What Influences Parents and Practitioners' Decisions to Share Personal Information within an Early Help (Social Care) Context? Implications for Practice in Sharing Digital Data across Sectors

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Abstract

Meeting the multiple and often complex needs of families (children, young people and adults) within 'Early Help' support is dependent upon practitioners from different sectors sharing relevant and timely information, after gaining a family's voluntary consent to share information. This article reports on qualitative one-to-one interviews with adults in families ($n = 32$), one mother/father dyad interview ($n = 2$) and focus groups with practitioners ($n = 47$) in five local authority areas in North East England receiving or providing Early Help support. We explored experiences of providing consent to share personal information and consider the usefulness of a digital health data system when providing Early Help support to families. Communication Privacy

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Management theory was used as a framework to analyse the data. Key themes in participants' accounts include the degree of need for help and support; the importance of trusting relationships; stronger and structured joint working practices; and understanding how information is shared. This work provides insights into current information sharing practices for some of the most vulnerable families and the wider social contexts. It has implications for the usefulness of a digital data system that shares GP health data with Early Help services and suggests the role this could have in the parent–practitioner relationship.

Introduction

UK policy highlights the importance of information sharing for improving outcomes for families, children and young people and requires all practitioners to share information to support early identification and assessment of those in need of support (HM Government, 2018a). The Data Protection Act (2018) and the UK General Data Protection Regulations (GDPR, 2018) set out the parameters of information sharing law in the UK. It requires individuals to provide consent for their information to be shared and to have choice and control about what information is shared and whom it is shared with, except under conditions listed under Article 6 of the UK GDPR. One of the legal exceptions to gaining consent is in relation to practitioners being concerned about the risk of harm to a child or vulnerable adult. Early Help services and support are delivered by UK local authorities and their partners to meet the needs of families with children less than eighteen years, and up to the age of twenty-five years where young people have a special educational need or disability. The service, which involves a multi-agency response, supports families who may have multiple and complex needs but do not meet the threshold for statutory safeguarding intervention (HM Government, 2018a). Partner agency practitioners who often but not exclusively contribute to delivering Early Help support alongside a local authority team include health visitors, education and Child and Adolescent Mental Health Services (CAMHS). Specialist service support is arranged depending on the local needs and provisions. Early Help support is guided by an Early Help Assessment in which the challenges and strengths within the family are identified and attempts made to overcome the challenges and build upon the strengths. A team of practitioners is convened depending on the identified unmet needs of the family, to support the family to achieve the change they have identified. Information sharing practice has become synonymous with multi-agency

working to support families and was highlighted by Munro (Department for Education, 2011) as key in the coordination and delivery of preventative Early Help services, and outlined in Working Together to Safeguard Children (HM Government, 2018a). The way information is shared across professional and organisational boundaries varies, however, along with differences in perceptions of professional responsibility outside of child protection.

Information sharing in multi-agency working

Government programmes tasked with improving the welfare of children and families in England have resulted in reformative and sometimes controversial policy changes, affecting families across the continuum of need (Laming, 2003; Children Act, 2004; Cabinet Office Social Exclusion Task Force, 2008; Munro, 2011; Department for Communities and Local Government (DCLG), 2016; HM Government, 2018a). Early Help preventative services are generally based on a family's voluntary engagement, and their agreement to share often sensitive information must be secured. Sharing information may afford better protection to vulnerable children and families, through being more responsive to their needs and reducing the likelihood of families having to repeatedly 'tell their story' to multiple professionals (Jones, 2008) which may cause them distress (Wood, 2016). However, the decision to share and disclose or protect and withhold can mean that practitioners may inappropriately over share or under share information (Richardson and Asthana, 2006). Consequently, practitioners can struggle with the decisions of whether to share or not and the decision is often left to the discretion and justification of social work practitioners (Van Haute *et al.*, 2020).

Previous research in information sharing

Few studies appear to have investigated how families experience and think about information sharing. One notable exception is Morris's (2013) study which examined experiences of information sharing with families who use multiple services, noting families dislike of repeating information and frustration that information is not always shared openly but do so to gain support. Boddy *et al.* (2016) describe the importance for families of disclosure taking place within trusting and empathetic relationships noting that this contrasts with the 'persistent' and 'assertive' language of policy documents, which do not recognise the complex contexts in which information sharing occurs.

Qualitative findings within a statutory social work context highlight the complexity of interagency information sharing in practice (Jones,

2008; Thompson, 2013; Lees, 2017) and illustrate that embedded professional cultures and historical relationships contribute to whether the information is shared (Richardson and Asthana, 2006). Understanding the types and parameters of information, and how to share it, requires practitioners to make difficult decisions (Thompson, 2013). Practitioners can weigh-up the impact of information sharing on their future relationships with families (Bellamy *et al.*, 2008), being mindful of the emotional and affective aspects of information sharing (Lees, 2017). In the context of the current move towards sharing information digitally, both the interoperability of systems reducing the perception of control of information and the rigid structure of individual systems can make sharing on these platforms challenging, especially when considered alongside the time pressures of practice making them difficult to adapt to (Baines *et al.*, 2010; Gillingham, 2013).

Despite the importance of information and data sharing in Early Help support, there has been little research with families and practitioners in this context, relating to electronic data sharing. Considering the voluntary nature of engaging in Early Help support and the requirement of families to 'opt in' to consent to share information, it is essential to understand the context and influence on decision making if digital information sharing is to be of benefit to improving outcomes for families. In this article, we aim to explore what influences parents and practitioners to share information, perceptions of how information is shared and the barriers to information sharing, to contribute to the knowledge gap in understanding how to implement digital data sharing systems in Early Help support. It is intended that these findings could be relevant to other preventative family support contexts. We consider the findings in the context of an increased move towards digital information sharing and the integration of health and social care as part of the Smart Interventions for Local Vulnerable Residents (SILVER) study. SILVER was intended to be a stand-alone digital data-sharing system that would add value to Early Help support by equipping Early Help practitioners with health information that was often missing from support plans. The intention was for this to be a read-only record that could be viewed by the named Early Help practitioner with a parent's explicit consent. This article reports on the first phase of the study, which contributed towards developing a digital system based on the requirements of Early Help practitioners and the families they support, to share electronic data with local authority Early Help preventative services.

Methods

The SILVER study was an interdisciplinary project that explored developing a digital system to share electronic data to support the care of

families accessing Early Help services in five local authority areas in North East England. The study had three planned phases: (i) exploratory phase; (ii) co-production workshops; and (iii) piloting of the SILVER platform for digital information sharing. The data for this article was collected between September 2017 and September 2018 as the exploratory phase of the SILVER study. Qualitative methods were used to investigate the depth and complexity (Byrne, 2004) of key stakeholders' experiences of sharing personal family information within the context of Early Help support and providing or receiving consent to do so. Our research adopts a critical realist approach which views the participant's accounts as evidence of an underlying reality (Fletcher, 2017), whilst at the same time noting that the data are created in interaction (Connelly, 2001). This approach was adopted as it is suited to understand practices about which relatively little is known.

The study conforms to accepted ethical guidelines and gained approval from Newcastle University Ethics Committee (1294/15362/2017). All participants provided written consent to participate in the study.

Sampling and recruitment

A stratified purposive sampling approach was adopted. We aimed to achieve a similar number of participants in each local authority area, practitioners from differing professions and families with a range of configurations; single-parent families, two-parent families and blended families. Parents/carers were recruited via their allocated Early Help worker, who gauged interest in the study during pre-arranged appointments. Parents interested in participating, completed consent to contact form, providing personal contact details which were returned securely to the research team. Researchers then contacted parents to explain the study and where parents expressed an interest in participating, an interview was arranged.

Practitioners were recruited via a key contact within each local authority's Early Help service. These contacts provided a wider network of practitioners who supported families accessing Early Help services, with standard information about the study and a copy of the participant information sheet. Practitioners interested in taking part were invited to attend a pre-arranged focus group that had been organised at a time it was felt would be convenient to most participants.

Data collection

Face-to-face semi-structured interviews were adopted for data collection with parents. The semi-structured format meant the interviews could focus on experiences of information sharing and providing consent while

the open-ended nature of questioning enabled participants to discuss aspects of this that they felt were most important to them (Byrne, 2004). Holding the interviews one-to-one and face-to-face afforded a level of privacy and helped the researcher to build rapport with the participants. Each interview began with the researcher assisting the participant to map the range of services their family received support from, which provided a visual aid to guide the discussion, exploring how they provided consent to share their information, if and how they had discussed what information was shared, and their understanding of how the information was shared. We used a topic guide to structure the interviews. As the interviews progressed and we identified common themes in the data, these themes were followed up in subsequent interviews, including exploring participant's views of how a digital data-sharing system to share health information with their Early Help worker would be perceived. Thirty-four interviews were undertaken by three researchers (K.J., D.S. and L.S.). Participants were mothers ($n = 26$), fathers ($n = 6$) and other caregivers ($n = 2$), from equal numbers of two-parent and single-parent households. Three fathers did not live with their children all the time, and there were circumstances of both regular and sporadic contact. The sample age range was seventeen to sixty plus years, with most parents/caregivers aged twenty-five to thirty-four years. All but one parent identified as white British. Adult family members interviewed will be referred to as parents. Thirty-two interviews were one-to-one and one mother/father dyad interview. Most took place in the family home ($n = 28$); $n = 2$ interviews in the participant's workplace, and $n = 4$ in a private space at a community and voluntary sector organisation they accessed. Interviews took an average of forty-five minutes.

Eight focus groups (mean $n = 7$ participants) were held with practitioners with a range of practice backgrounds, across five local authority areas. They were structured around practice experiences of information sharing and consent. Professional diversity within the groups enabled differing positions and experiences of information sharing to be explored (Clavering and McLaughlin, 2007). Forty-seven practitioners from a range of disciplines participated in focus groups, held in local authority venues in the locality in which they worked; including Early Help and preventative services ($n = 22$); education including early years and pastoral support ($n = 7$); health practitioners including school health, CAMHS, midwifery and health visiting ($n = 6$); offending and justice services ($n = 2$); troubled families data officers and employment advisors ($n = 8$) and other children and community services ($n = 2$) from five local authority areas.

To aid the introduction to the session, group discussion began with the use of a scenario-based tool to prompt practitioners to consider how data for a whole family across multiple organisations are shared. A focus group discussion followed this. Divergent points of discussion were prompted by the researcher. The focus groups took an average of

seventy-five minutes. All the interviews and focus groups were audio-recorded and transcribed verbatim with participant consent.

Data analysis

The method of analysis drew on inductive techniques of thematic analysis (Boyatzis, 1998). Initially, the audio files were transcribed by a transcription company that had signed a confidentiality agreement. The transcripts were checked for accuracy against the audio files and anonymised by two researchers (author initials). This process helped with data familiarisation. Four members of the research team read and re-read the data, and separately coded the parent's data transcripts (D.S., K.J. and L.S.) and the professional data transcripts (D.S., K.J. and H.A.). These researchers worked with the principal investigator (R.M.) to identity sub-themes for two initial coding frameworks, one for the practitioners' data and the other for the parents' data. The data were stored in NVIVO and the four researchers applied the coding frameworks to the data, adding and refining the frameworks where appropriate. The data were then analysed using the lens of Communication Privacy Management (CPM); a theoretical framework that seeks to explain how people make decisions about sharing their information (Petronio, 2002). CPM theory highlights that people perceive ownership over their private information and that because they own their information, they can choose to share it with others (Schoeman, 1984). Using the metaphor of boundaries, CPM posits that three privacy rules influence if and how private information is shared: permeability (breadth and depth of information shared), ownership (the extent of control the co-owner has over the information) and linkages (how people negotiate the sharing of information aside from the current co-owner). The findings of this article are organised under these three broad themes, with subthemes of getting the right help; the importance of trusting relationships; understanding of how information is shared; boundary turbulence and stronger and more structured joint working practices.

Findings

Boundary permeability

Getting the right help

There were varying reasons families accessed Early Help services including parental skill development; family dysfunction; parental mental illness; the on-going impact of domestic abuse in previous relationships and children diagnosed or undergoing assessment for mental health

conditions. Most mothers described that before accessing Early Help support they had taken responsibility for coordinating their family's care. This involved repetitively sharing information with multiple care services. Some parents said that the right package of care had not come readily, and they had to ask for help multiple times. Once engaged with Early Help, getting the right help became the incentive to provide consent for information to be shared directly between services. Parents acknowledged that they would need to share information about themselves with their lead practitioner, who would then share it with other agencies to get access to the support they needed.

> Like I say, we were lost beforehand through that. [They] just didn't bother, but since (s)he was at [school] it just all fell into place. We're getting all the help everything has just come together. I'd been trying to get it for years, but I just couldn't
>
> (Participant 2, Mother of three children).

Importance of trusting relationships

The quality of the relationship with the lead professional ultimately affected whether families felt they could trust a practitioner with their data. Overall, the parent's accounts pointed to the importance of good and trusting relationships with practitioners to aid their willingness to consent to share information and data. Trust was underpinned by tasks being actioned, progress being achieved and families feeling that they had been listened to. Within the context of a trusting relationship, the lead practitioner was often perceived as the 'safe keeper' of information. Some parents said that information, such as historical substance use when the parent had been in recovery for many years, was too personal or sensitive to share. Parents worried about being judged by professionals, particularly if data sharing was completed electronically without supplement of the explicit information that the trusted professional could provide. This was often influenced by previous experiences with statutory services and concerns about sharing sensitive information and data around mental illness, substance use or offending history. There was little consensus within both parents' and practitioners' accounts about the appropriate level of boundary permeability when discussing sensitive historical data, and the conflicting beliefs of relevance to the current family context.

> I don't always like everybody to know my past history ... but I think they have to know because if they're working with you, they have to know everything about you and they have to know your history
>
> (Participant 24, Mother of two children)
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> I think, for me, obviously, it's talking about your past, because that's exactly what your past is, but it does seem to follow you. Although

you've dealt with it and got past it, the people that are meeting you for the first time are only just knowing

(Participant 8, Mother of three children).

A small number of participants described times when they had not wanted to share information with practitioners for fear of being judged which had resulted in not being able to access the help they needed. The fathers in the sample who did not reside with their child(ren) explained that contact with professionals supporting their children was irregular. The main caregiver, usually the child's mother, was the main point of contact for practitioners to obtain and share information. They expressed their wish for professionals to build a relationship with them and not feel pre-judged because of historical information.

... I never see them anyway, everyone just goes to my mum now. I'm just in the background. I'm the dad, and everything like that, but ...

(Participant 34, Father of two children).

Practitioners from across sectors acknowledged a parent's need to trust practitioners if family information is to be shared. Allowing time for relationships to develop encouraged information sharing on the part of both practitioners and parents.

It's also dependent on the information that the parent/client, whatever, gives you, because often the bigger picture develops over a period of time as more trusting relationships are made as the different members of multi-agency teams join in the team around the family

(Area C focus group 1).

Trust and good working relationships were also important to practitioners' willingness to share information with other agencies. Several practitioners referenced being more likely to share information with other workers and agencies they trusted than those they did not.

Co-ownership of information

Understanding how information is shared

The parents handed over the responsibility of their information to the safe keeper, including the ability to share information with others with whom the parent was yet to build a trusting relationship with. A trusting relationship led family members to assume that their information would only be shared for the right reasons as the quote from a Mother below illustrates.

You've always got to be able to trust the people that you're working with. I think it's down to them to make the right kind of judgements

(Participant 16, Mother of three children).

Family perceptions of how Early Help practitioners shared their information with other professionals, particularly across sectors varied, with reference made to information and data sharing occurring both formally and informally. The parents' accounts suggested they were aware that their information was shared between professionals but could not definitively explain the arrangements.

> I know, obviously, the Early Help and the health visitor, and generally Sure Start because they're all in the same building, even if it's just passing in the office or emails, whatever like that. I know they do communicate, because they can be... Like, my health visitor, I might see her and I'll go, "Oh, I'm having a bit of a down day," or something like that, for whatever reason. Then, like, four hours later I'll get a phone call off my Early Help worker. "What's the matter?" It's like, "How do you know?" I know they do communicate behind my back, but in a good way, sort of thing
>
> (Participant 27, Mother of one child).

A small number of parents could recall specifically negotiating ownership and privacy rules with the Early Help practitioner, wherein they identified which professionals and what information they were happy for them to share, whilst others trusted their Early Help practitioner to make that judgement. Parents were reassured that practitioners would have a clear purpose for sharing information with other practitioners before doing so and as such, appeared to be comfortable with the co-ownership arrangements linked to their privacy boundary. However, they could not often recall circumstances in which they had explicitly discussed this with their worker. Arrangements for sharing information in circumstances in which a child was at risk of harm were recounted more readily.

Although practitioners described seeking consent from families to share their information, there was uncertainty amongst professionals as to whether parents truly understood the extent to which they were agreeing for their information to be shared.

> But do they actually know who that information is shared with? That's my question. I don't think families know the extent of where information is shared . . .
>
> (Area B focus group 2).

Boundary turbulence

Boundary turbulence occurs when there are disruptions, mistakes or breaches in the control or flow of information co-owners of information have not reached an agreement of how and when information can be shared beyond the current owners (Petronio and Durham, 2008). Within many of the focus groups, practitioners reported an absence of an

established protocol for information sharing and referred to a subsequent lack of clarity or understanding in what was acceptable to share. This often generated a fear of organisational accountability. Practitioners also acknowledged their professional views on sharing information were influenced by their personal perceptions, particularly in relation to health information.

> Individual practitioners are quite happy to share, but it's just the boundaries of our organisation that sometimes you get like, 'Am I going to get fired if I tell them that?'
>
> > (Area D focus group 1).
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> I think the other aspect about sharing is people just don't know that they can and can't share, and that's an interpretation of that, the people who want to share will share, and others are just thinking, 'Hang on a minute, I could get disciplined or lose my job,' or they're just told not to
>
> > (Area B focus group 1).

Whilst practitioners were typically clear about the parameters of information sharing within their employing organisation, they rarely understood the parameters of data sharing of cross-sector organisations and were unclear why the approach differed between sectors, for example between local authority and health. This led to frustration when information was not shared in the way they expected and hindered understanding of a family's current needs. Perceived lack of co-operation impacted the likelihood of some professionals attempting to request information if they believed their attempts to secure family information would not be successful.

It was notable that several Early Help practitioners said they did not try to source information from health colleagues because they perceived that it would not be shared with them due to governance arrangements.

> …you've got to do your own investigations…basically, to find out what information you need and where you're going to get it
>
> > (Area B focus group 1).
>
> I think it can be difficult in terms of governing bodies in terms about, you know, that governance within health is very clear in terms about sharing information and within CAMHS, there's psychiatrists, psychologists, nursing, social workers, there's all different agencies within there and their governing bodies have a different opinion in terms of- not opinion, but guidelines they've got to follow in terms of consent
>
> > (Area B focus group 2).

Several practitioners providing early intervention said that securing health information from health colleagues was difficult. Practitioners perceived this barrier to relate with health providers lacking confidence

that consent had been provided by the family. Furthermore, it was reported that health colleagues would often question the legal basis for information sharing. The subsequent absence of health data was felt to greatly impact upon the Early Help assessment and full understanding of a family's need for support.

> GPs are reluctant to share information with us because it's their information and they have to keep hold of that information because they haven't had the consent, you know? Sometimes that's quite valuable to us when we're looking after our families and it could be the troubled families or if it's a mam with mental health problems, so, people who could help support mams and stuff like that
>
> (Area C Focus Group 1).

Linkages

Stronger and more structured joint working practices

There was a general sense of a move over recent years, towards better multi-agency information sharing for the perceived benefit of families. This was reflected in how practitioners communicated with each other, often within multi-agency meetings. There was a belief that local authority implemented arrangements (such as professional conversation protocols being in place to enable practitioners to share data about families) to aid multi-disciplinary data sharing had improved.

> I think our partnership working is stronger and our communication links, within that, are stronger. That's more vocally as opposed to system. So, [practitioners] kind of are more confident in a multi-agency arena and professional meetings to share information without barriers, whether that's right, wrong or indifferent. I think that that's something that's moved forward positively and has improved outcomes because we'll share that information, confidently knowing that it's about getting better outcomes. So, some of the barriers have been removed with multi-agency working
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> (Area C focus group 1).

An allocated practitioner from a local authority Early Help team was usually the main point of contact for a family and had oversight of their plan of support. Families' experiences of support from Early Help services generally followed the model of a Team Around the Family (TAF), which involved multi-agency practitioners and family members attending meetings to discuss successes, challenges and plan support. When the model of support was perceived to be working well, many mothers felt that effective information sharing took the pressure off them to be in constant contact with all practitioners within their family's team.

> I was very thankful that [family support worker], who was the family support, was going to take over all the calling around and the constant chasing people up from what I'm trying to do while I'm working. So, she took over that for me, so it's been a massive relief

(Participant 20, Mother of three children).

However, it was acknowledged that information sharing arrangements to promote cross-sector sharing had not developed at the same rate in all disciplines. Information sharing between health and social care services remained challenging. Notably, with the exception of health visitors and public health nurses, the involvement of health colleagues in TAFs was scarce. As the TAF was the established means of information sharing, with inconsistently implemented alternatives, there was a paucity of input from health into the multi-agency support of families. Several parents expressed frustration about the lack of interaction between health practitioners which impacted the timeliness of care.

> It's quite hitty-missy because CAMHS aren't the greatest at keeping up to speed... I was meant to get shared care sorted between the mental health service for my son and the GP so the GP could prescribe his medication to save me having to ring... Nothing was done. So, again, it just feels like you're continually having to chase up things. "Has this been done? Has this been done? Why has this not been done?"

(Participant 26, Mother of three children, and pregnant).

There was further frustration from practitioners who acknowledged that even when alternative opportunities for information existed in the form of electronic systems, these had not progressed sufficiently to support cross-sector digital data sharing.

> ... We have health visitors who now work for the council, but we still can't access their data. They use [system name] but we don't have it

(Area B focus group 1).

Discussion

The findings of our research illustrate that both parents and practitioners are broadly supportive of multi-agency information sharing and that where it happens, it is generally considered beneficial to the care of families with multiple and complex needs. By applying a framework of CPM theory, we were able to show that the parents could see a benefit of allowing key information to be shared and permeate their privacy boundary. Parents were willing to negotiate co-ownership of their information with Early Help practitioners; typically expressing high confidence in the Early Help practitioner's ability to effectively manage their information, however, it is important to remember the trepidation expressed by some families in relation to sensitive information such as

historic substance use. Boundary turbulence was experienced by practitioners who often expressed professional vulnerability when seeking to control and manage the appropriate flow of information. This was most notable when applying linkage privacy rules when the Early Help practitioner sought to push or pull information with other professionals across organisational divides. Whilst there are examples of effective information sharing within multi-agency networks, the influence of interpersonal relationships between professionals to such practices persist. Typically, information sharing across organisational boundaries is reliant upon regular, in-person interactions, sharing information that is 'known' rather than data that are stored. Where interpersonal relationships are less developed, or there is infrequent contact, information was rarely shared even when explicit consent from the parent had been provided. This was particularly evident when considering the flow of information and data between health and social care. These findings raise discussion of several issues relevant to all organisations and practitioners providing consent-based preventative level support to families. Whilst practitioners working with families across the continuum of need share information to safeguard children and their families, there are significant differences in the legal parameters of those providing support outside of statutory provision. Where a child's safety may be at risk, the UK GDPR and Data Protection Act (2018) provides a legal basis for information sharing without consent, and the Children Act (2004) places a duty upon key organisations to share information. Families accessing support from any organisation at a preventative level have a right to choose to share their personal information or not without this restricting the direct support they can receive from any single agency. Practitioners must fulfil their role in relation to information sharing within the parameters of their organisational and professional boundaries (HM Government, 2018b) and have learned to do so by navigating social aspects that influence information sharing to be of greatest benefit by developing inter-personal relationships. The findings of our research highlight the importance of parents observing a balance within the risk and benefits before choosing to negotiate co-ownership of their private information. The power associated with the roles practitioners have in navigating access to support for families can be persuasive and questions the basis on which families provide fully informed consent. Jupp (2005) highlights the need for social work practitioners to consider the power balance that exists between them and the people they provide support to as well as those present in the systems in which they operate. Taking an approach to seeking consent to share information has the potential to empower families if as Jupp (2019) suggests this is in a facilitative rather than directive capacity, balancing this with a family's right to privacy.

Previous qualitative studies point to the complicated and nonlinear ways that information is shared between practitioners and the

complexity of factors that affect information sharing. Differences in professional culture (Richardson and Asthana, 2005) time pressures from everyday practice (Baines *et al.*, 2010), and practitioners adopting different strategies to determine their justification to share information (Van Haute *et al.*, 2020) highlight the influencing factors. The accounts of families using multiple services, (Morris, 2013), highlights the need to include family members not living in households with children, including fathers, if all members providing care are to remain abreast of changing family circumstances and support plans. This omission often leaves family members to share difficult information with each other. Morris' findings resonate with the accounts of fathers not residing with their children interviewed in this study and highlight this aperture as contributing to a child's unchanged world; conflicting with the very reason information sharing is promoted; to safeguard children. The gendered dichotomised view of fathers as either a 'risk' or 'resource' contributes to a failure in 'whole family' approaches which do not effectively engage fathers (Philip *et al.*, 2019). A digital information sharing system capable of holding multiple individual level consents for family members who do not reside together would assist practitioners to understand the health status of multiple caregivers and better inform their assessment of a child's current experiences, and overcome some of the barriers to the effective whole family working.

In the UK, the move towards the integration of health and social care, and the promotion of cross-sector digital data sharing systems continues to pick up momentum, albeit at a faster pace within adult social care than children's social care.

Whilst it was intended that the SILVER digital information-sharing platform would progress to the pilot phase, the project experienced delays within the information-sharing agreement stage and as such, we were unable to complete all stages of the project. However, this study highlights the important learning for those developing costly digital information-sharing systems that are assumed to improve information and data sharing, not to lose sight of the reasons parents and practitioners chose to share information and the factors that encourage and deter it. Digital systems that automate data sharing independent of practitioner supported information sharing are unlikely to be considered an acceptable means of sharing sensitive data, particularly when the parent does not recognise it as being currently 'relevant' to their care. Determining relevance, however, presents a great challenge (Cairns et al., 2018). Sharing a health record with social care would include healthcare-relevant data; the purpose and necessity of this information may not translate into a social care setting and the perceived benefit of the boundary permeability is lost. The significant variation in the needs of the families being supported by Early Help services further precludes the ability to determine *a priori* relevance of information.

Socio-technological factors will greatly influence practitioner acceptance of digital approaches to information sharing (Kutia *et al.*, 2019). Digital data should seek to support interpersonal relationships between parents and practitioners as well as inter-professionally, rather than replace this. The absence of regular professional interaction between key areas of health and social care gives support to the use of digital information sharing between these organisations. General Practice is most closely aligned to Early Help preventative services, with access to information most likely to offer the greatest benefit to the largest number of families. The automated flow of data via a digital system following the logging of parent consent should act as a prompt to initiate discussion about sensitive topics with both the family and GPs, to determine relevance to current family circumstances and risk. Such an approach to the integration of digital information sharing within Early Help support will facilitate further the lead practitioner role within the multi-agency response whilst also avoiding practitioner resistance which has been found in cases of over-integration of client information within an information technology system (Baines *et al.*, 2010). The use of a system that shares digital health data with Early Help practitioners would remove the influence of practitioners' personal beliefs about sharing health information and would rely largely upon individual parents' decision to share their health records or not. Sharing health data would no longer be at the discretion of the practitioner, but the parent. Moreover, the digital platform could make explicit the consent process and agreement which our research found few parents were able to recall.

Study strength and limitations

To our knowledge, this is the first study that has sought to understand how parents engaging in Early Help services perceive and experience their sensitive data being shared, to build a digital information-sharing system that is acceptable, beneficial and meets legal requirements. The study was a collaboration between academic and practice partners, ensuring robust and ethical conduct. Three researchers (D.S., K.J. and L.S.) with extensive qualitative experience interviewed both parents and practitioners; two of whom have a practitioner background delivering services to families and young people. Knowledge of the services and systems that family's access and navigate was essential to provide context and probe questioning.

A limitation of the study is that only parents who were in contact with an Early Help practitioner at the time of the study were invited to participate. We did not interview parents who had disengaged with support and may therefore have been dissatisfied and provided different accounts of their experiences of sharing information. Similarly, we did

not interview families who had gone on to later access statutory Children's Social Care. As these families are likely to hold a different view on information sharing between services, this remains an area of study that requires further exploration. To minimise this limitation, we probed around past involvement in services in interviews with parents and negative experiences of information sharing within practitioner focus groups. As parent and professional participants were able to relate their experiences to occasions past and present of both positive and negative information sharing, we anticipate that socially desirable responses was mitigated. The parent sample was overrepresented by people from a White British background and thus this limited exploration of differing cultural attitudes towards information sharing. Early-help workers reported limited contact with fathers who were not the primary carer, this is reflected in the number of fathers recruited directly from Early Help services and the need to approach a specialist voluntary sector project to fill this gap in recruitment.

Practitioners engaged in Early Help support participated in the study, which resulted in General Practitioners not being represented, as they do not routinely form part of a team around the family structure.

Within our interviews with parents, we probed around both in-person information sharing and digital data sharing. Parents made little distinction between their information and their data, beyond contrasting a practitioner's ability to negotiate appropriate detail relating to sensitive or historical information and the unfiltered presentation of facts stored within a data system. Health data being shared digitally was discussed as a concept, as this does not currently occur between health services and Early Help services, and therefore participants could only reflect on how they would perceive this to be of benefit or challenge. Further research is needed to pilot the experimental system and examine its acceptability to parents as well as its usefulness to Early Help practitioners in their efforts to support families with multiple and complex needs.

Conclusion

Our study has identified a need for digital information sharing between general practice and Early Help support based on appropriately informed consent. Our findings contribute to understanding the information sharing practices of some of the most vulnerable families and the practitioners who support them. It has implications for the usefulness of a digital health data sharing system and suggests areas for consideration in a systems approach to digital information sharing development.

Those developing and adopting digital data systems need to ensure they account for the relational and social contexts in which information sharing takes place. Moreover, it is important to appreciate the key role

of relationships both between parents and professionals, and inter-professional relationships.

The implementation of data sharing procedures relies on trust-based relationships within complex systems that are designed to safeguard children and family members. The development of a learning health system would aid the construction of a system that would assist practitioners and system developers to understand social, legal and technological influences on information sharing in a way that best supports families.

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