

Understanding and Improving Human Data Relations

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Contents

1	Case Study One: Accessing and Using Civic Data in Early Help	2
1.1	Context: Data Use in Early Help	3
1.1.1	Data-centric Family Intervention in UK Social Care	3
1.1.2	Current Practice: Early Help Case Records as a Source of Truth	4
1.1.3	Rethinking the Role of Data in Early Help Support Relationships	6
1.2	Preliminary Explorations of Family Civic Data: Families' and Support Workers' Perspectives	7
1.2.1	What is Family Civic Data?	7
1.2.2	What is the Family Perspective on Their Civic Data and its Use?	9
1.2.3	What is the Staff Perspective on Family Civic Data and its Use?	10
1.2.4	Seeking an Equitable and Mutually Beneficial Data Use Model: Shared Data Interaction	10
1.2.5	The Workshops	11
1.2.6	Sensitising Participants and Discovering Shared Values . .	12
1.3	Thematic Findings	14
1.3.1	Themes & Subthemes	14
1.3.2	Theme 1: Meaningful Data Interaction for families	20
1.3.2.1	Understandable Information Summaries	20
1.3.2.2	Interact With Data Together	21
1.3.2.3	Direct and Unified Data Access	22
1.3.2.4	Ongoing Data Access and Support	22
1.3.3	Theme 2: Giving a Voice to the Family	23
1.3.3.1	People not Records	23
1.3.3.2	Checking Data Together	24
1.3.3.3	Changing Lives Means Changing Data and Changing Consent	25
1.3.3.4	Individual Agency & Family-sourced Data	26

1.3.3.5	Granular Access Controls	27
1.3.4	Theme 3: Earning Trust through Transparency	27
1.3.4.1	Transparent, Respectful Data Handling	27
1.3.4.2	Always Seek and Demonstrate Greater Understanding	29
1.3.4.3	Pro-actively Challenge Data-centric Norms	29
1.4	Discussion	31
1.4.1	The Value of Involving People With Their Data	31
1.4.2	Effective Data Access Requires Human Interaction	34
1.4.3	The Implications of Shifting the Locus of Decision-making Through Shared Data Interaction	36
1.5	Summation	39

Bibliography	43
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1 Case Study One: Accessing and Using Civic Data in Early Help

“If you can see the invisible, then you can see the possible and provide the opportunities for trust, commitment and ways of empowering others to manage their past, present and future.” - Ken Wyatt (Australian politician, teacher and equal rights campaigner)

In this chapter, I describe the first major case study of this PhD, in which I ran four 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, a targeted social care provision offered by local authorities to ‘*at risk*’ families across the UK. 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, 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 (4.4.3). 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.

1.1 Context: Data Use in Early Help

[TODO add section about Pilot study, or refer back to one in Chapter 3]

1.1.1 Data-centric Family Intervention in UK Social Care

In the UK, the social care system been shaped by a history of efforts, initially under the *Every Child Matters* policy programme [ADD 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 around children and young people [REF Wilson et al 2011; Cornford, Baines and Wilson (2013)], later expanding to include their families (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* [Cornford, Baines and Wilson (2013); REF Crossley] 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

¹The term ‘*Troubled Families*’, popularised by the TFP, has fallen from 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.

their clients or service users. The use of data by the state as a means to represent and think about families is considered problematic (Cornford, Baines and Wilson, 2013; Barbosa Neves and Casimiro, 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 (Corra and Willer, 2002). 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 (Field, 2010; OFSTED, 2015; Bate and Bellis, 2018; Department for Education, 2018).

1.1.2 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’ [ADD 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 (OFSTED, 2015). 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 (Morozov, 2013) being applied to try and solve a problem that was created by a data-centric approach in the first place.

1.1.3 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); REF White and Wastell; REF 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 (Cornford, Baines and Wilson, 2013) 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, Baines and Wilson, 2013; Lowe and Wilson, 2015). 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, Baines and Wilson, 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.

1.2 Preliminary Explorations of Family Civic Data: Families’ and Support Workers’ Perspectives

1.2.1 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 1: 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.
Education	Children	Parentage, adoption, fostering, childcare.
	School Records	Attendance (truancy), special needs.
Welfare	Academic Results	SATs, reports, exam failures, training courses.
	Social Support	Social worker visits & notes, details of family crises, interventions, allegations.
	Welfare Benefits	Jobseeker’s Allowance, child support, Disability Living Allowance, tax credits

Category	Type of data	Examples/Details
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.
Medical	Domestic Violence	Allegations made, medical records, social/legal interventions, victim support.
	GP records	GP's notes, prescriptions, tests, referrals.
	Hospital records	Operations, hospital stays, emergency care.
	Medical conditions	Diagnoses, diseases, allergies, blood type.
Leisure ²	Mental health	PTSD, breakdowns, depression, sectioning.
	Addictions	Substance abuse, gambling, rehab, crime.
	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

²Some 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.

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 colours 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.

1.2.2 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

³The first of these interviews was a ‘trial run’ with a couple selected by convenience sample, and conducted in a University meeting room not their home at the participants' request.

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.

1.2.3 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 (Morozov, 2013) framing, the SILVER project gave priority to the support worker perspective as its requirements 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’ nor to pursue a purely data-centric solution; I wanted to explore whether it might be possible to satisfy the needs of both parties and to maintain focus on human-centricity and the need for a balanced relationship.

1.2.4 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 emerged in part from the participants in the first phase (see below) of the research engagement, and became a main focus for the second phase, so that we would not only be exploring RQ1 and especially RQ2 in the context of current practice, but also be asking participants to imagine a different set of practices that might potentially serve their needs better. In doing so, we would be able assess whether the imagined 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 be helpful as it would put participants in a speculative, co-design mindset that would elicit deeper insights about how civic data *should* be used, not just expressing opinions on how it was used currently.

1.2.5 The Workshops

Table 2: 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	- 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 (in total)	- Data Card Sorting- Sentence Ranking- Ideation Grids- Poster Design- Scenario Discussion- Interface Discussion

Workshop	Engagement	Phase	Number of Participants	Activities
Workshop C	Combined Staff and Parents' Design Workshop	2	3 support workers and 4 parents from supported families	- 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 to 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.

1.2.6 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 and the complete list of sentences are included in [INSERT REF TO APPENDIX SECTION HERE]) 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 (discussed further in 4.3.3.1),

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.

[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] [TODO: use a different word than ‘agreement’ within coloured boxes to avoid confusion; explain ‘neutral’]

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.

1.3 Thematic Findings

The transcribed corpus from audio recordings of workshops A, B and C (approximately 120,000 words) was divided by activity, group, and family or staff focus into 85 different source texts. Each text was thematically coded and the coded texts were analysed through four cycles of analysis using the Miles and Huberman approach (Huberman and Miles, 2002). During this reductive process, participant creations, activity outputs and ranking data were referenced to add additional context to the interpretation. In this section, the qualitative findings from the thematic analysis of transcripts of workshops A, B and C are presented. In 4.3.1 the three main themes and subthemes are introduced, then each theme is further detailed in sections 4.3.2 to 4.3.4, including participant quotes⁴.

1.3.1 Themes & Subthemes

Given that our conversations with participants were framed as explorations of data use within the early help relationship, our findings are expressed as desirable best practices, some of which involved the proposed model of shared data interaction, within three core areas that participants see as beneficial to the early help relationship and ultimately to the family being supported: **Meaningful Data Interaction** (Theme 1), **Giving a Voice to the Family** (Theme 2), and **Earning Trust through Transparency** (Theme 3). From explicit and implicit statements from participants, contextual clues, and accumulated knowledge from

⁴The notation used for the quote references is as follows:

- FQnn = Family Quote - a quote from the families-only workshop (A)
- SQnn = Staff Quote - a quote from a staff-only workshop (B)
- CQnn = Combined Quote - a quote from the combined workshop (C).
- Sn = Sentence n - a sentence from the Sentence Ranking exercise, see [INSERT REF TO SENTENCES IN APPENDIX]

The number after FQ/CQ/SQ provides a unique identifier for each quote, which can be used to look up the referenced quote in [INSERT REF TO APPENDIX SECTION HERE]. Individual speakers are identified only by their role: within each quote, or in brackets afterwards, the speakers are identified as Worker, Parent, Child, or Researcher.

<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." "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." "Support workers should be able to see family medical records." "A family's data should not be joined up and looked at together." "Labels like 'domestic abuse' are damaging to families and hard to shake off." "Numerical scores are <u>not</u> a good way to compare the progress families have made." "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." "Families should have a right to see their data and how it is used" "Information stored about families must be fair and accurate." "Just looking at data doesn't tell you everything about a family." "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." "Families won't mind lots of data being collected about them if they can see it." "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>

Figure 1: Figure 21: Participants' Shared Values Deduced from Sentence Rankings Data

being embedded in this context, we were able to judge whether the discussed best practices were commonly in use (“*current*”), happening occasionally/partially (“*emergent*”) or not yet occurring at all (“*imagined*”)⁵. Tables 5, 6 and 7 shows the subthemes within these themes, along with illustrative participant quotes, and indicates the current, emergent or imagined status for each subtheme. Structuring the themes in this way facilitates the functioning of these findings as constructive, actionable input for Early Help (or other social care) system and process designers.

Table 3: Table 5. **Theme 1 - Meaningful Data Interaction for Families.** Subthemes & Participant Quotes.

Subtheme	Description & Quote	Status
Understandable Information Summaries	To maximise understanding, simple summaries of the information within families’ data should be available to both families and support workers. Visualisations should be used to ease comprehension, and information should be contextualised at different levels (individual, family, community). <i>“There’s so much data that’s stored. For me, for a parent [I want] to understand that through a text or email but just in point form. [...] The less written, the better for the parent. [What we need is] a small synopsis [...] like a summary view.”</i> [Parent, SQ44] <i>“Some families will go, ‘Well you know that information because it’s all there somewhere.’ We’re like, ‘Yes, but we don’t want to trawl back to eight years ago.’ There’s reams and reams and reams of it [data].”</i> [Worker, SQ40]	Emergent
Interact With Data Together	Support workers should work to actively counter the knowledge imbalance by informing families what their data says. They should make use of specific datapoints as talking points to aid planning conversations. <i>“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 [take these specific steps], even though you’ve got a criminal record, you could progress to this level.”</i> [Worker, SQ29]	Emergent / Imagined

⁵As judged at the time of the workshops - summer 2018.

Subtheme	Description & Quote	Status
Direct and unified data access	Individuals should be able to directly access their civic data through a personal interface; this should be a single, common place where all of an individual or family's data is brought together to give a complete and consistent overview to all parties with a need to know. " <i>[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.</i> " [Parent, FQ8]	Imagined
Ongoing Data Access and Support	It is not sufficient simply to give access to data. Families should be able to access information in their own time and should be supported in understanding it. Most importantly they should be able to ask questions, challenge data records or start a conversation to discuss their data at will. " <i>[The families would have] a little app which they can log into and read all their information - what's recorded about themselves, [...] who we share the information with [...]. If they're not happy [...] they can fire off an email to us and let us know what they disagree with or if they want their information taken down or their consent.</i> " [Worker, SQ51]	Imagined

Table 4: Table 6. **Theme 2 - Giving a Voice to the Family.**
Subthemes & Participant Quotes.

Subtheme	Description & Quote	Status
People not Records	Support workers must always treat people like individuals, that are more than a data record. They should review family data before contact, but must always engage at a human level too, avoiding making any judgements based solely on data. Worker A: " <i>You should never make a judgement on data... that data could be wrong.</i> " Worker B: " <i>It takes individuality, working with that person as well, doesn't it?</i> " [SQ11]	Current / Emergent

Subtheme	Description & Quote	Status
Checking Data Together	Families should be explicitly invited to review, discuss, check, correct and approve data records. Data recording should be visible, and workers and families should check data together. “[<i>The parent could</i>] countersign. [<i>The worker would</i>] say, ‘I feel that we’ve talked about this today so I’m going to write that down. I’m going to show you. Can you sign and me sign if you’re happy and I’m going to share this.’ That’s a bit different [better].” [Parent, FQ12]	Emergent / Imagined
Changing Lives Means Changing Data and Changing Consent	Recognising that families’ lives are in constant flux, routine reviews of data should occur, and they should be invited to regularly review their choices regarding data collection, keeping and sharing. All systems and processes should treat data as fluid and flexible, not static unchanging facts. Feeds of recent changes should be available to both parties. “[<i>There’s</i>] 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]	Imagined
Individual Agency & Family-sourced Data	Individuals should be able to create or contribute their own data to tell their own story and annotate particular datapoints with their own explanations. Worker A: “[<i>If you read information [...] about me, you wouldn’t expect to meet the person you meet.</i>]” Worker B: “[<i>That’s it. It’s the same for everybody.</i>]” Worker A: “[<i>...</i>] It just [has] basic things in most of the time, doesn’t it [...]. You’re not a person [in the data record] are you really?” Worker B: “[<i>I’d like it if you could</i>] give your bit of personal data, your own story.” Worker A: “[<i>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. [They’re] getting judged by having one thing [but they should be able to write] ‘Yes, I did this because of this situation but this is what I’ve done to make myself [better]...’</i>]” [FQ10]	Imagined

Subtheme	Description & Quote	Status
Granular Access Controls	Families should be given controls to manage access to their data and configure and change preferences at a fine-grained level. “[<i>Families need to</i>] feel they’re being involved. [...] [<i>We need to be able to</i>] sit together and say, ‘Right, that’s the information I’ll allow you to share. I don’t want that bit shared. But this bit, because it will help me and the family [...]’. Say in this [scenario] family, she might have been married before and had domestic violence so she doesn’t want that bit shared, that’s in the past. So it’s [only] certain up-to-date information about the family [that would be shared] because this [the family suggested by the data] isn’t her family.” [Parent, FQ16]	Imagined

Table 5: Table 7. **Theme 3 - Earning Families’ Trust Through Transparency.** Subthemes & Participant Quotes.

Subtheme	Description & Quote	Status
Transparent, Respectful Data Handling	Support workers should treat families’ data with the utmost respect, keeping it safe, ensuring it is not used beyond its intended purposes, shared without consent or put at risk. When talking to families about data, it is helpful to focus on positives and strengths and not use it as a means to criticise. “ <i>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.</i> ” [Parent, CQ7]	Current
Always Seek and Demonstrate Greater Understanding	Support workers should always assume that their understanding from data is incomplete and should seek to learn about individuals and build a more complete picture of their lives. By showing this effort and their growing understanding, they will engender trust. “ <i>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.</i> ” [Worker, SQ74]	Emergent

Subtheme	Description & Quote	Status
Pro-actively Challenge Data-centric Norms	Support workers and agencies can recognise that current systems and processes are data-centric and imbalanced, and can strive to change this through their actions: being as open as possible about how families’ data will be handled, ensuring that proper oversight mechanisms exist for data handling especially in the sake of contentious issues, and that data is shared openly but consensually between authorities. <i>“It hasn’t been explained properly to this [scenario] family that their information will be shared with other professionals. So, they’ve been left feeling really let down and probably quite angry about it. So, although that information does need to be shared, they [the support workers involved] ought to make the family properly aware that information will be shared.”</i> [Worker, SQ18]	Imagined

1.3.2 Theme 1: Meaningful Data Interaction for families

Through our discussions with families and support workers we gained a deep understanding of what sort of data interactions were considered ideal for a family. Setting aside interface considerations, which were not the main focus of our enquiry, and focusing on the wider sociotechnical context around the data and its access, the key requirement we uncovered was that in order to maximise understanding for all parties, data interaction needs to be *meaningful* – this is the first theme of these findings. Encompassed within this concept are the need for understandable and effective summaries and visualisations, the need for direct and ongoing data access with human support, and the recommendation for families and support workers to interact with data together within the support interaction.

1.3.2.1 Understandable Information Summaries 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 [...] 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 [shown] at the highest level.” [Parent, CQ10]

Because the amassing of large volumes of historical data is expected, 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 felt they should not be given greater data access, fearing greater liability to ‘*trawl through data*’ so that they know everything.

This need for summaries can also be seen an echo of Gurstein’s call for ‘*effective data use for everyone*’ (Gurstein (2011)). It is not sufficient to simply open up public sector databases to allow individual record access; families need 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 tables are insufficient and may need to be supported by visualisations: “*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*.” [Worker, SQ43]. Participants suggested pie charts, graphs, spider diagrams and timelines [SQ30, SQ31] or even an audio interface for the visually impaired [SQ45] to aid understanding. Visualisations also need verbal explanations [CQ11].

We noted that it is not clear who could or should do the skilled knowledge work of creating these representative and accurate tailored summaries and visualisations.

1.3.2.2 Interact With Data Together 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]

The showing of data performs an additional important purpose, combatting the lack of *awareness* of what data exists and who holds it [SQ39]. Currently, much of the data stored about families is invisible to them: “*Families really only see the data that we [support workers] want to present.*” [Worker, SQ37] Regardless of families’ legal rights to request copies of their data, our understanding is that this right is rarely used [SQ38], and typically only when filing complaints. Lack of awareness can not only cause suspicion [SQ17], but also incorrect assumptions that support workers ‘*already know everything*’.

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 to track progress [SQ29, shown above in Table 5]. This could

motivate and reinforce progress [SQ6] by relating behaviours to consequences [SQ32] – essentially facilitating data-based decision-making. Reviewing historical data is preferable to verbal description: *“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].

1.3.2.3 Direct and Unified Data Access Despite the reality that families currently have no direct access to their civic data, family participants all eagerly described designs including apps, intranet terminals, online chat facilities, and self-service webpages, all offering individuals the ability to view their own data; there is a clear demand for *personal data interfaces*, which could empower families to use their own data: *“they could quickly tap onto the app [...] and show somebody else where they’re at.”* [SQ54]

“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, FQ7]

Workers and families shared a desire for one single point of access for data, usable by all parties [SQ25, SQ26], though families *‘don’t want to be responsible for looking after all our data’* [FQ17, S5]. Bringing together data from multiple sources would allow patterns to be spotted by correlating data from different sources, which workers perceived would help their preparation: *“[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.”* [SQ8]

1.3.2.4 Ongoing Data Access and Support Families, being accustomed to accessing information in other parts of their lives through smartphones and web interfaces, expect that any civic data interface would allow them to access data *“in their own time, at their own pace”* [Parent, CQ12]. Currently access only possible via the support worker, functioning as a gatekeeper within the support interaction, so opportunities to reflect upon the data are limited in time and coverage:

“[If conflict occurs,] I 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]

Timely access to data could be empowering, as families could track their own progress, enabling them to make plans outside of the support relationship, reducing dependency upon support, in line with the ultimate goals of the programme:

“If we were working with a family about school attendance, could we then link

that in to [the families'] app so parents [would be] aware of what their attendance looks like at this point in time and they [...] [could] monitor it themselves and take accountability.” [Worker, SQ49]

As well as having ongoing access to data, families need human support to understand that data [SQ49, CQ11]. All participants agreed that ‘*Families should be able to talk to someone about their data*’ [S7]. Explanations are needed [CQ11] with language and vocabulary adjusted to individual literacy [SQ46] or age [SQ47]:

“No matter which [presentation of data is offered], 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]

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, letting their disagreement be known and empowering them to be part of a dialogue about what is recorded [SQ60].

1.3.3 Theme 2: Giving a Voice to the Family

The second theme of these findings is that there is a need to update processes and systems, which currently rely largely excessively upon the ‘facts’ within the data record, need to be updated to give the family an empowered role within their civic information ecosystem. 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; impressions of that truth can be formed either by reading the data or by talking to the family. We uncovered benefits and dangers of relying solely on either source. Families should become agents in the data ecosystem, and this involvement should lead to both greater empowerment and better evidence-based decisions.

1.3.3.1 People not Records We found evidence, consistent with literature (Gitelman (2013)) and my earlier study (Bowyer *et al.* (2018)), that data can never represent absolute truth - it is often biased or incomplete, and this can mislead [SQ59 (shown in Table 6 above), FQ11A]. 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 [SQ77], 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 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”* [S18] disagreed with it.

In spite of the warnings above, the data record is undeniably useful; over 80 comments from workers contend the current practice of reviewing a family’s data prior to meeting in person is beneficial, because it provides useful background that will help them identify support needs. For example: *“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].”* [SQ1] Additional benefits identified included safeguarding workers [SQ3] or giving them an ability to *‘check the family’s claims’* so that they might constructively challenge individuals [SQ4]. Supported families echoed the value of workers reviewing data [FQ1A], and saw benefits included *‘not having to repeat your story’* [SQ5].

The compromise that participants identified over the use of data is that workers should avoid making judgements based solely on data. While sometimes providing essential background to a worker [FQ11B, SQ62], historical data in particular often leads to inadvertent prejudice, especially where labels are used [SQ9]. No participant disagreed with the sentence *“Labels like ‘domestic abuse’ are damaging to families and hard to shake off”* [S15], and workers recounted experiences of being uncertain how to judge historical issues: *“[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 [still true]?’”* [Worker, SQ61]

Many participants concluded that only *‘relevant’* information should be available, to those who *‘need to know’*, but the wide range of opinions we saw expressed suggest that this is a highly subjective judgement that would be difficult to determine. A cut-off period before which workers should have no right to look was suggested [Parent, CQ15], but the sentence *‘Officials should be able to see historical records about families’* [S17] was contentious. Some workers feared any restriction in access might mean they miss important background on an individual’s past, such as sexual abuse or mental health issues [Worker, SQ76]. The solution to this dilemma is unclear, but transparency about what is in the data would seem to be a critical ingredient (see 4.3.4).

1.3.3.2 Checking Data Together The idea of families and support workers reviewing data **together** arose from many of our participants in workshops A and B, and this led us to explore this concept of ‘shared data interaction’ in more depth through the storyboarding exercise in workshop C (see 4.2.4 above). Families perceived value in having not just data representations (as in 4.3.2.2

above) but a data interface present within their care meeting, so they that they could see actual data and have it explained to them. One practice embodying the concept of transparency that is emerging in some care services is the use of ‘2-in-1’ devices (laptop/tablet hybrids) within the care engagement so that workers can visibly record data in front of families and then ask them to ‘*approve*’ the accuracy on screen [FQ12, SQ67]. Participants believed this would help to build trust between the support workers and families; if a family begins to feel powerless, they may disengage [SQ35], but even minor involvement, such as this emergent practice of signing off approval of data records [FQ12] or an imagined process of checking & correcting data records together (see next section) could make families feel more empowered which could make the support relationship more productive.

Family participants imagined going beyond just seeing and getting verbal explanations of their data to being able to review their data and be asked for their approval of accuracy [FQ3]. Maintaining accurate data is important because that data is used to decide care plans and support strategies. Families are thought to be better placed than anyone else to identify inaccuracies or gaps in their civic data, and participants believe family corrections would increase data accuracy. This does not mean free editing of records (as, for example, as discovered in the earlier study (Bowyer *et al.* (2018)) fears and/or self-interest could lead to families misrepresenting themselves in data) but rather taking a role in reviewing, annotating, explaining, or requesting changes, through direct data-centred collaboration between involving 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]

Shared data interaction carries the potential to bring benefits in accountability, accuracy, simplicity [SQ25, SQ26] and consent.

1.3.3.3 Changing Lives Means Changing Data and Changing Consent

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 and other changes, data can become out-of-date simply through inaction. Given this, asking consent once at the start was considered insufficient [S3]. Data is inherently static – it does not change, but people do [SQ61, SQ63]. This was the basis for participants’ desired practice that not only the content of the data, but the family’s consent over what happens to that data that both need to be reviewed regularly [CQ16]. A process of regular reviews around data use could prevent unwelcome surprises about how family data is handled [CQ2, CQ17] which could damage trust and hinder co-operation. Participants imagined data systems issuing notifications or update feeds for families and support workers showing significant events or data updates [SQ64].

Support workers currently get notified of police incidents, safeguarding concerns and hospital admissions, but alerts of data changes across the care ecosystem could provide useful triggers for reviews or discussions:

Worker A: “*We would get a report through to say...*” Worker B: “*They’ve recorded something.*” Worker A: “*Yes. Then I suppose we would follow it up [...] face to face.*” [SQ65]

Regardless of the particular mechanism, it was ultimately felt that both data systems and support processes need to do a better job of supporting change.

1.3.3.4 Individual Agency & Family-sourced Data The idea of families reviewing data has significance not just for how it can help within the support interaction, but because it can give families an independent role in their data ecosystem. Both families and support workers imagined the family being able to interact with their civic data on their own, something that is currently not possible. This is a vital step for empowerment: if something goes wrong, families must be able to discover this and 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). Thinking about data interaction at home unlocked additional thinking, such as 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 would empower them to ‘*tell their own story*’ [FQ10]. Many participants saw this as-yet-unavailable capability as expected common sense:

“*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]

Rather than solely relying on dialogue, families could provide new data more directly, e.g. through a ‘family network app’, which could also increase their sense of data ownership:

“*It would [ask them] who [professionals the family is involved with] 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]

With new ways for self-expression, families could add context for support workers [FQ9, SQ55], unlocking new support topics [SQ56]. The overriding sense from both groups was 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*’, as illustrated in [FQ10, shown in Table 7 above].

1.3.3.5 Granular Access Controls 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]. Psychological harm could be caused through information leakage, for example an adopted child finding out their true parentage (Bowyer *et al.* (2018)). To avoid this, data should be managed carefully with consent being less binary and more fine-grained access controls being offered:

Worker 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?*” Worker B: “*I think it’s confidential.*” Worker 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.*” [SQ53]

Once such capabilities are established, this could enable much more careful and deliberate forms of data-sharing which could support the creation of a personal data ecosystem (see section 2.3.4) beyond, but centred upon, the individual family member, all the while remaining under that individual family member’s control:

“*[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]

Looking at Theme 2 as a whole, 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.

1.3.4 Theme 3: Earning Trust through Transparency

The third theme looks at these imagined new data access capabilities and empowered role for data subjects in the wider sociotechnical context of how they could affect the support relationship. The topic of trust arose directly or indirectly in almost all participant conversations, and our findings show that transparent and open data handling and decision-making processes are key to support workers to earn the trust of supported families. Currently, families are mostly unaware of what data is held about them and what discussions about them are being had and have no choice but to trust both the support workers, and all the parties and technologies involved in the surrounding care ecosystem, which is very hard to do when they have little to no visibility of it. Without visibility, any error or surprise can be very damaging to this fragile trust and can harm the relationship, and conversely, increase transparency and explanation can avoid surprises and increase trust, improving the relationship.

1.3.4.1 Transparent, Respectful Data Handling The findings in Themes 1 and 2 above clearly suggest that in seeking the best possible understanding, families must be engaged in a fact-centric way, which requires trust in the support

worker (to interpret and record data fairly and accurately) and in the system (to keep data safe and prevent misuse). A good relationship with the support worker is critical [FQ1] to the family's care. Workers recognise the importance of being transparent with families:

"I think that [families] have got a right to know what is held about them and what is said about them." [Worker, SQ50]

Even for data that would itself would be considered uncontroversial, a lack of awareness to that data or a lack of transparency on how data is informing judgements can cause great worry to families:

"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]

The current approach, which relies on the support workers mentioning data that they consider relevant, can reassure families when they are kept thoroughly and regularly informed, but can result in expectations being broken by accidental sharing of information if its sensitivity is overlooked:

"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]

Data must be handled respectfully, with attention to family and individual privacy. A 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 extreme scrutiny to what they are told: "You can get families who [no longer] 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]

Respectful data handling also includes using tact and discretion when referencing data, and a common current practice is the use of a *strength-based approach* [multiple workers in workshop B] when presenting or referencing data that could be perceived as particularly negative or judgemental; looking for the opportunities for growth rather than seeking to criticise.

An open and respectful approach is rooted not just 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]. Being transparent with data can also help with accountability and accuracy, which can detect and prevent mistakes earlier:

“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 [in the data record] as three bottles a day. That could have caused an issue was anyone ever to ask.” [Parent, CQ7]

In current practice, data handling *is* generally respectful - data mishandling and unexpected uses of data are currently mostly avoided; but transparency is low, making the perception of respectful handling quite fragile and entirely based upon trust rather than direct experience.

1.3.4.2 Always Seek and Demonstrate Greater Understanding In order to earn, build and maintain trust, support workers must always be seeking to form a complete and more up-to-date picture of the family, in line with the finding in 4.3.3.1 that individuals are more than what is stored in their records, and this requires human interaction to uncover. Demonstrating a deep understanding of the family, and that a family’s lived reality has greater priority than what a database says can be a critical to trust-building: *“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, if workers had to show all available data to families this could make it challenging to maintain good relations, *“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 Theme 2 above), a transparent approach ensures that the privacy of families is respected, because data is not used in decisions without the chance for explanation:

Parent: *“I don’t want everybody knowing how rubbish I am with money.”* Child: *“That’s my life.”* [FQ2]

Participants also indicated that families’ desire for transparency (as mentioned in the previous section) does not just imply reporting data usage, they need dialogue and human engagement to give them reassurance; trust and reassurance can be best achieved through a conversation [FQ1], not a data interface. 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.

1.3.4.3 Pro-actively Challenge Data-centric Norms Exploring this need for reassuring dialogue in more depth, we see that 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 that can arise without that transparency – giving them instead confidence that their interests are being protected, thus putting them at ease [SQ20]. To our understanding, data handling processes is only done once in very loose terms during initial engagement with a family for the purposes of collecting informed consent and rarely revisited. We found that workers could easily imagine explaining data practices 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.

Workers however lack control over the quality, coverage and timeliness of the family data and see this as a systemic issue they could not adequately address. From my experience with early help teams through the SILVER project (see 3.4.1.1) 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, suggesting that greater openness with data would benefit not just the family, but other civic actors involved in the family’s lives and in their care. Some participants suggested that openness about data handling needs to accompany data access, so for example if browsing information together (as described in 4.3.2.2 and 4.3.3.2), it would be important to explain where the information has come from and why the support worker has it, rather than just reporting its content:

Parent: *“[if the worker knew sensitive medical information] the family would be really annoyed, they would just want you [the worker] to go.”* Worker: *“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].”* [CQ6]

As mentioned in 4.3.3.3, there is a need to replace the current practice of treating consent as a one-off formality at the start of the support process with something better. In our earlier study we identified this as a need for *dynamic consent* (Bowyer *et al.* (2018);Kaye *et al.* (2015);Williams *et al.* (2015)). A common heuristic expressed by families here and in the earlier study is that data should only be seen by those that *‘need to know’*, but this is very hard to achieve: first, because without transparency of data handling, a family cannot verify whether this is happening, so has to rely only on feelings and supposition to inform their trust. Second, the need for fair judgement over who should access families data is objectively important given that some support workers expressed a belief that their right to access families’ data should overrule families’ consent:

Worker A: *“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.”* Researcher: *“Regardless of what they say?”* Worker A: *“I do, yes.”* Researcher: *“Does everyone feel the same way then, that they don’t get a say?”* Worker B: *“Yes, because you need as much information as what you can.”* [SQ22]

This suggests that to ensure the ‘need to know’ is determined fairly and accountably, independent oversight might be needed; other situations that would benefit from this include 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].

These findings suggest that not just transparency but a progressive attitude to data practice, actively challenging current data centric norms, would enhance trust around data handling access and decision-making as requirements and lead to a healthier support relationship. This could even include thinking about new ways of using data, for example at a collective community level [SQ78], to promote an open data-sharing culture.

1.4 Discussion

Through the workshops described in 4.2.5, I have successfully advanced my understanding of the human experience of data (RQ1) and the role of data within service relationships (RQ2), specifically for the Early Help context. In the section, the findings described above in 4.3 (and the preliminary findings in 4.2) will now be contextualised in respect of existing literature from Chapter 2 and beyond, drawing conclusions as the value of involving people with their data (4.4.1), the need for human interaction to make data access effective (4.4.2), and the possible impacts of a shared data interaction approach in terms of shifting the locus of decision-making closer to the supported family (4.4.3).

1.4.1 The Value of Involving People With Their Data

The above analysis of attitudes to data usage in the UK early help context reveals that data about supported individuals and their families is already an integral part of current care practice, providing great value in 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, just as in the commercial sector (see 2.1.2 on dataism), families’ civic data is considered as a resource to be utilised. This mindset carries an implicit assumption that data is an objective source of truth, which our participants tell us it can never be. 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. The present data-centric approach across civic systems mean that stored data can often serve as a proxy for families’ involvement, and without any involvement of the family in checking data accuracy, 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 (Bowyer *et al.*, 2018).

Our findings that trust is critical to an effective support relationship are consistent with literature which states that trust in the independence and integrity of the data-collecting and data-holding institutions is essential (Dijck, 2014). Trust currently rests upon feelings and impressions rather than the true accountability families would get by seeing what data is held and how it is used. This trust is often absent or reduced due to Early Help services not involving families with their data. Families must trust not only the system, but the support worker themselves; our findings suggest 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, Baines and Wilson, 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, which would be very powerful in building trust. 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 (established as requirements from families in the preliminary study (Bowyer *et al.*, 2018)). 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, Kim and Church, 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. 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 personal data interfaces would unlock 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 - a ‘*point of severance*’ (Luger and Rodden, 2013). In effect, the ongoing access to and direct use of data by families 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 onboard with the way their data is being used, since their ongoing awareness combined with the 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 simpler processing and reducing liability. Families will be happier with the use of their data if they can see it, notice issues 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; data becomes a resource that both parties make use of to inform their conversation, rather than the support worker’s sole responsibility. 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, Baines and Wilson, 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 taking a position of authority, passing judgement and delivering 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 Theme 2); this is also a practical instance of the HDI concept of *agency* (Mortier *et al.*, 2014), and in shifting the power balance toward the family it can also be seen as an antidote to current data-centrism in the system and society at large (see 2.1.2). 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.

1.4.2 Effective Data Access Requires Human Interaction

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 meaningfully effect change based on what they learn from it. This involves the translation of raw data into meaningful information (see 2.1.1) – through summaries, visualisations and explanations – a need that we have identified even though the creation of information representations such would be challenging as it is not clear who would have the access, skills and mandate to do this. In the designs and desires of our participants we see confirmation that, as described in one of the central tenets of HDI, the information available to the individuals must be *legible* (see 2.3.2 and (Mortier *et al.*, 2014)) but also that their access must be effective (see 2.1.4 and (Gurstein, 2011)). This includes providing suitable opportunities for access — for example via personal data interfaces and not just within the support meetings — as well as addressing technology, literacy, mental or physical handicaps. Our participants’ ideas around audio interfaces are a good example of the extra steps that would be needed to provide effective access for all. Supporting the range of all possible needs means that to be effect, information access **must** be supported by a human relationship — one where someone can both explain the data as well as answer questions about it (see 4.3.2.4). 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; the storage of and access to data necessitates an ongoing conversation between data holder and data subject. The system needs to have a human face or point of contact that the individual may put their trust in and to whom they can address their questions; as others have noted, simply giving access to raw data would be inadequate and limiting (Cornford, Baines and Wilson, 2013).

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 could 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 (Star, 1989, 2010; Bowker *et al.*, 2015), just as my Data Cards did within my own research. 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, even if only to query or challenge something at first. Many of

our participants talked about how looking at data would provide a discussion stimulus or serve as a conversation starter. This initial use could lead on to using that data, as it changes from meeting to meeting, as a metric against which to measure progress, something which could bring a feeling of reward and accomplishment to the family and contribute to their future success. 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 research (see 3.5.2). In particular in workshop C, 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. This interchange within a research setting, gives some insight into how the dynamics of shared data interaction might work if implemented in practice. Having access to the data within the context of the support relationship is a key enabler of *agency* (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 in line with our findings that regular reviews of consent and data need to take place and that the ability to raise a question or start a conversation at any time is needed, we can consider that the availability of these capabilities on an ongoing basis would satisfy a second HDI requirement, *negotiability*. 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 protection regimes (described in 2.1.3) 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.*’ [S4, see also 4.3.3.1]. 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)

1.4.3 The Implications of Shifting the Locus of Decision-making Through Shared Data Interaction

In pursuit of RQ2, the four Case Study One workshops and the preliminary research have explored the role of data within the Early Help support relationship (see 2.2.5), looking separately at family and staff perspectives before bringing both parties together to discuss how both parties’ goals might be served by a model of *shared data interaction*. In workshop C, we explored the mechanics of shared data interaction at an interpersonal, sociotechnical level (see 2.3.3), mapping out a possible narrative in terms of human-human and human-data interactions. I present here a model for understanding why this could be important for rebalancing power between the supported family and the state, based upon a concept I have developed called *shifting the locus of decision-making’ (LDM)*. This concept is distinct from *locus of control* (Spector, 1982) which normally refers to personal willpower, and *locus of power*, which refers to the concentration of power within an organizational hierarchy. LDM refers to **the place where decisions are made**, and it may or may not coincide with existing authority structures. A pattern can be stipulated, in which decisions are typically made, germinated or championed **close to where data is accessed**. In an effect that has been expected since as early as 1970 (Klatzky, 1970) the increasing use of data in services across private and public sectors (a phenomenon detailed in 2.1.2) has concentrated the LDM with data holders, who collect service users’ data to serve their own purposes.



[TODO: Replace with higher resolution version]

The current and imagined approaches are shown in Figure 22 above. In the current model (left), all access to data by families is through the support worker as gatekeeper, who decides the scope, content and nature of their access – here the LDM is effectively locked away from the family’s participation. The use of data by families is limited because any data must flow through the support worker as gatekeeper. In a more equitable model (right), both support worker and family member are positioned as allies looking at the data together. This model changes the nature of the support relationship, as 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) would now take place in a different context – the two-party context of the support meeting itself. The removal of the gatekeeper role redistributes the power to interpret, select and judge data much more equitably between the two parties; families would no longer be prevented from participating in data-based decision-making. I theorise that shifting the data access from the domain of the support worker to the shared domain of the meeting between the two parties, would therefore move the LDM closer to the middle of the relationship, where it will rest at the heart of the support relationship, creating a more balanced relationship and increasing families’ agency and power. Within the findings above we see evidence that both families and staff would value a shared data interaction approach, with multiple participants independently suggesting potential benefits that could be gained by techniques such as reviewing data and consent together (4.3.2.2, 4.3.3.2, and 4.3.3.3). While participants perceive shared data interaction as an improvement, such an approach has not been tested in practice, so it is important to consider what the benefits and implications of such a shift might be:

The potential benefits 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 (Bowyer *et al.*, 2018). 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 only indirectly possible, if at all. By shifting the locus of decision-making, families could 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 (see 2.2.3 and (Abiteboul, André and Kaplan, 2015)), thus ‘*encouraging the family to take full accountability for their own responsibilities*’ as one support worker put it [SQ75]. In their 2016 paper, Crabtree and Mortier also recognise the importance of exposing individuals to actual data if accountability is to be achieved (Crabtree and Mortier, 2016). The perceived benefit of individuals directly using data-based 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 LDM 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 provided the data subject remains engaged, informed and understands the data and processes that exist, 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 4.1.2) 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, Dunn and McKenna, 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 or misleading workers for personal gain). While very unlikely to be a mainstream issue, this is a fringe possibility that any process or system must still consider 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 in part because it cannot manage to provide human relationships with every individual citizen. 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, not just in practice but in political ambition, 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, 2005; Steyaert and Gould, 2009).

My model that shifts the LDM is theoretical; it does not yet provide an implementable solution that could be rolled out at scale, rather it should be thought of as useful mental model to stimulate further discussion about how care providers could or should change their processes and systems. The value of this contribution is that it shines a light on the positive and negative impacts of current data-handling and data-use procedures upon relationship effectiveness, and identifies imagined practices that could be preferable and more efficient than current practice. The 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 in pursuit of the primary goal of Early Help; to empower families to help themselves as effectively as possible.

1.5 Summation

Through four participatory co-design workshops with supported families and support workers in North-East England, I 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 fragile, 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 even just to see themselves in data as the state sees them, opportunities are missed to truly empower families to be better represented and to better themselves.

Through these explorations of shared data interaction and personal data interaction, I have shown there is both a need and a desire for a new approach. 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 over families’ civic data 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 could 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.

Further benefits of a shared data interaction approach have also been uncovered;

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 currently 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, much like the reflection capabilities we see in the self-informatics space. The shift from support workers reporting what the data says to *‘looking at data together’* would help 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 a combination of data and dialogue. Individual family members would 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 data that is as accurate as possible, the quality of decision-making would naturally improve and conversations would be likely to be more effective and efficient as they would 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, treats the family with more respect 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, would allow 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 to open up new opportunities to individuals for using their data for their own ends in ways that were not previously possible. It is through the adoption of such measures that we could begin to facilitate the emergence of a human-centred personal data ecosystem (as described in 2.3.4) in a civic context.

In exploring the usage of civic 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 Human-Data Interaction itself needs to be developed as a concept. As a sub-field of Human-Computer Interaction, HDI is largely considered in the traditional context of interacting with data through an interface, but this work, which has, guided by our participants, focused less upon layout and screen interaction and more upon the wider sociotechnical context of the support relationship, suggests that HDI can be more effective when the word

‘interaction’ is considered in an interpersonal sense, and these insights begin to address the research gap identified in 2.3.5, to define the research agenda for human centricity in practice. Informed in part by this idea I have explored further in a workshop paper how the HDI field needs to advance to consider the sociotechnical level as well as the interface level, which is outlined in (Bowyer, 2021).

Capabilities – or their absence – matter more than the on-screen technicalities of the data interaction. Data interfaces are limited by their operating context as to how much they can offer, but considering data interaction as a sociotechnical process, including the wider human-facing relationship between the individual and the representative of the state as well as the data interface itself, 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 the sentence ranking exercises I have been able to gather a snapshot overview of what this sample of support workers and supported families think about data, and where they agree and disagree (see Figure 21). The detailed analysis of 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 best practices, seen in the subthemes of sections 4.3.2, 4.3.3 and 4.3.4 and expressed in our CHI 2019 publication as 38 specific practices for Early Help services (Bowyer *et al.*, 2019), many of which are currently imagined or only just emerging. Participants believe these best practices would improve families engagement and the support they receive. 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 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 this work serves as a reminder that as we move into the data-driven age it is important that **data should stay close to the people it is about**, rather than to those that use the data to provide services, and that service practice and processes should remain human-centric rather than data-centric.

The general principles expressed here could be equally applied to other domains including education, healthcare, democracy and commerce, and this emphasis upon individual capability over interface design is a useful mindset that could be applied to many human-computer interaction and design endeavours.

Bibliography

Abiteboul, S., André, B. and Kaplan, D. (2015) *Managing your digital life with a Personal information management system*. 5. ACM, pp. 32–35. doi: 10.1145/2670528.

Barbosa Neves, B. and Casimiro, C. (2018) *Connecting Families?: Information & Communication Technologies, Generations, and the Life Course*. Policy Press.

Bate, A. and Bellis, A. (2018) *The Troubled Families programme (England)*. July.

Bowker, G. C. *et al.* (2015) *Boundary objects and beyond : working with Leigh Star*. MIT Press, p. 548. Available at: <https://books.google.co.uk/books?hl=en&lr=&id=nmSkCwAAQBAJ&oi=fnd> Objects and Beyond%3A Working with Leigh Star&f=false.

Bowyer, A. *et al.* (2018) ‘Understanding the Family Perspective on the Storage, Sharing and Handling of Family Civic Data’, in *Conference on human factors in computing systems - proceedings*. New York, New York, USA: ACM Press, pp. 1–13. doi: 10.1145/3173574.3173710.

Bowyer, A. *et al.* (2019) ‘Human-data interaction in the context of care: Co-designing family civic data interfaces and practices’, in *Conference on human factors in computing systems - proceedings*. doi: 10.1145/3290607.3312998.

Bowyer, A. (2021) ‘Human-Data Interaction has two purposes: Personal Data Control and Life Information Exploration’. Available at: <https://eprints.ncl.ac.uk/273832#>.

Brandt, E. and Messeter, J. (2004) ‘Facilitating collaboration through design games’, in *Proceedings of the eighth conference on participatory design artful integration: Interweaving media, materials and practices - PDC 04*. New York, New York, USA: ACM Press, p. 121. doi: 10.1145/1011870.1011885.

Bridle, J. (2016) ‘Algorithmic Citizenship, Digital Statelessness’, *GeoHumanities*. James Bridle, 2(2), pp. 377–381. doi: 10.1080/2373566x.2016.1237858.

Copeland, E. (2015) *Small Pieces Loosely Joined: How smarter use of technology and data can deliver real reform of local government*. Available at: www.policyexchange.org.uk <https://policyexchange.org.uk/publication/small-pieces-loosely-joined-how-smarter-use-of-technology-and-data-can-deliver-real-reform-of-local-government/>.

Cornford, J., Baines, S. and Wilson, R. (2013) ‘Representing the family: how does the state ‘think family’?’, *Policy & Politics*, 41(1), pp. 1–19. doi: 10.1332/030557312X645838.

Corra, M. and Willer, D. (2002) ‘The gatekeeper’, *Sociological Theory*. SAGE Publications Sage CA: Los Angeles, CA, 20(2), pp. 180–207.

Crabtree, A. and Mortier, R. (2016) ‘Personal Data, Privacy and the Internet of Things: The Shifting Locus of Agency and Control’, *SSRN Electronic Journal*,

pp. 1–20. doi: 10.2139/ssrn.2874312.

Department for Education (2018) *Working Together to Safeguard Children*. March, p. 393. doi: 10.1080/13561820020003919.

Dijk, J. van (2014) ‘Datafication, dataism and dataveillance: Big data between scientific paradigm and ideology’, *Surveillance and Society*. Surveillance Studies Network, 12(2), pp. 197–208. doi: 10.24908/ss.v12i2.4776.

European Commission (2014) *Research and Innovation in the field of ICT for Health, Wellbeing and Ageing Well: an overview*, p. 39.

Field, F. (2010) *The Foundation Years: preventing poor children becoming poor adults*. Available at: www.frankfield.co.uk <http://www.inspiredbybabies.org.uk/Page2NationalrelevantDocsresour>
Field Preventing poor children becoming poor adults 2011.pdf.

Gitelman, L. (2013) *Raw data is an oxymoron*. Edited by Lisa Gitelman. MIT Press, p. 182. Available at: <https://mitpress.mit.edu/books/raw-data-oxymoron>.

Gurstein, M. B. (2011) ‘Open data: Empowering the empowered or effective data use for everyone?’, *First Monday*. First Monday, 16(2). doi: 10.5210/fm.v16i2.3316.

Harbird, R. (2006) ‘Novel Applications for Information Technology in Risk Assessment for Children’s Social Care in the UK’, *Rn*. Available at: http://www.cs.ucl.ac.uk/research/researchnotes/documents/RN_06_11.pdf.

Herselman, M. *et al.* (2016) ‘A Digital Health Innovation Ecosystem for South Africa’, in *2016 IST-africa conference, IST-africa 2016*. doi: 10.1109/ISTAFRICA.2016.7530615.

Honeyman, M., Dunn, P. and McKenna, H. (2016) *A digital NHS?*

Huberman, M. and Miles, M. B. (2002) *The qualitative researcher’s companion*. Sage.

Johnson, S. L., Kim, Y. M. and Church, K. (2010) ‘Towards client-centered counseling: Development and testing of the WHO Decision-Making Tool’, *Patient Education and Counseling*. Elsevier Ireland Ltd, 81(3), pp. 355–361. doi: 10.1016/j.pec.2010.10.011.

Kalvet, T. (2005) ‘Digital divide and the ICT paradigm generally and in Estonia’, in *Encyclopedia of developing regional communities with information and communication technology*. IGI Global, pp. 182–187. doi: 10.4018/978-1-59140-575-7.ch032.

Kaye, J. *et al.* (2015) ‘Dynamic consent: a patient interface for twenty-first century research networks’, *European Journal of Human Genetics*. Nature Publishing Group, 23(2), pp. 141–146. doi: 10.1038/ejhg.2014.71.

Klatzky, S. R. (1970) ‘Automation, size, and the locus of decision making: the cascade effect’, *The Journal of Business*. JSTOR, 43(2), pp. 141–151. Available at: <https://www.jstor.org/stable/pdf/2352107.pdf?refreqid=excelsior%3A24bde6bf7de0eccf42c6ea1f8446d38>.

Kostkova, P. (2015) ‘Grand Challenges in Digital Health’, *Frontiers in Public Health*. Frontiers Media SA, 3. doi: 10.3389/fpubh.2015.00134.

Kriisk, K. and Minas, R. (2017) ‘Social rights and spatial access to local social services: The role of structural conditions in access to local social services in Estonia’, *Social Work and Society*, 15(1). Available at: <https://www.socwork>.

net/sws/article/view/503/1007.

Lecluijze, I. *et al.* (2015) 'Co-production of ICT and children at risk: The introduction of the Child Index in Dutch child welfare', *Children and Youth Services Review*. Elsevier Ltd, 56, pp. 161–168. doi: 10.1016/j.childyouth.2015.07.003.

Lowe, T. and Wilson, R. (2015) 'Playing the game of outcomes-based performance management', *Is Gamesmanship Inevitable*.

Luger, E. and Rodden, T. (2013) 'An informed view on consent for ubicomp', in *UbiComp 2013 - proceedings of the 2013 ACM international joint conference on pervasive and ubiquitous computing*. New York, New York, USA: ACM Press, pp. 529–538. doi: 10.1145/2493432.2493446.

Malomo, F. and Sena, V. (2017) 'Data Intelligence for Local Government? Assessing the Benefits and Barriers to Use of Big Data in the Public Sector', *Policy and Internet*, 9(1), pp. 7–27. doi: 10.1002/poi3.141.

Miettinen, R. (2013) *Innovation, human capabilities, and democracy: Towards an enabling welfare state*. Oxford University Press.

Morozov, E. (2013) *To save everything, click here: The folly of technological solutionism*. Public Affairs.

Mortier, R. *et al.* (2014) 'Human-data interaction: The human face of the data-driven society', *Available at SSRN 2508051*. doi: 10.2139/ssrn.2508051.

Neff, G. (2013) 'Why Big Data Won't Cure Us', *Big Data*, 1(3), pp. 117–123. doi: 10.1089/big.2013.0029.

OFSTED (2015) *Early help: whose responsibility?*, p. 32. Available at: [www.ofsted.gov.uk https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/410378/Early-help-whose-responsibility.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/410378/Early-help-whose-responsibility.pdf)

Papert, S. (1980) 'Mindstorms: children, computers, and powerful ideas'. Basic Books, Inc.

Pollock, R. (2011) 'Building the (Open) Data Ecosystem – Open Knowledge Foundation Blog'. Available at: <https://blog.okfn.org/2011/03/31/building-the-open-data-ecosystem/> (Accessed: 23 July 2019).

Soja, E. (2015) 'Supporting Healthcare of the Elderly through ICT: Socio-demographic Conditions and Digital Inclusion', in *Knowledge economy society - challenges and development trends of modern economy, finance and information technology*, pp. 279–290.

Spector, P. E. (1982) 'Behavior in organizations as a function of employee's locus of control', *Psychological Bulletin*, 91(3), pp. 482–497. doi: 10.1037/0033-2909.91.3.482.

Star, S. L. (1989) 'The Structure of Ill-Structured Solutions: Boundary Objects and Heterogeneous Distributed Problem Solving', in *Distributed artificial intelligence*. Elsevier, pp. 37–54. doi: 10.1016/b978-1-55860-092-8.50006-x.

Star, S. L. (2010) 'This is not a boundary object: Reflections on the origin of a concept', *Science Technology and Human Values*, 35(5), pp. 601–617. doi: 10.1177/0162243910377624.

Steyaert, J. and Gould, N. (2009) 'Social work and the changing face of the digital divide', *British Journal of Social Work*, 39(4), pp. 740–753. doi: 10.1093/bjsw/bcp022.

Tregeagle, S. and Darcy, M. (2008) 'Child welfare and information and communication technology: Today's challenge', *British Journal of Social Work*, 38(8),

pp. 1481–1498. doi: 10.1093/bjsw/bcm048.

Williams, H. *et al.* (2015) ‘Dynamic consent: a possible solution to improve patient confidence and trust in how electronic patient records are used in medical research.’, *JMIR medical informatics*. JMIR Publications Inc., 3(1), p. e3. doi: 10.2196/medinform.3525.

Wilson, L., Wilson, R. and Martin, M. (2020) *Health and Care Practitioner Insights: Understanding Information Sharing in Constellations of Care - Report on Amy’s Page workshop series*. Great North Care Record. Available at: <https://www.greatnorthcarerecord.org.uk>.

Wilson, R. *et al.* (2011) ‘Re-Mixing Digital Economies in the Voluntary Community Sector? Governing Identity Information and Information Sharing in the Mixed Economy of Care for Children and Young People*’, *Social Policy and Society*. Cambridge University Press, 10(3), pp. 379–391. doi: 10.1017/s1474746411000108.