# Human-Data Interaction in the Context of Care: Co-designing Family Civic Data Interfaces and Practices

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## ABSTRACT

By storing data about citizens for the purposes of service provision, private and public organizations have disempowered the people they serve, shifting the balance of power toward themselves as data holders. Through three co-production engagements involving families receiving "early help" support from their local authority and support workers involved in supplying this care, we have identified existing data usage practices, explored the impact of those practices upon the supported families, and co-designed new and improved approaches – both technological and practice-based – that are perceived to offer families fairer treatment, greater influence, and to benefit from better decision-making.

**KEYWORDS:** family civic data, human-data interaction, participatory design, family data interaction, storyboarding, interaction design, boundary objects, locus of decision-making, data access.

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Our findings show that by applying Human-Data Interaction and giving supported families direct access to see and manipulate their own data, both during and outside of the support engagement, the locus of decision-making could be shifted towards the data subject.

## 1 INTRODUCTION

In recent years, service organizations in both the public and the private sector have embraced data warehousing and have reconfigured their organizations to replace local, human interactions with large-scale data processing, call centers, self-service portals and algorithmic decision-making [1]. As a result of adopting such digital approaches, there has been a cost for service users – increasingly data is used as a proxy for user involvement [2], and a power imbalance has been created where users have less agency over their data, and less involvement in the decisions that affect their service interactions and their lives [3]. In order to identify citizens that may be at risk of poverty or crime, local authorities in the UK now offer "Early help services", which provide social support to residents before they become in need of statutory social care [4]. The Troubled Families Programme [5] was set up in 2014 as an early-help-based civic policy to help at-risk families "overlooked" by systemic handling, through regular face-to-face engagement with an individual support worker. The worker is informed by data and backed by a team of professionals from their "constellation of care," including health visitors, social housing officers, schools or police. The early help context provides a useful setting to explore how data is used in practice, and to explore what improved practices might better help citizens. As the WEF suggests, people need to be "empowered, giving them the power to influence how [their] data is used, while being careful not to conceal the value of personal data and its use." [3] Previous work in exploring the social impacts of data usage in a care service context have tended to focus solely on either a practitioner/ provider perspective [6] or a service user perspective [7]. We believe that examining the support interaction as a whole, through co-production activities with both groups, can yield a greater understanding of how data use affects personal empowerment, and how care could be improved by rethinking data practice. The data for this paper were collected as part of the interface development work for the SILVER project[8]. The data is part of a wider PhD program of work.

## 2 STUDY DESIGN

In earlier work with families [2] and with support workers [9] from similar populations, we had established that both parties have a desire for greater access to family civic data; however, the priorities of the two groups appeared to be different, with workers seeing data as a means better to inform family care, and families seeing data as a means to achieve greater inclusion, fairer treatment and empowerment within official processes. On this basis, we designed a series of participatory design engagements (see Fig. 1), first with families and support workers separately, and then together. These first explored the two groups' perspectives on how data is used within the support relationship and how current practices with data affect that relationship. These explorations informed the co-design of new data practices that could improve the support relationship and redistribute power towards the family.

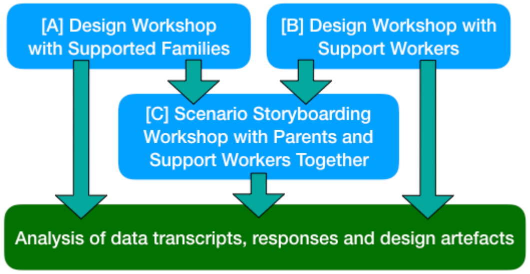

**Figure 1: Overview of participatory design engagements for this study**

**Figure 2: Ideation Grid Exercise (workshops [A] & [B])**

**Figure 3: Extract of sample scenario storyboarding exercise walkthrough (workshop [C])**

Three 2-hour workshops were conducted: with families [A] (8 parents, 9 children), with staff [B] (36 workers), and together [C] (3 workers, 4 parents). In workshops [A] and [B], sensitization tasks were designed with the aim of bringing participants to an informed understanding of the problem space. Families were invited to use Family Data Cards[2] to express what access they would need to different types of data, recognizing they might not be familiar with thinking in these terms. Staff, already familiar with data, received a presentation to focus them on the family perspective. All three workshops began with a ranking task. Groups were presented with sentences from a pool and asked to classify their agreement with each, and rate its importance. The sentences (Table 1) were derived from prior findings from earlier work [2][9] and were intended as provocations to stimulate debate, sensitize participants and establish a consensus understanding of design requirements. [A] and [B] followed with an ideation task using ideation grids [10] (Fig. 2). Participants then created posters imagining family data interfaces (Fig. 5, 6). Groups were then invited to discuss impacts of data use within fictional scenarios. Workshop [C] built upon this: participants used storyboard cards (Fig. 3) to map out how the support interaction would flow in each scenario, and how data would be used. All activities were audio-recorded and transcribed, then coded and organized through reductive data display cycles, as per the Miles and Huberman framework [11]. Card choices, rankings, poster designs and other outputs were examined to add context during text analysis.

## 3 FINDINGS

From the sentence ranking exercises, we deduced aggregate opinions on various aspects of data handling (see Fig. 4 and Table 1). There was universal agreement that families should be treated like people (S4), should have rights to see their data (S8), and should always be able to talk to someone about their data (S7). Participants agreed information must be fair and accurate (S12); that looking at data doesn't tell the whole picture (S14); and that workers need access to mental health details (S13). There was near universal disagreement that an initial consent check at the start of the relationship is sufficient (S3).

Analysis of the 120,000-word workshop transcript corpus[1] identified 38 existing (reported) or imagined practices concerning family data. All participants saw the direct access and usage of data. in the context of a supportive conversation as universally positive and highly beneficial to the supported families' care–only 2 of the identified practices had negatives or risks identified. The 38 practices, classified as *current*, *emerging* or *imagined* are shown in Table 2, 3 and 4 respectively. Our findings, expressed as advice for an optimal support relationship, are consistent with the following six key suggestions that participants believe will help support the families, which are each linked back to the practices and sentences in Tables 1-4. Statements are not given equal weighting given there were different activities involving different numbers of participants.

**Figure 4: Ranked opinions about sentence provocations aggregated from all three workshops.**
See Table 1 below for the sentences mapping to each sentence number in the graph.

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[1] Data supporting this publication is not openly available due to confidentiality considerations. Access may be possible under appropriate agreement. Additional metadata record at http://dx.doi.org/10.17634/154300-107. Please contact Newcastle Research Data Service at rdm@ncl.ac.uk for further information or access requests.

**Table 1: Ranked sentences (Legend for Figure 4)**

| *#* | *Sentence / Provocation* |
|---|---|
| S1 | A family's data should all be joined up and looked at together. |
| S2 | Any info from more than five years ago should be hidden from staff. |
| S3 | Asking for consent to share data just once at the start is enough. |
| S4 | Councils should treat families like people, not records in a database. |
| S5 | Families don't want to be responsible for looking after data. |
| S6 | Setting privacy preferences is annoying and tedious. |
| S7 | Families should always be able to talk to someone about their data. |
| S8 | Families should have rights to see their data and how it is used. |
| S9 | Families will be willing to spend time checking their data is correct. |
| S10 | Families won't mind their data being collected if they can see it. |
| S11 | Families' data should be private unless they say it can be shared. |
| S12 | Information stored about families must be fair and accurate. |
| S13 | It is important for support workers to know mental health details. |
| S14 | Just looking at data doesn't tell you everything about a family. |
| S15 | Labels like "domestic abuse" are damaging & hard to shake off. |
| S16 | Numerical scores are useful for comparing family progress made. |
| S17 | Officials should be able to see historical records about families. |
| S18 | Good judgements can be made just by looking at families' data. |
| S19 | Support workers make better decisions with more family data. |
| S20 | Support workers should be able to see family medical records. |
| S21 | Police should see all a family's data. |

**(i) Workers should use family data positively, to build empathy and trust.** Existing practices of reviewing family data before and after support visits are perceived to be effective, when used by workers to develop and maintain a strong understanding of the family's lived experience which they can demonstrate through conversation. One risk identified of this practice was that when information is viewed by workers in advance, this supports prejudice – one worker gave an example of police being called to an argument at a family's home and it being recorded on their record as "domestic abuse" which resulted in the family subsequently being judged unfairly. (S4, S15, S16, S18, S19, X1, X3, X5, X7, Y2, Z7)

**(ii) Data holders should be transparent with families about data handling processes**. Workers are beginning to share some specific details with families about how their data is being used. Browsing data together could foster even greater trust, as this exchange from [C] shows:

*Parent: [if the worker knew sensitive medical information] I'd be annoyed, I'd be like "How did you get all this?"*
*Worker: That'd be my first reaction [too...] but if we [were to] browse the information together, [it'd be a lot more productive].*

Workers must proactively counter the inherent knowledge imbalance of the current council-held, family-inaccessible databases. But since workers have no control over the quality, coverage and timeliness of family data they see, this is a systemic, not a practice, issue. (S8, X6, Y9, Z1, Z5, Z11)

**(iii) Support services should directly involve the family with their data.** Direct use of data records within support conversations can enable reflection and planning conversations. Families can be explicitly invited to contribute data on their own perspectives. Data can be recorded visibly, in front of the family, who can then digitally "sign-off" their approval of the record's accuracy. (S8, Y3, Y4, Y10, Z12, Z13, Z15)

**(iv) Workers should take care to support and recognize change**. Current systems and processes do not reflect the continually changing nature of a family's reality, and so workers should, with the families, conduct regular reviews of data records (to ensure they are kept up-to-date) and of families' consent (to reflect any changes in their preferences around data handling). Workers need to ensure that data is never mishandled, that consent is never assumed or broken, that privacy (at both a family and individual level) is always respected, and should always be seeking to build a more complete picture of the family through data. Independent oversight may be required to judge contentious issues such as which information "needs to be known" when legal obligations may overrule consent, or when a family feels unfairly treated. (S1, S3, S9, S11, S12, S14, S19, S20, X2, X4, Y1, Y7, Y9, Z2, Z3, Z6)

**(v) Families would benefit from new data interaction capabilities**. Families need to be able to view their own data *"in their own time, at their own pace"*, as one parent put it, in order to identify issues and hold data-holders to account. They need to be able to initiate conversations or queries about their records at any time, as the opportunities presented to them by the support relationship are limited in time and coverage. Families need to be able to get mistakes corrected and add their own perspective to potentially misleading records. (S7, Z14, Z16, Z17, Z18)

**Table 2: Current effective practices**

| *Activity* |
|---|
| X1 Workers review family data before contact. |
| X2 Respect family & individual privacy. |
| X3 Show and maintain deep understanding. |
| X4 Avoid data mishandling (unexpected uses). |
| X5 Treat family like people, not records. |
| X6 Explaining how data will be used & shared. |
| X7 Use strength-based approach with data. |

**Table 3: Emerging practices**

| *Activity* |
|---|
| Y1 Ensure that consent is never assumed. |
| Y2 Avoid forming judgements based on data. |
| Y3 Talking to families with reference to data. |
| Y4 Use data within planning conversations. |
| Y5 Data summaries available to both parties. |
| Y6 Visual presentation of data to families. |
| Y7 Deal with data at different levels. |
| Y8 Visible data recording with family sign-off. |
| Y9 Keeping family fully informed about data. |
| Y10 Explicitly involve fam. in data processing. |

**Table 4: Imagined practices**

| *Activity* |
|---|
| Z1 Families directly viewing own current data. |
| Z2 Regular reviews of data/consent w/ family. |
| Z3 Independent oversight - contentious issues. |
| Z4 Systems & processes that support change. |
| Z5 Promote an open data-sharing culture. |
| Z6 Always seek a more complete picture. |
| Z7 A 'feed' of updates of family data changes. |
| Z8 Checking the data records together. |
| Z9 Workers to be open as possible about data. |
| Z10 Meaningful data access (clear, supported). |
| Z11 Proactively counter knowledge imbalance. |
| Z12 Families annotate data with new info. |
| Z13 Family create/contribute own data. |
| Z14 Family able to initiate conversations. |
| Z15 Family manages data access controls. |
| Z16 Family able to get data changed. |
| Z17 Family able to question own data records. |
| Z18 Individuals having own interface to data. |
| Z19 One single place for family data access. |

**(vi) Access to data is insufficient; simple, meaningful information should be available**. Workers must use vocabulary and communication appropriate to the literacy and/or cognitive abilities of the supported families. Summaries and overviews of data records are critical communication tools. Visual representations such as graphs and timelines can be a powerful aid to understanding. A single, unified point of information access was desired by many (in contrast to the myriad separate systems in use today). (X6, Y5, Y6, Y7, Y8, Z10, Z19)

# 4 DISCUSSION

## 4.1 Shifting the Locus of Decision-Making

The need to move the data subject closer to the handling of their data can also be expressed as a need to shift the *locus of decision-making (*LDM). This concept (distinct from "locus of control" and "locus of power") refers to 'the place where decisions are made'. It may or may not coincide with existing authority structures. It seems that decisions are made close to where data is accessed. In an effect that has been expected since as early as 1970 [12], the increasing use of data in services across private and public sectors has concentrated the LDM with data holders, who collect service users' data to serve their own purposes. This is borne out in our findings, where staff talked about the acquisition of consent as a one-time formality, after which they were free to use the data records however they wished. An existing example of an effort to move the LDM closer to users can be seen in the WHO Decision Making Tool, which developed a counselling tool to support family-planning counselling in three developing countries [13] – this particular tool was successful by transforming support processes to be more evidence-based.

## 4.2 Rethinking the role of data in service interactions: Data as boundary object

Our participants described perceived benefits of direct and thoughtful data usage in almost all of the activities identified. Furthermore, there seems to be a theme that in the mind of the practitioners the more 'tangible' and 'understandable' the data, the more effective the conversation—for example, workers described the benefits of using numerical data points to set goals, track progress and celebrate achievements. The mobilization of representations of family data [14] within the support conversation between families, family members and practitioners could be potentially effective because it might function as a 'boundary object' that both parties can relate to and use as the way of generating co-created understanding, with the risks that this may entail [15]. Our previous work showed that conversations about data can be improved by using representations of data as detached-but-relatable 'things to think with' [2]. The WHO study's success suggests that direct use of data in practice can be transformative; our findings offer specific practices for using family data within the early help relationship which can now be evaluated in practice.

# 5 CONCLUSION

Through our co-design work with support workers and supported families, we have shown that a power and knowledge imbalance exists: the locus of decision-making rests much more with the local authority data holders than the families.

**Figure 5: Example interface for viewing school attendance data created by a participating family in workshop [A].**

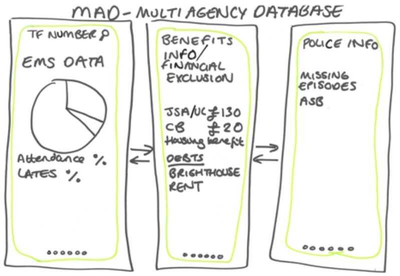
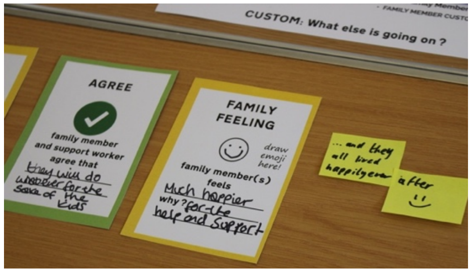


**Figure 6: Example interface design for viewing family civic data including school, benefit and crime data by a group of support workers in workshop [B].**


CUSTOM: What else is going on?

AGREE

family member and support worker agree that they will do whatever for the sake of the kids

FAMILY FEELING

draw emoji here!

family member(s) feels Much happier why? for the help and support

... and they all lived happily ever after

**Figure 7: Part of a completed storyboard created by a parent/worker team in workshop [C].**

Support workers act as gatekeepers who control what the data subjects (the families) can know about how they are represented in data and how they are represented in data and how their data will be used. Families are not currently involved with data for which they are the subject, and this lack of involvement can cause issues of fairness, trust and capability. We have identified specific data use practices that participants believe would help rebalance power towards the family. These practices collectively can be seen as providing Human-Data Interaction (HDI) capabilities [16], in other words to support them in a direct relationship with their data: *Legibility* (making the data, its handling and any implications transparent and comprehensible) can be seen in findings (ii) and (vi), *negotiability* (being able to make use of your data) in (iii) and (iv), and *agency* (ability to act within the system) in (iii) and (v).

Participants believe that these HDI practices are needed to involve families more in decision-making. In the families' case, this is motivated by a desire for fairness; in the workers' case, by a belief that greater involvement can improve trust and hence support effectiveness. Our work so far provides a roadmap to evaluate the actual benefits of HDI. Our data can be further analyzed to explore differing attitudes to data practice between workers and families, and our six suggestions can be applied as design guidelines in future studies exploring family civic data interface designs or family civic data interaction techniques.

## 6 ACKNOWLEDGEMENTS

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