldn’t expect to meet the person you meet.” B: “That’s it. It’s the same for everybody.” A: [...] “it just [has] basic things in most of the time, doesn’t it, especially Social Services and stuff like that. You’re not a person [in the data record] are you really?” [...] B: “[I’d like it if you could] give your bit of personal data, your own story.” A: “Yes, because everybody makes mistakes and there’s probably thousands of people out there who have got a criminal record and have never done anything since. So how come they’re getting judged by having one thing whereas if you [could write]” Yes, I did this because of this situation but this is what I’ve done to make myself [better]...” [Parents, FQ10]

8.2.4. Empowering the Family The above findings indicate that an ongoing involvement of family members and support workers in data-based discussions can be beneficial – decisions can be of a better quality if they are based in data, and the family’s involvement can be empowering for them while also improving accuracy and ensuring ongoing consent. Our fourth theme expands on this stipulating that rather than viewing families as a source of data, data interaction provides an opportunity to give families a more direct role in their relations with state and society. Accordingly, families should be empowered as agents in the data ecosystem; i.e. they should be given the ability to act with independence within the system.

If a family begins to feel powerless, they may disengage [SQ35]. Even minor involvement, such as signing off approval of data records [FQ12], can make the support relationship more productive. When considering their relationship to their civic data, families (and support workers) imagined the family being able to act alone. This unlocked additional thinking, for example families helping to fill gaps in data [SQ57] or contribute new data that may not otherwise be recorded [SQ58]. Giving families the ability to contribute new data could be very empowering as it would allow them to ‘tell their own story’ [FQ10]. This is vital because, not only because families’ civic data will never be enough to adequately represent complex lived experience (Bowyer et al., 2018) and it is important to ensure the data is accurate: If something goes wrong, families must be able to do something about it. Without a cycle of feedback involving individuals as stakeholders having the ability to review and correct data, data will quickly become inaccurate (Pollock, 2011). A role in data reviewing, production and recording is empowering, as families are then able to hold information holders to account to ensure fair treatment, something that is currently very difficult to achieve. “I think that [families] have got a right to know what is held about them and what is said about them.” [Worker, SQ50] “I just generally want to see [what is stored about me] just to know what people are saying and then obviously if it’s wrong, I can correct them on it.” [Parent, CQ14] Some ideas and opinions expressed by both groups shared a common element of the individual taking power for themselves through data-related actions. Designs included apps, intranet terminals, online chat facilities, and self-service webpages, all sharing the ability for individuals to act and take the initiative to look at, or query, their own data: A: “Right, our first [idea] is the lovely [child’s name] has made an app. [It’s] free to download, you can make your own password and there’s going to be a button on it so you can press it and then query the information that’s held on you straight away.” [Parent & Child, FQ7] One participant pointed out that families may wish to use their civic data for their own ends, for purposes that have not previously been considered, such as sharing data with others): “[if family members had their own app] they could quickly tap on to the app and see what progress [they’d made] or show somebody else where they’re at.” [Worker, SQ54] Participants identified that it is important to consider that different individuals within the family would have different roles, access and summaries, in order to respect individual privacy [SQ52, SQ48]. This could extend beyond just giving consent to managing more fine-grained access controls: A: “When a child turns 16, when they go to the

doctors, is that confidential between me and my GP or can my parents see that?" B: "I think it's confidential." A: "Exactly. So in this interface, I [would be] able to see that – [as the] 16 year old - you as my support worker could also, but not my mother." [Workers, SQ53] "[I'm imagining an] online database of personal family info accessible [only] by people, practitioners that have permission [...] I would say that it's only who you want [to give access to, that can see it]. You would have your private code which you could hand out, like the doctors give you appointments." [Parent, FQ8] We can see that giving families a role in the creation and stewardship of their data-selves has great potential to unlock new capabilities and a sense of empowerment for families.

4.3.4 Theme 3: Earning Trust through Data and Process Transparency

[Target 1,500 words] [Then (perhaps including saved back longer quotes that were too big for the table) explain each subtheme, similar to in past papers you've done, with reference to the table - what is this subtheme, why is it important, why did I include it, analyse what it shows. This is the 'Explain' part.]

COUPLE OF REFS THAT COULD BE ADDED ARE AT https://miro.com/app/board/o9J_kvbFr24=?moveToWidget=3074457347460447992&cot=13

The findings above clearly suggest that in seeking best possible understanding, families must be engaged in a fact-centric way, which requires trust in the support worker and in the system - A good relationship with the support worker is critical [FQ1]. Our findings show that transparent and open data handling and decision-making processing are key and can allow support workers to earn the trust of supported families. The key topic of trust arose directly or indirectly in almost all participant conversations. Currently, families are typically unaware of what data is held about them and what discussions about them are being had. Even if the data itself would be considered uncontroversial, this lack of transparency and how data informs judgements can cause great worry to families: A: "Some people that I've worked with, I think as soon as they know you're holding information about them they get really tight and [say], "What are you holding about me? [...] They don't like people knowing what's going on in their lives." [Worker, SQ70] Lack of transparency and trust can lead to an atmosphere of suspicion [SQ17] where families have 'a totally overwhelming feeling of people checking up on them' [SQ71] and apply greater scrutiny to what they are told: "You can get families who [...] don't believe what's being said about them." [Worker, SQ73]. Fearful of consequences [SQ72], families may withhold information: "Well my thing would be who is [my data] going to be shared with? Which authorities? What is going to be shared? [...] If I ask for help because my son has got massive behavioural issues and I've been trying for years to get help with him and [...] if I go to social services, are they going to come in and think I can't cope because I'm on my own with five kids? Are they going to take all the kids away? That's my thing. So I'm terrified of Social Services, I really am." (Parent, FQ14) To avoid damaging negative spirals of emotion, deliberate openness is needed from support workers (and the entire care system) [SQ18] as to what information is held, and how it will be used and shared, in order to alleviate fears of data being used against families, instead giving them confidence that their interests are being protected, thus putting them at ease [SQ20]. To our understanding, this is only done once in very loose terms during initial engagement for the purposes of collecting informed consent. Families imagined going beyond verbal explanations and being able to visibly review records that their support workers were creating and signing them off [FQ3]. Demonstrating a deep understanding of the family, and that they are prioritising a family's lived reality above what the database says can be a key principle for workers to build trust: "You don't want to reduce them to this number in a database. You want to understand their actual experiences and support them in getting better." [Worker, SQ74]. It is important that families understand workers' good intentions when accessing data about them [FQ15]. However, having to show all the data to families could make it challenging to make that case convincingly, "because literally [the data we have] is like everything, isn't it? So I don't know how I would feel..." [Worker, SQ21]. In addition to avoiding breaches of expectations [see 8.2.1 above (CQ2)], a transparent approach ensures that the privacy of families is respected, because data is not viewed without the chance for explanation: A: "I don't want everybody knowing how rubbish I am with money." B: That's my life. [Parent & Child, FQ2] The current approach, which relies on the support workers mentioning data that they consider relevant, can result in expectations being broken by accidental sharing of information for which sensitivity is not recognised: "That

tends to be the biggest problem with this, these little bits of information that nobody ever thinks are relevant to bring up in everyday conversation and they're coming out." [Parent, CQ3] Ultimately an open and respectful approach is not just rooted in decency but in practicality as a co-operative family is easier to support: "Because if someone is feeling judged or stressed or angry or whatever, then they can stop the conversation" [Parent, CQ5]. It can also help with accountability and accuracy: "There was a time where I was at the doctors' and they asked how many units of alcohol I drank, and I said, probably about three bottles a week, at the time, not any more but later on [the support worker] pulled me up on it and they had it down as three bottles a day. That could have caused an issue was anyone ever to ask." [Parent, CQ7] A common phrase that emerged here and in our prior research (Bowyer et al., 2018) is that data should only be seen by those that "need to know." Without transparency of data handling, a family cannot verify whether this is happening. This is especially important given that some support workers expressed a belief that their right to access families' data could overrule families' consent: "I think to enable us to work with families, we need to have as much information to give them the best possible service. So, I think we should be able to [access their information] regardless of what families say." [Workers, SQ22] We also found evidence of other reasons why accountability is important such as the difficulty of deciding what parts of a medical history are 'relevant' [SQ23], arbitrating situations where legal duties may require the breaking of consent [SQ24], and being able to identify and address situations where recorded information may not tell the full story [CQ8]. Participants also indicated that the desired transparency is not just about reporting data usage. Dialogue and engagement is needed. Support processes need to change to better recognise the role of dialogue, rather than just consultation of a database, as the best way to achieve a rich and nuanced understanding. Some participants suggested that openness to increase trust could go as far as browsing new information together rather than just having the support worker get it first and report its content: A: "[if the worker knew sensitive medical information] the family would be really annoyed, they would just want you [the worker] to go. B: "I'm the same, me. I'd be like 'I don't know how you got all this?'. That would be my first reaction but then if we [were to] discuss it and browse the information with the family [that would work better]." [Parent & Worker, CQ6] We see evidence that transparency and openness are key to building trust around data access and decision-making as requirements for a healthy support relationship. Shared data interaction could be one way to achieve this, bringing benefits in accountability, accuracy, simplicity [SQ25, SQ26] and consent.

4.4 Discussion

[Target 3,000 words or maybe more?] [Then comes the 'Interpret' part. Where you assess how these things matter, do they confirm or disconfirm theory, relating it back to the literature. This part heavily references theory from your lit review. Frames the themes/subthemes as knowledge contributions.]

4.4.1 The Value of Involving People With Their Data

THIS IS PROBABLY OK AS IS – ALL TO REVIEW/CONFIRM OK? SOME REFS THAT COULD BE ADDED ARE AT https://miro.com/app/board/o9J_kvbFr24=/?moveToWidget=3074457347460357355&cot=13

Through our analysis of attitudes to data usage in the UK early help context we have shown that data about supported individuals and their families is already providing great value to building up a more complete picture of a family's life, in service of better support and decision-making. However, this comes at a cost to the family's autonomy and we have identified a number of problems with the prevalent mindset in the care system – which is that families' civic data is considered as a resource to be utilised. Such a mindset (sometimes known as 'dataism') carries an implicit assumption that data is an objective source of truth, however this would require trust in the independence and integrity of the data-collecting and data-holding institutions (van Dijck, 2014), which we have shown is often absent. Supported families lack awareness of what data is held about them and how it is used: this can lead to false expectations and surprises and in the worst cases, this can feed feelings of fear or suspicion which can harm the effectiveness of the overall care relationship. Stored data can often serve as a proxy for their involvement (Bowyer et al., 2018), and without

any involvement of the family in checking data accuracy, the current system is susceptible to inaccuracies and errors of judgement due to out-of-date, incorrect or missing data, which can directly affect supported families in the form of prejudice, discrimination, or privacy violations. A key finding we have uncovered is that trust is critical to a support relationship – trust in the support worker, and trust in the system as a whole, and that the current usage of families' data is not conducive to trust. The best way for a support worker to build trust with a family is to show that they have, and are continually striving to develop, an ongoing and deep understanding of the family as individuals, whose perspective is more important than 'what the computer says'. The more they are treated as people, not 'objects to be administered' (Cornford et al., 2013), and the greater awareness and access they have to data records and data handling and decision-making processes, the greater the trust they can have in the system and the more effective the relationship will be. Shared data interaction practices such as checking data together, visible data recording, family sign-off, or contribution of their own perspectives as data, give the family direct evidence that they are being listened to and that their viewpoint is important even when it contradicts the digital record, and this would be very powerful in building trust. Furthermore, transparency of processing allows accountability – something that is currently all but impossible, and this would further empower families by allowing them to gain confidence that they are being treated fairly and that data about them is accurate. It is evident from our findings that a trustworthy care system requires the direct involvement of the individual(s) being cared for and that the mechanisms of shared data interaction offer specific shapes in which that involvement could take place. Consistent with field studies such as the World Health Organisation's decision-making tool (Johnson et al., 2010), we found evidence that staff and supported families believe they would be able to collaborate more efficiently through shared data interaction as it would be more evidence-based (see 8.2.3 above). This has the potential to remove inefficiencies such as spending time correcting misunderstandings or repairing damaged relations caused by misjudgement, and the emergent practices of using data to track progress are already proving to be an effective and tangible way for families to improve their situation; giving them the ability to track this data outside of the support engagement would empower them even more to be self-sufficient. A digital health innovation project in South Africa echoes our findings on the importance of trust, agency and involvement of the individual: "The user must feel or experience trust, have to change behaviour, feel that they can control and increase their own access to a system. Their uptake and use are essential for such a [digital ecosystem] to work or to be regarded as a sustainable solution." (Herselman et al., 2016) Viewing data as a shared resource to be curated together would also solve the problem that the current system is in effect lacking a true consent mechanism, since the initial consent is in practice, a handover of power that gives the care authority carte blanche to collect and use data about the individuals (see 8.2.2). In effect, the ongoing access to and direct use of data by families (see 8.2.3) would serve as a practical implementation of a 'dynamic consent' model (Kaye et al., 2015; Williams et al., 2015). Instead of consent being seen as the acquisition of a formal permission that has to be certified, stored, reviewed and modified, adopting simple practices such as talking families through their data and carrying out regular checks together could provide a practical but less bureaucratic guarantee that families are on-board with the way their data is being used, since their ongoing awareness and absence of complaint can be taken as satisfaction. If implemented in a robust manner, this approach has the potential to greatly simplify the consent challenge for authorities, requiring less process and reducing liability. Families will be happier with the use of their data if they can see it, notice and speak up when they feel something is amiss. Additionally the sharing of responsibility for data stewardship between both parties can reduce the liability for support workers; some were fearful of missing something important when given access to large amounts of families' data – in this model where conversations are more focussed upon data, relevant information can be identified more quickly while at the same time mistakes can be spotted sooner. With families involved in checking and shaping their own data, that data can become more reliable and accurate, which goes some way to addressing the problems described by Cornford et al. of the state forcing families to be represented through data models that are not up to the task of representing the complexity of their lives (Cornford et al., 2013). This need to give the user a role in understanding and influencing the life of their own data is identified as a key ingredient of moving towards a more progressive model of digital citizenship. In 2016, Bridle explained: "If, instead of disempowering users in the name of simplicity and ease of use, we acted to empower them and ourselves through increased literacy in the

technologies employed, and constructed systems where data about behaviour can be more easily quantified and controlled by the user, then we would have the tools at our disposal for a more equitable negotiation with commercial and governmental forms of power.”(Bridle, 2016) Perhaps the greatest benefit to the care organisation of shared data interaction approaches would be the inclusion of supported families to a much greater degree as a stakeholder in their ‘case’. Instead of the care worker using their authority to pass judgement and deliver advice, the care worker becomes an ally, with the family member(s) empowered as an agent in their own self-care, with a greater ability to take action and drive things forward than they had previously (see 8.2.4.). Supported families would be able to trust that their interests are being looked out for and that through their ability to contribute to and access their ‘data self’, to take part in informed decisions that could improve their lives, and to use their data in new ways to serve their own ends.

4.4.2 Effective Data Access Requires Human Interaction

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Our findings reveal that the current inequality over families’ civic data will not be solved simply by opening up databases to families and giving them access. They must be able to meaningfully comprehend the data and meaningful effect change based on what they learn from it. This involves the translation of raw data into meaningful information – through summaries, visualisations and explanations (the challenge of who can or would create these information representations is an area for future study). The information available to the individuals must be – as described in one of the central tenets of Human-Data Interaction – legible (Mortier et al., 2014) but also their access must be effective (Gurstein, 2011). This includes providing suitable opportunities for access – not just within the support meetings, for example – and addressing technology, literacy, mental or physical handicaps and means that the information should be supported by a human relationship – one where someone can both explain the data as well as answer questions about it (see 8.2.3). It is the combination of effective data access and human-to-human interaction that makes data access meaningful, and the former without the latter will not empower the individual concerned. Access to data must be supported by a conversation. The system needs to have a human face that the individual may put their trust in and to which they can address their questions; simply giving access to raw data would be inadequate (see 8.2.3), and limiting (Cornford et al., 2013). As a sub-field of Human-Computer Interaction, it is easy to assume that HDI is simply about interaction in the traditional sense of users interacting with data through an interface, but our work, which has, guided by our participants, focussed less upon layout and screen interaction and more upon the wider sociotechnical context of the support relationship, suggests that HDI can be more effective sought when the word ‘interaction’ is considered in an interpersonal sense. By focussing on the human aspect of the proposed use of data within the support relationship, we can see that as well as improving accuracy, consent and trust, shared data interaction can bring practical benefits by facilitating a better interpersonal interaction. By physically bringing data into the interaction – be it a printout of a table or graph, or a tablet or 2-in-1 device – rather than just reporting it verbally, this representation serves as a focal point for discussion, bringing both parties to the same topic space faster and more efficiently than abstract discussion would. The data records here function as a boundary object (Bowker et al., 2015; Star, 2010, 1989) – the families understand it because it relates to their life, and the support workers understand it because they are familiar with the systems it came from. As such, it can become a valuable tool for encouraging families to open up. Many of our participants talked about how looking at data would provide a discussion stimulus or serve as a conversation starter (see 8.2.1). Also, it provides support workers an opportunity to be less adversarial, by positioning themselves as equals looking at the data together (‘let’s make sure this data is right’) rather than appearing as if they side with the data by being the ones who voice it (‘Our records say that you have....’). The effectiveness of having data representations as “things to think with” that can establish common ground is discussed in our prior work (Bowyer et al., 2018) and is also echoed in the methods in this study. In particular in our third workshop, which brought support workers and supported family members together, used storyboarding action cards in specific fictional scenarios. These cards provided a focal point for discussions and helped the participants to quickly imagine a realistic situation, again serving as boundary objects. The yellow (for families) and blue

(for staff) borders on the cards helped ensure that both parties owned a piece of the puzzle: We had given no direction about who would place which cards, but we observed parents feeling confident to place yellow cards and support workers keen to place blue cards, because the card helped them identify with the corresponding role in the scenario and feel ownership over the choice of options that would be available to them. Similarly, the green bordered cards (which corresponded to those actions involve both parties) almost always resulted in both parties discussing and agreeing a view before the card was placed. If we relate this to an imagined discussion of actual data records, we can envisage that the presentation of the data as being “yours” or “ours” would have a noticeable effect upon how the families would engage with it, and the strength with which they would perceive the power of the data holder over them. Having access to the data within the context of the support relationship is a key enabler of the Human-Data Interaction properties of agency and negotiability (Mortier et al., 2014) for the family members; an ability to interact with and correct or comment on the data directly would give them some agency that do not currently have, but if there is no ability for their comments or corrections to the data to actually influence the support discussion and the work being done, then they have no negotiability - their data access is not really part of the system, it would be tangential to the actual support process. Therefore, efforts to deliver effective HDI capabilities in future should focus on interpersonal interaction, and the role of the human in the information system, as a data interface is limited by its operational context as to its ability to truly empower a data subject (indeed, even the term ‘data subject’ which persists even in progressive data paradigms such as the EU’s General Data Protection Regulations (European Parliament, 2016) embodies the prevalent problematic stance, evoking as it does imagery of a medieval king looking down upon his subservients). As our participants all strongly agreed, supported families ‘should be treated like people, not database records.’ (see S4 and Table 3, in section 8.1). This framing can inadvertently become problematic in early help practice focusing upon child welfare: “children [can be seen as] the objects of a variety of concerns which need to be acted upon rather than agents of their own lives”(European Commission, 2014). Analysis of the Child Index, an early warning electronic information for child welfare in the Netherlands, drew a similar conclusion on the importance of maintaining a compassionate human aspect in family-state relations: “Taking into account that [care] professionals’ first love is the best interest of and care for a child, it is recommended for policymakers to provide enough room for the ‘love’ between future technologies and their social actors to flourish.” (Lecluijze et al., 2015)

4.4.3 The Benefits and Implications of shifting the Locus of Decision-making

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Through our discussions and activities with support workers and supported families, we have explored the possibilities of shared data interaction and our concept of shifting the locus of decision-making – the idea that power concentrates close to the point where data is accessed, and that by shifting the point where data is access to the centre of the support interaction, this would necessarily shift decision-making closer to the individuals and thus swing the power balance in their favour (see section 7.2 above for a full explanation and refer to Figure 1 for an illustration of the concept). In this section we examine the potential benefits and implications of such a shift. The introduction of data interaction into the interpersonal interaction of the support relationship can be seen as a change to the nature of the support relationship, in that some of the work that was previously done solely in the domain of the data holder (specifically, data maintenance and the direct use of data to inform judgements and plans) is now taking place in a different context – the two-party context of the support engagement itself. So at a basic level, the power is shifted by the new approach. The use of data in current practice is limited because any data must flow through the support worker as gatekeeper – the removal of the gatekeeper role redistributes the power to interpret, select and judge data much more equitably between the two parties. The potential benefits of this shift in terms of empowering families are significant. As detailed above it would give them a role to play as agents in the life of their data, and a new ability to create and curate their own ‘data self’ – the representation of them that is seen by the state – so that it is as fair, accurate and representative as possible. But more than that, given the increased visibility of the metrics by which their progress is judged, they are now empowered to take

steps to influence any poorer metrics by making improvements in their own life that would result in those metrics improving visibly, which then could then use as evidence to prove their achievements – a positive feedback cycle that was previously inaccessible. By shifting the locus of decision-making, families can take more responsibility for their own lives, through an increased ability to reflect and make plans – an important element of harnessing one’s personal data for self-improvement (Abiteboul et al., 2015; Li et al., 2010), thus ‘encouraging the family to take full accountability for their own responsibilities’ as one support worker put it [SQ75]. The perceived benefit of individuals directly using digital interfaces for health and wellbeing are already accepted, with 93% of doctors believing that apps can improve health outcomes (Kostkova, 2015). The above are benefits to the supported individual, which of course can be seen as benefits to the care provider as well, given that the function of the early help service is to help the supported family improve their situation as effectively as possible. But shifting the locus of decision making also carries practical benefits for the care provider too. If the family are involved in the stewardship of their data, this reduces the burden and responsibility upon the authority to look after that data – instead, the responsibility for ensuring completeness, accuracy and fairness is now a shared responsibility. And if responsibility is shared, this must surely also reduce the likelihood of complaints or litigation, because it can transform the way that families think of the care provider away from ‘us and them’ thinking towards a more equitable stance. An additional advantage of a cooperative approach to data stewardship is that the consent problem is solved; the scope for non-consent is reduced because at every single meeting (and perhaps even outside those meetings if individual personal data interfaces are available) the supported families are involved in a conversation that directly enables them to voice their approval or concerns for the ways their data is being used. However, implementing such a change to the system would not be without its challenges. There would be significant costs: New equipment such as tablets or 2-in-1 devices might need to be purchased if support workers do not already have these. New software interfaces would need to be commissioned, developed and purchased. The existing configuration of IT systems in the public sector (see section 6) is not well suited to the creation of such unified data interfaces due to its fragmented nature (Copeland, 2015). Identity management in this context is already very challenging to negotiate (Wilson et al., 2011). Support workers would need additional training both on software and hardware. The need to increase digital skills across health and social care has already been identified as a current issue in the UK (Honeyman et al., 2016) and in other countries such as Poland where it is deemed critical (Soja, 2015). This will become particularly important in a system where the care workers are also the ones who would be helping individuals to make sense of digital information. The use of computer-based communication and information approaches would need particular care with child welfare (Tregeagle and Darcy, 2008). Local authority business processes would need significant overhauls to recognise the individual members of the public as an important part of the system – which would likely carry with it new considerations for system access controls, technical support and public liability insurance. In particular the provision of personal data interfaces to the public, and new communication channels for public enquiry, would carry with it a large human resource burden to manage and support those channels and usages. While the creation of a direct communication channel between supported individuals and support services does on the face of it have the potential to carry some savings for the state in terms of reducing the amount of “in-the-home” contact necessary – which is particularly challenging and costly to deliver in rural areas far from major towns (Kriisk and Minas, 2017) – the idea of the data access being supported by human contact, and of making more decisions together, may ultimately require a greater investment of manpower in communicating with supported families. Measures would have to be put in place for when things go wrong: dispute resolution procedures and additional legal and information governance support would be likely to be needed. It is also possible that giving more power to families could create new challenges: it is not impossible that particular individuals, for whatever motivation, might try to be destructive, manipulative or otherwise challenging to the system, and they might try and use their new powers against the state (for example, hiding criminal activity, misleading workers etc. for personal gain). While very unlikely to be a mainstream issue, this is a fringe possibility that must still be considered and planned for. It would be fair to criticise this model of human-centred state interaction in that it would be not be cheap or scalable; in essence this model creates mechanisms for families to have more interactions with the state, which means that every case would take more worker time in a system that is already overburdened and underfunded (Copeland, 2015)[ADD REF

Local Government Association]. The state has increasingly adopted a data-centric approach to citizen interaction because it cannot manage to provide human relationships with individual citizens. But now this approach has become ingrained into government approaches to citizen relations – “it is no longer a technological necessity but it has become a political intention” (Bridle, 2016). What we have identified is that there is a need to reverse this trend, if people’s interests are to be best served, and if a welfare state is to be truly ‘enabling’ (Miettinen, 2013). By taking a more innovative approach to digital policy, it is possible that governments could be more effective in helping to involve those citizens that have become disadvantaged by the current system – a more human-centred approach could help to combat the digital divide (Kalvet and Tan, 2008; Steyaert and Gould, 2009). In our model that shifts the locus of decision-making, we have not sought to provide an implementable solution that could be rolled out at scale, rather we consider our model to be a useful mental model to stimulate further discussion - our contribution’s value is that it shines a light on the positive and negative impacts of current procedures on relationship effectiveness, and identifies imagined practices that could be preferable and more efficient than current practice. Our findings serve as a challenge to the status quo, that should encourage early help providers to question their priorities when it comes to the use of people’s civic data and when they consider reconfiguring their services.

4.5 Summation

[Target 1,500 words or maybe less?] [Finally after the TSEI structure for each theme, there is a combination/conclusion part of the chapter, bringing the three themes together.] [In 4.5, I will summarise the case study in terms of how these insights expand our understanding of the research questions and their wider significance.]

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Through our participatory co-design workshops with supported families and support workers in North-East England, we have highlighted five major problem areas which our participants perceive to exist with current personal data practices: 1. A power imbalance – Families’ personal civic data is collected by care organisations and viewed as a resource to be utilised by the support workers, creating a structural power imbalance against families which is further emphasised by the authority, influence and network centrality of the support service with each family’s data landscape. 2. A closed and opaque data ecosystem – Families lack awareness of what data is held about them and how it is used, with support workers (who themselves have limits to their access) functioning as gatekeepers to what families will be told about. 3. Ineffective, meaningless consent – The current consent model, while legally satisfactory, is ineffective, as it is viewed as a one-time initial hurdle after which support workers can do whatever they deem necessary with families’ data and those families are never again given any meaningful choices about what happens to their data. 4. No accountability and limited trust – Without any transparency or ability to request or demand changes to data or data practices, families have no ability to hold data handlers to account. The lack of visibility makes families’ trust in the system hard to earn and fragile to maintain. 5. A lack of agency or true empowerment – With families having no ability to shape the way they are represented in data or see themselves in data, opportunities are missed to truly empower families to be better represented and to better themselves. Through our explorations of a shared data interaction and personal data interfaces, we have found both a need and a desire for a new approach. We have shown that a model in which support services are deliberately open with families’ data and bring it to the heart of their face-to-face consultations could address all five of these problems. The removal of the gatekeeper role would shift the power balance towards the family as it would give them a role in the stewardship of their own data. Providing families with a transparent view of stored data, and with clear visibility of data recording and usage, would enable accountability, which has previously been absent, which in turn can help to improve trust. With the family involved at every stage and able to see their data at any time, the consent problem would be largely solved – because families would be able to immediately speak up at any point should their wishes change in the light of new developments or new information. With the family becoming truly involved in data-informed support conversations that can make better decisions, and being more able to influence the way they are

represented, they would be more empowered to make changes in their own lives and could achieve a previously unattainable level of agency. We have also uncovered additional benefits of a shared data interaction approach. Data visualisations and summaries could be very effective as conversation starters and as boundary objects, potentially leading to more effective conversations. The ability to reference specific data points over time can provide an objective measure against which to track progress – whose primary value is not to the support organisations (where they are used to measure service effectiveness) but in fact to the families themselves, who are now able to directly see the effects of their own actions in their data. The shift from support workers reporting what the data says to ‘looking at data together’ helps to shift the dynamic of the support interaction away from ‘us and them’ thinking towards a more collaborative approach and would be less adversarial. The inclusion of individuals in the stewardship of their own data would lead to more accurate data, because in reality the truth lies somewhere between what the data says and the family’s own perspective, and can only emerge through dialogue. Individual family members will be able to notice mistakes or gaps, and contribute explanations, context or additional data to enrich the picture. By ensuring the discussions are based on more accurate data, the quality of decision-making would naturally improve and conversations will be likely to be more effective and efficient as they will be more grounded in reality. In particular, we have shown that giving the family a role could be very powerful, because the ability to contribute their own data or have visibility of data recording would provide them with direct evidence that they are being listened to and that their perspective is seen to matter more than ‘what the computer says’. The ability to ask questions about their data, and to explain or clarify things seen in the data places more respect upon the family than the purely data-and-technology-based approach of the state-citizen service infrastructure experienced on the whole by non-supported families. The ability to act independently, in their own time and in contexts outside of the support interaction, allows individuals to alleviate concerns quickly and maintain confidence that their data selves, the version of themselves used by the state to inform decisions, remain fair and accurate, but also opens up new opportunities to individuals for using their data for their own ends in ways that were not previously possible. In exploring the usage of data in its full sociotechnical context, not just from the provider’s perspective or citizen’s perspective, we have shown that merely providing people with access to data would be insufficient to properly address the identified problems, and that in applying the principles of Human-Data Interaction we need to consider interaction in an interpersonal sense. Capabilities – or their absence – matter more than the nature of the data interaction. Data interfaces are limited by their operating context as to how much they can offer, but considering the wider human-facing relationship between the individual and the representative of the state allows us to imagine a more holistic solution that can better address any situation arising. It is vital that the human perspective be given the highest priority, so that professionals’ flexibility is not limited, but also because data cannot adequately represent the complexities of human life – people are more than just data, and you have to talk to them to make sense of their lives and to avoid excluding them. The usage of data must always be supported with dialogue and engagement. It is the need to focus on the human aspect that explains why trust underpinned nearly every single problem imagined by our participants – without an open system that encourages dialogue and discussion it is very hard not to close doors, create suspicion and harm trust. Through our sentence ranking exercises we have been able to offer a snapshot overview of what this sample of support workers and supported families think about data, and where they agree and disagree (see Table 3). Our detailed analysis of our workshop transcripts has provided an understanding of the positive and negative impacts on the support relationship of current civic data practices within early help, and through our qualitative analysis we have been able to identify 38 specific practices, many of which are currently imagined or only just emerging, which participants believe would improve families engagement and the support they receive (see Table 4). We believe these suggestions can serve as a challenge to the status quo that could inform policymakers attempting to reform care services or digital citizenship offerings. There would be significant challenges in adopting our proposed changes, in cost, training, manpower and emergency planning, as with any systemic practice change in an organisation, but our findings suggest that such an approach may get closer to the heart of the real issue of empowering ‘left-behind’ (disempowered) families than a purely state-centred approach to problem solving, and that this may offer part of a route to a more enabling welfare state. More generally our work serves as a reminder that as we move into the data-driven age it is important that data stays close to the people it is about, rather than those that use the data

to provide services, and that service practice and processes should remain human-centric rather than data-centric. This is a general principle that could be equally applied to other domains including education, healthcare, democracy and commerce, and our emphasis upon individual capability over interface design is a useful mindset that can be applied to many human-computer interaction and design endeavours.

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1. The term 'troubled families', popularised by the TFP, has fallen in use, as it was considered to be negative and judgemental. A latter term 'vulnerable families' has also been criticised for being disempowering. Most councils now refer simply to 'families' or sometimes 'supported families', and the rest of this thesis adopts this convention.↩
 2. Some leisure categories (namely Shopping and Transport) were included that are not strictly civic data, as these are useful for exploring issues of ethics and helping participants to have a reference point when discussing the "big data" benefits of data linking.↩
 3. The first interview was a 'trial run' with a couple selected by convenience sample, and conducted in a University meeting room at the participants request.↩