

UNDERSTANDING THE BARRIERS TO SHARING DATA ABOUT UNPAID CARERS ACROSS THE DERBY & DERBYSHIRE HEALTH AND CARE SYSTEM

“One of the [paid] carers said to the other ‘don't listen to her. She's only the family’...And when you said respect, you know, that's it. I'm nobody. I'm nobody.”

(Unpaid carer in one of our focus groups.)

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1. INTRODUCTION- ABOUT THE PROJECT

The 2021 Census data indicates there are 4.7 million unpaid carers (or 8.9% of the population) in England, providing almost £152 billion worth of equivalent care. The House of Lords Adult Social Care Committee (2022) and The Kings Fund (2023) have both warned that without unpaid carers, the social care system would collapse. Although councils have a duty to identify carers in their area and offer them a carer's assessment on the appearance of need, a [recent study \(Alcock et al 2023\)](#) found that at most only 5.1% of carers were known to their council compared to the census. When records held by primary care and councils were combined, at most, 26% of unpaid carers were known to the local system compared to the census. The Alcock study found little overlap in the carer data held, suggesting different groups of carers are being identified by councils and primary care.

Information about unpaid carers is held in different parts of the local care and health system but there are no mechanisms for this data to be shared in any consistent or meaningful way so that carers can be identified early and offered seamless support which enables them to continue caring and look after their wellbeing. The need for shared information on unpaid carers was highlighted during the Covid 19 pandemic when carers were a priority group for vaccination but systems struggled to reach them because there is no co-ordinated register of unpaid carers at either national or local level; whilst some unpaid carers were known to their council or primary care, a much larger group of unpaid carers were unknown to the local health and care system and disadvantaged in taking up the vaccination offer as a result. One participant in the project said that *“there was optimism then [during the pandemic] that this would probably create a new dawn for data sharing [but] I don't think it has for us.”*

If we are to improve outcomes for unpaid carers, and intervene early to prevent carer breakdown, then we need to tackle the barriers to sharing this information. Following discussion with the ADASS Carers Policy Group, regional ADASS sector-led improvement leads and the Department of Health and Social Care, Partners in Care and Health (a partnership of the Local Government Association and the Association of Directors of Adult Social Services), agreed that one of its strategic objectives for 2025-26 would be improving unpaid carer data sharing across local systems –including councils, the NHS, providers, and by carers themselves.

Partners in Care and Health (PCH) provided funding and resources to undertake a targeted support offer aimed at better understanding the barriers to sharing unpaid carer data across two local care and health systems and exploring the feasibility of a data sharing agreement. ‘Local care and health systems’ were defined as councils, primary & secondary NHS care providers, commissioned and non-commissioned carers service providers and community groups, and others identified by the stakeholders in each project.

Outcomes & benefits for participating councils and systems:

- All data generated as part of the project will be returned to the council, anonymised where necessary
- Unpaid carers experience will be central to the design and delivery of this project and will influence recommendations and solutions
- Bespoke report for the local system with key learning and recommendations

- Greater understanding and awareness of local system barriers to data sharing and options for improving this, including using a data sharing agreement
- Greater understanding and awareness of the barriers to carer self-identification and actions which can be taken to increase confidence on the part of carers in coming forward for help
- Evidence in support of improving the experience of carers in accessing seamless support at the right time for them and enabling them to continue caring and look after their wellbeing.

Derbyshire Council were keen to take up this offer of support and worked with local partners to secure the necessary buy-in and commitment. Project Oversight came from a small group of partners including Derby & Derbyshire councils, the ICB, and each council's carers service provider.

2. PROJECT APPROACH AND METHODOLOGY

2.1 There are five elements to the project's design and delivery:

- Project scoping: project design, desk research, including extensive literature review, and identifying two participant councils and local systems – preferably on an ICB footprint.
- Project delivery: interviews, online survey and focus groups with system partners, including unpaid carers.
- Thematic analysis of data (both qualitative and quantitative).
- Sharing analysis, learning and insights with system participants (this report).
- Guage support for the development of a local data sharing agreement.
- Sharing learning and insights from the project with the sector at a national learning event once both targeted support offers are complete.

2.2 Methodology

The project methodology, scoping and desk research was informed by a research study undertaken by the PCH researcher, Liz Greer, into the barriers to professionals and unpaid carers sharing their information with their local system as part of an MSC Research Methods course at the University of Birmingham. The project was designed to test whether these barriers were the most significant ones, identify others not yet considered, and propose some possible next steps for the local system. For more information about project methodology please email pch@local.goc.uk

2.3 Project delivery

There were three elements to the collection of insights relevant to the project:

- A series of 1-1 interviews with key professional stakeholders identified by the project oversight group
- Three focus groups with unpaid carers - online and face to face
- An online insight survey aimed at professionals across the local care and health system

2.4 Analysis of data and insights

Building on the literature review undertaken by the PCH researcher, Liz Greer, analysis of the data and insights collected during the project are structured around key themes identified through previous research on barriers to cross-organisational data sharing and data sharing by unpaid carers. These barriers were not specific to unpaid carers as there is very little research in this area.

2.5 Analysis of carers experiences and perceptions of information sharing

Key learning and insights from the focus groups with unpaid carers are incorporated in [section 7 of this report](#) and have influenced and shaped the recommendations in this report. Given the rich and detailed insights emerging from the focus groups with unpaid carers, we have also produced a more detailed insight report for project stakeholders which you can read by contacting ASCH.ac-commissioning@derbyshire.gov.uk

3. PROJECT PARTICIPANTS

87 professionals and unpaid carers participated in the project.

- 52 professionals participated in the online survey and 11 professionals were interviewed on a one-to-one basis.
- We ran 3 focus groups involving 21 unpaid carers plus 3 one-to-one interviews following direct approaches from carers.

4. PROFESSIONAL VIEWS: BARRIERS TO SHARING DATA ABOUT UNPAID CARERS ACROSS THE DERBY & DERBYSHIRE HEALTH AND CARE SYSTEM

SUMMARY

- A culture of risk aversion and fear of the potential consequences of inadvertently breaching legal and organisational rules around data protection, consent, confidentiality and GDPR.
- Burdensome and complex organisation protocols which stifle attempts to share information
- Lack of a standardised and consistent approach to collecting, reporting and sharing information about unpaid carers, and concerns about data quality and reliability.
- Reluctance by some professionals to share or trust their information about unpaid carers with others.
- Data sharing (both internally and with external partners) is not valued or prioritised by organisations and there is a lack of emphasis on the positive benefits of sharing information.
- The use cases data which is collected about unpaid carers can be limited and not widely understood.

4.1 A culture of risk aversion and fear of breaching data protection rules

By far the biggest barrier identified by professionals working in the local health and care system was a fear of the potential consequences (both for themselves and for their employer) of inadvertently breaching legal and organisational rules around data protection, consent, confidentiality and GDPR. Professionals described a pervasive culture of risk aversion in which there was little or no discussion about the significant benefits that data sharing could bring. Most respondents lacked confidence and understanding about when data can be shared lawfully and for the public good, and as a result, erred on the side of not sharing. This fear and risk aversion is reinforced by employers' mandatory training on data protection which almost entirely focuses on avoiding data

breaches, and what NOT to do, saying little about when information can and should be shared, or the benefits of doing so.

“This combination of fear and ignorance of the legal framework leads some organisations and individuals to take an overly cautious approach to sharing information.” National Data Guardian (2020).

“The conversation around data sharing and linkage continues to focus on the risks – from the individual privacy risks to the reputational risks to data owners and government departments. Yet effective data sharing and linkage ...offers considerable benefits for the public good.” (Office for Statistics Regulation (OSR) 2024: [Data Sharing and Linkage for the Public Good: Follow-Up Report](#))

In many cases, professionals regarded information sharing as an exception, mainly in the context of safeguarding. Even where they did recognise the potential benefits of sharing information, they still felt that the risks outweighed the benefits, added to which were the complexities of securing agreement to share information through burdensome and complex organisational information governance processes. Interestingly, several unpaid carers believed professionals in both social care and the NHS ‘hid behind’ confidentiality, consent and GDPR, and used it as an excuse not to share essential information with them with them about the person they were supporting or about their status as a carer with other professionals.

4.2 Lack of standardised and consistent approach to data sharing

The second most significant barrier for professionals was the absence of a standardised and consistent approach to collecting, reporting and sharing information about unpaid carers, and concerns about data quality and reliability *“...I am not sure we have been thorough in our explanations to carers about how their data will be used. I also don’t think the quality can be assured. This would make me hesitant to share at this time.”*

For councils, a significant amount of carer information is collected on their behalf by commissioned third party carers support providers, alongside frontline staff such as social workers who populate in-house systems; this data however isn’t shared “across the border” as one participant put it. When asked, data analysts were unsure about whether any quality assurance was in place for both in-house and third-party sources for the information they were analysing or reporting on. They were also unclear about the use cases for this data *“[We don’t] always understand how information is used and stored outside of our organisation.”*

There was a tacit acknowledgement that data quality might be poor as once “on the system” it was unclear whose responsibility it was to keep it updated. Several professionals talked about their fears of contacting carers in case the person they supported had died. One data analyst said *“I always put a time barrier on everything because [if] it’s not been touched in 12 months, then I don’t see that as reliable data.”* Overall, professionals were somewhat more confident in the quality and reliability of in-house data than that provided by third parties where there were a greater number of ‘don’t know’ responses, but this seemed to be based more on an assumption than solid evidence. This lack of consistency and standardisation is also illustrated by answers to Question 4e in the online survey which asked professionals whether there was an explicit agreement in place with

commissioned providers setting out what carer information is to be collected and reported back. Most respondents 60% (9) said they didn't know.

Some professionals in our survey held valuable information about carers but had never been asked to share or record it, others said that though supportive in principle of data sharing, their systems weren't up to the task. Professionals were aware there were probably sources of information about unpaid carers which remain untapped eg when the fire service do safety checks. Others felt there was little point sharing information if nothing would change for carers as a result.

Although survey responses suggested a degree of confidence among professionals that their organisation took a standardised approach to collecting information about carers, this was not supported by the narrative sections of the survey, or the 1-1 interviews. As with data quality and reliability, this view seemed based more on an assumption than solid evidence. Professionals were less confident their organisation is clear with external partners and unpaid carers about how information about it uses the information it collects about unpaid carers.

Responses to statements about whether carers can easily find out how their information will be used, and understand how it will be used to improve support for carers in their area, show a significant degree of optimism bias on the part of professionals. There was no evidence from discussions with 24 carers taking part in the project that they knew how their information was being used or who it was shared with, or how it was used to improve services for carers in their area. This is a priority area for action.

4.3 Lack of trust in sharing information with partners

The third barrier centred on the willingness by professionals to share or trust their information about unpaid carers with others. Although 49% (25) of professionals said that they had "no concerns" about sharing their information with other organisations, the narrative sections of the survey suggest more work to build trust and confidence in mutual data sharing would be needed if the system wishes to develop a data sharing agreement. In some cases, concerns about data quality may also affect a willingness to share information. The NHS was especially felt to have a "one way" approach to sharing information-they expected access to partners' data, but not to share their own. Whilst most participants felt that it would be hugely beneficial to have access to GP data about unpaid carers for example, GPs themselves were nervous about the risks attached to this for themselves.

Some in the voluntary and community sector felt they played "second fiddle" to the NHS and the council, and that their knowledge and expertise was not equally valued or trusted. They felt that the benefits of sharing information should be based on collaboration and firmly rooted in the interests of carers; a "top down" approach to sharing information was unlikely to succeed. Any agreement to share information about unpaid carers by commissioned and non-commissioned providers would need underpinned by a commitment to everyone being on the "same page" and fully involved in co-producing it and making it work. One unanticipated barrier emerging from the research was a reluctance to share information between those in the voluntary and community sector who may be bidding for contracts from the council or the NHS and who see their information commercially sensitive. These concerns should be addressed as part of any sharing information agreement.

4.4 Data sharing is not an organisational priority, and the benefits are not well understood

Professionals generally felt that data sharing (both internally and with external partners) is not valued or a priority within their own organisation and this can lead to siloes and a lack of standardisation and consistency which in turn impedes efforts to share data in any meaningful way.

“I feel the value of the unpaid carer data is viewed as low compared to other types of information that is collected and stored. I don’t feel we give enough emphasis to timely completion, accuracy and quality.”

Organisational support for data sharing initiatives generally was felt to be low, often underfunded, with analytics resources frequently diverted to other service areas. There was concern about unfunded extra burdens on carers support providers to collect and report information. Whilst almost all professionals supported the principle of data sharing, anything which increased the pressure on overstretched services would be challenging to implement. Professionals felt that there needed to be much stronger business cases made for sharing information.

This lack of organisational focus on the benefits of data sharing is linked to commentary elsewhere from professionals (and unpaid carers) that the benefits of sharing information are not explicit or widely understood, which in turn impacts on data quality and consistency as professionals and carers don’t know or understand the uses to which the data is being put.

“We are not in the habit of using data to make decisions and [our culture] doesn’t support data sharing or the pushing of boundaries of how data is used.”

“I feel there is a ‘general’ sense [in organisations] that sharing data is a helpful and useful thing to do but I think there needs to be more commitment to the data quality and mechanisms in place to assure carers their preferences for sharing information will be respected.”

When we asked councils and the NHS how the information collected and reported to them by third party providers was being used, the top two uses were to improve the provider’s service to carers and manage contract performance. Strategic planning, commissioning and benchmarking uses of the information were less common which means the visibility of carers’ experience is likely to be low at leadership level.

Some professionals felt that carers wouldn’t want their information shared however this belief needs challenging. Research evidence tells us that where the public feel informed about data use cases, they are much more likely to support data sharing. Carers in our focus groups said that if they knew why their information was being shared, and the benefits of this for them (and the person they support) were explicit, they were happy for this to be shared. There was no evidence from the focus groups with carers however, that this is being communicated to carers by professionals.

“The public’s key concern regarding data use remains data security. It is therefore likely that many people’s attitudes towards data sharing and linkage continue to be influenced by concerns around data security, particularly when data are identifiable. A UK-wide [public dialogue report produced by](#)

OSR and ADR UK showed that the public support the use of government data in research and statistics, as long as they're informed of their use and what safeguarding is in place" (OSR, 2024).

5. PROFESSIONAL VIEWS: KEY BENEFITS OF SHARING DATA ABOUT UNPAID CARERS BETWEEN LOCAL HEALTH & CARE ORGANISATIONS

In the survey, we asked professionals working in the care and health system what they perceived the key benefits of sharing data between health and care organisations to be. The top two benefits were a reduced burden on carers from having to repeat their stories multiple times, and the early identification of carers which would reduce the likelihood of a crisis or breakdown in care occurring. Strategic or 'whole population' benefits were not rated as highly. It's also notable that although improved targeting of timely advice, support and information for carers should have a beneficial impact on reducing the likelihood of a crisis occurring, this was the lowest rated benefit.

6. PROFESSIONAL VIEWS: ORGANISATIONAL SUPPORT NEEDED TO SHARE INFORMATION THROUGH A DATA SHARING AGREEMENT

We wanted to explore whether professionals felt supported by their organisation to share information about unpaid carers with others. Given what we've already heard about a risk averse culture around information sharing, they were unlikely to feel confident about taking individual decisions to share information without leadership or their employer's support. Only 42% of respondents felt fully supported to do this, with 46% saying they felt partially supported. When asked specifically about their leadership's support for information sharing, 51% said they felt fully supported by their leadership in overcoming barriers to information sharing. Anecdotally, we heard that individual teams or service areas were committed and supported in sharing information but recognised this may not be universal throughout their organisation. When we asked for more detail about the ways in which professionals did not feel supported, and what might help them feel more supported, they still tended to focus on the legal and policy barriers to sharing information, rather than on what the enablers might be.

It was encouraging that every professional participant in the survey supported the principle of a data sharing agreement. 48% fully supported this, and 44% supported the idea with certain conditions. The perceived benefits of a data sharing agreement were wide and varied ([see list at Appendix 1.](#)) and included reducing duplication, improving consistency of approach and multi-agency information sharing, providing clear guidelines, protecting privacy, building trust and improving collaboration and joined up working, ensuring carers are recognised and supported, and providing accurate figures on unpaid carers which are likely currently underestimated.

Professionals who felt certain conditions would need to be satisfied in order for the to support a data sharing agreement majored on the need to see internal support, investment and buy-in, with robust systems and processes in place to assure carers their information was being shared appropriately, clarity and consistency around informed consent, confidentiality and risk, being clear with carers and what information is shared and why, staff training, and a process for updating information ([see full list at Appendix 2.](#)) *"I have limited power to influence and change policies/procedures. However, if funding was tied to a service model that would allow more cross-system signposting and data sharing, it is something that my employer would help and support."*

We also asked professionals what they'd need from their organisation if there was agreement between partners to proceed with a data sharing agreement. The main things were clear communication about who is expected to do what, not having to repeat information in several different places, information which pulls through where needed for reporting and sharing, clear guidelines, strong data protection measures, help to review current IT systems to see how they fit with the aspiration to improve data sharing, a clear, forward-thinking plan and documentation on how this will work for staff to read and have for reference, an agreed format for what will be shared plus an overarching agreement, combining policies and approach with staff training and regular communication between partners to improve knowledge and understanding. From the perspective of carers, organisations need to *“Ensure that the unpaid carers are aware that we all have one system to input information with certain parameters on who can access what and at what level so as to ensure there is a level of confidentiality maintained and safeguard people's personal information.”* (See list at Appendix 3.)

We gave professionals the opportunity to add anything else they'd like to see happen to improve the sharing of information about unpaid carers across their local care and health system—for a full list see Appendix 4. One interesting suggestion is *“It would be helpful from a professional standpoint to have a carers promise: something which could tell us what we can expect from other services around supporting carers. If this was provided, it could mean we as another service could cater what we are offering to extend support when required.”* Another said *“[we need] Carer identification across different platforms eg cards, shared care records. Carers should be able to update their own data eg when no longer a carer.”*

7. CARERS VIEWS: BARRIERS TO SHARING THEIR DATA WITH THE DERBY & DERBYSHIRE HEALTH AND CARE SYSTEM

As part of this project, twenty-four unpaid carers participated in three focus groups and three individual interviews. We summarise here the key themes and messages emerging for these discussions about carers' experiences. It was clear from these discussions that carers understand that health and care services are under pressure, and their asks of the system are modest. They put the needs of the person they support before their own, and many only get help when they are at crisis point, and their own health and wellbeing is affected. They are exhausted and suffering from stress. Despite this, far too many are having to repeat their stories to professionals over and over again, are being signposted to the same services multiple times, have regular battles to be recognised as their loved one's carer, and find clear, consistent information and the right support tailored to them difficult to come by.

“One of the [paid] carers said to the other ‘don't listen to her. She's only the family’...And when you said respect, you know, that's it. I'm nobody. I'm nobody.”

“Every single time I ring up the doctors I have to explain. ‘Yes, I can talk about my wife because I'm a carer. It's on your file. Look at it’. And I've seen it. It's on there on the first page, but they don't read it, so it's just very tiresome having to keep going over things and getting pushed back.”

“A carer is something you become without being asked, it's not a choice.”

Key findings from focus groups with unpaid carers

7.1 Carers are not clear what the benefits of registering as a carer are

Despite the emphasis on registering as a carer, carers said that in the main, there seemed to be little benefit to them of telling their GP they were a carer; for many, registration was simply a “tick-box exercise” which changed little in their lives.

7.2 People don't always identify or recognise themselves as a carer

Carers described how caring ‘crept up’ on them gradually and they had only recently recognised themselves as a carer. Carers prioritise the needs of the person they support over themselves, making identification as a carer less likely. During focus groups, carers struggled to talk about their own needs “*I see everything I do as for my wife’s benefit, not my own.*” Professionals need to be being able to spot the signs of stress or burnout in carers. It’s also important not to label or stigmatise carers as “not coping” when in fact they need practical help with their caring role.

7.3 Not everyone wants to be labelled as a carer

One person described the risks associated with being labelled as a carer and how that had impacted on her own health and wellbeing and sense of identity. Some carers felt stereotyped as a carer “*The council have a stereotype of what a carer should be like, if you have an ill person in the household, you are automatically a carer and that you and the person you are caring for have no aspirations in life and that’s it.*” Carers described breaking down in tears at their GP surgery because of the stress of caring, only to be referred to the local mental health team as “not coping.” This had the effect of them being less likely to say they were finding things hard in the future.

7.4 Carers face constant battles with professionals over being recognised as a person’s carer and think professionals use confidentiality as a way of avoiding consulting carers or sharing essential information with them about the person they support

Professionals refusing to talk to carers about their loved one, even if they were registered as a carer, was a constant and recurring theme throughout all discussions with carers. Listening to their stories, it’s not surprising that there was a lot of scepticism about what the tangible benefits were of registering or identifying as a carer with the care and health system. There was a widely-held view that professionals often hid behind issues of consent, confidentiality and GDPR, and were very risk averse about sharing potentially critical information with carers. This lack of willingness to share information by professionals compounded the feeling that carers were not respected or valued as equal partners in caring for their loved one.

7.5 Carers know that their information isn’t being shared or taken account of by the health and care system based on their experience of having to tell their stories repeatedly and constantly having to ‘confirm’ they are a carer

When carers were asked in focus groups if they thought their information was being shared with partners in their local system there was ironic laughter “*No, it’s blatantly obvious that they’re not.*” “*Everything’s fragmented. There’s no joined-up-ness about it.*”

7.6 Professionals are not routinely and proactively identifying carers

Carers felt that professionals needed to be much better at proactively identifying carers and knowing what was available locally to support them. There needs to be a clear, common definition

and understanding by professionals of what a carer is, particularly as we know from published research that many carers don't necessarily recognise themselves as such "And if you're not being given that opportunity to identify yourself as a carer, how much harder to recognise yourself as one and then to advocate for yourself as such?" Carers felt it was an important task for the local primary care network to ensure GPs are routinely identifying carers, and can identify stress and burnout.

7.7 Carers often don't feel respected as an equal partner and team member in caring for the person they support

One carer and a sibling caring for their mum who needed hoisted found the paid carers who came in didn't listen to them or respect their experience, even though they'd had training in using the hoist. A lack of respect for the knowledge and expertise of carers about their loved was a common theme.

7.8 Carers want more pro-active awareness raising about caring at local and national level

There was consensus that the health and care system needed to be much more proactive and diverse in its communications and marketing, raising awareness among unpaid carers and clarifying what they meant by a 'carer' and helping them navigate the local system. Carers described considerable variation in the approach to them by professionals.

7.9 The importance of getting language right and avoiding jargon

One carer described the stigma which is still attached to asking 'social services' for help. A lot of carers had initially associated the term 'carer' with paid carers (eg home care workers) which is an important message for services when thinking about reaching out to people who may be caring. Some people though a carers assessment meant their ability to care was being judged. Some preferred the term informal care. The issue of language and an awareness of stigma is very important in the context of supporting carers from black and minority ethnic communities "*some of the communities are so close knit that they think that if they declare themselves as carers, they might be labelled by other community members or extended families that are around as not doing a good job.*"

7.10 If asked whether they are a carer, professionals need to know what the next step is

Carers made the point several times that if a professional asks if someone is a carer, then they know what to do next if the answer is "yes I am" or "maybe" or "I'm not sure." It was frustrating and disappointing that having taken the step of identifying themselves as a carer to professionals, that the next step didn't happen, and nothing changed for them

7.11 Most carers are happy for their GP, carers support organisation or the council to share information with each other as long as they can trust that its being safely and securely handled

Most carers are supportive of sharing their information with others in the local system as long as they are told why the information is being shared and who with, know it is being safely and securely handled, and crucially, what the benefit to them would be. Carers said that anything which reduced the number of times they had to tell their stories or 'prove' they were a carer was a good thing. The issue of trust in services and professionals was a common theme throughout discussions. Where carers had had a negative experience after sharing their personal information, they were much less

likely to trust the system again *“It’s hard to seek help then the door is shut -hope is worse and then you don’t get it [help].”*

7.12 ‘Signposting’ carers to other support isn’t always experienced a helpful, especially when multiple professionals signpost to the same support

Carers are frequently signposted to generic support, advice or information about caring when what they need is practical help tailored to their particular needs and circumstances *“I’ve got booklets coming out of my ears! What I want is a solution or coping strategy.”* For some, ‘signposting’ this was synonymous with simply being passed around the system. For others, endless form filling in order to secure a small amount of help was daunting and off-putting *“We are on our knees; I can’t face pages of silly questions to get a tiny bit of money.”*

7.13 Carers worry they don’t deserve help

Carers were acutely aware that resources in social care, general practice and the NHS generally were stretched and this impacted on whether they felt they were “worthy” of support when others may be struggling much more than them. One carer said they felt they had ‘imposter syndrome’ and that they weren’t really a ‘legitimate’ carer *“I think for me at one point it was a bit of, there are other people that are in a lot more difficult situation than me, that I don’t have the right to look for support or ask for support.”* Many carers in our focus groups had only found help when at crisis point, when earlier support may have helped reduce the chances of a crisis occurring.

7.14 Parent-carers report especially poor experiences of information sharing

Parent-carers were much more likely to report consistently bad experiences of trying to get help from the care and health system over the lifetime of the young person they were supporting, in some cases over many decades. Parent-carers face significant challenges during the transition between children’s and adult health and care services. As a result of these experiences, they were much less likely to trust professionals with their information and that of their loved one. They felt that in battling to get support they were often labelled as awkward and difficult and that they were not respected or valued.

7.15 Summary

One of the points made by a carer was that carers are not a homogenous group and should not be treated as such. This was seen by some as a downside of ‘generic’ carers support, and there were pleas for more specialist support for carers of people with mental health issues, younger age or working carers, and parent-carers for example. Too many carers are simply being offered “signposting” to other services or websites (often getting the same information from multiple professionals) but experience this as being passed around the system with little practical help on offer. Registering as a carer with a GP was far from the ticket to additional support and consideration which most carers in our focus groups had hoped for. The need to repeat their stories multiple times to professionals was probably the most frustrating thing of all. This experience significantly reduces confidence that the system values or respects carers, but despite this, in the main, and subject to the necessary safeguards, carers were happy to share their information, as long as it was of clear benefit to them and their loved ones. Carers were also keen that sharing their own experience, including participating in our focus groups, would benefit other carers in their area. They were also very clear however, that at present, they didn’t know how their information was

being used by the local system, or who it was shared with, or how it was used to improve services for carers in their area. This must be a priority area for action by professionals in the local care and health system. For a full list of other actions carers would like to see happening in their local system, please see Appendix 5.

For a copy of the full Insight Report which gives more detailed feedback on carers views and experience, please contact ASCH.ac-commissioning@derbyshire.gov.uk

8. CONCLUSION AND RECOMMENDATIONS

8.1 It was reassuring that there was professional support in principle for improving the sharing of information about unpaid carers across the local system, and that carers themselves were supportive as long as they could be assured that their information would be handled safely and securely, and it was clear to them from the outset the beneficial uses to which their information would be put. Much of the discussion -whether with professionals or carers- centred on the sharing of personal identifiable information and how risks would be managed and mitigated if this information were to be shared. It should be possible for organisations to share valuable insights and data which do not use identifiable information and for where consent, confidentiality and GDPR do not apply. This may be a good place to start, given the pervasive fear about the consequences of breaching data protection which seem to act as the main brake on improved data sharing.

8.2 The cultural imperative in organisations against sharing data is strong, myths and misconceptions abound, and will take time to tackle. Where professionals aren't confident about information sharing, they err on the side of not doing so. Training seems to centre almost entirely on stopping bad things happening and preventing damage to reputations, with little focus on GDPR as an enabler or the benefits of sharing information. As one person said, "*there's no cost-benefit analysis done of not sharing information about unpaid carers.*" It's important to identify those in organisations who will support and champion information sharing and who will garner leadership support for this "*So I have an attitude of we share the data we need to and we do it safely and it's about how we manage that sharing of the data. It's not whether we do share it or not*".

8.3 Another consideration is whether agreement can be reached on a common set of information which would be collected about unpaid carers, every time they have contact with the local system. Without some basic standardisation, and commitment to updating, it will be impossible to have confidence in the quality and reliability of the information. Alongside this, it's essential that front-line staff know why reporting this consistently matters. The use cases for carer information were quite narrow (contract management, service improvement) and rarely explicit, either internally or externally. Good quality information could and should be used to inform strategic commissioning intentions for carer services going forward and it seems likely that there is a great deal of valuable insight and information about unpaid carers which is missed and goes unreported. Participants were keen to caution against any additional burden from standardisation so a light touch approach may be best to get started. It was clear early in the project that any possibility of each stakeholder's IT systems "talking" to each other was a distant possibility. The alternative is to explore a safe and secure repository for a mutually agreed set of data, accessible to all partners signed up to data sharing. There would be some costs attached to this, but it may be the best way to build trust and

confidence that this approach could work. One of the main challenges would be getting proportionate information governance (IG) processes in place. Building support and understanding for the objectives and benefits of sharing this information with individual stakeholders IG controllers would be an important next step.

8.4 It would improve the experience of unpaid carers if a single pathway could be developed which would operate regardless of which part of the local system first had contact with an unpaid carer. We heard about the frustration of carers having to tell their stories repeatedly, and of being constantly referred to the same sources of support. [Leeds City council](#) developed a pathway which could be used as a model by anyone identifying a carer for the first time. In Leeds, this relates to identifying young carers, but could easily be adapted. It's supported with training, shared resources (a brief assessment), designated carers leads, and quality standards.

8.5 The local primary care network was felt to be key in ensuring that GPs are routinely identifying carers and able to identify carer stress and burnout. Although we know that GPs are more likely to be registering or identifying unpaid carers than the council, most carers felt this was a 'tick-box' exercise and made little difference to their experience. Carers felt there was little point in them identifying themselves as a carer if professionals then didn't know what to do next with that information. Signposting and leaflets were felt to be a poor substitute for practical help tailored to their needs.

8.6 Despite the optimism of professionals completing our survey, there was no evidence from discussions with the 24 carers taking part in the project that they knew or had been told how their information was being used, who it was shared with, or how it was used to improve services for carers in their area. If this was more explicit, as well as the benefits of identifying as a carer, all the evidence points to carers increased willingness to share their information.

8.7 In terms of barriers to people identifying as a carer, there are important messages from carers about the language used, fears about being stigmatised or a loss of identity, about understanding the benefits of seeking help, and clear information about how and why their information is needed and will be used to help them and their loved ones, as well as other carers in their area. Bad experiences influence carers willingness to trust health and carer services, and professionals who are not confident about when they can and can't share information may hide behind consent and GDPR. As we said elsewhere in this report, carers understand that health and care services are under pressure, and their asks of the system are modest. If anything, they worry that they are not "legitimate" carers when other carers seem to be struggling more than they are. Carers knew they were saving the state considerable amounts of money but as one carer said:

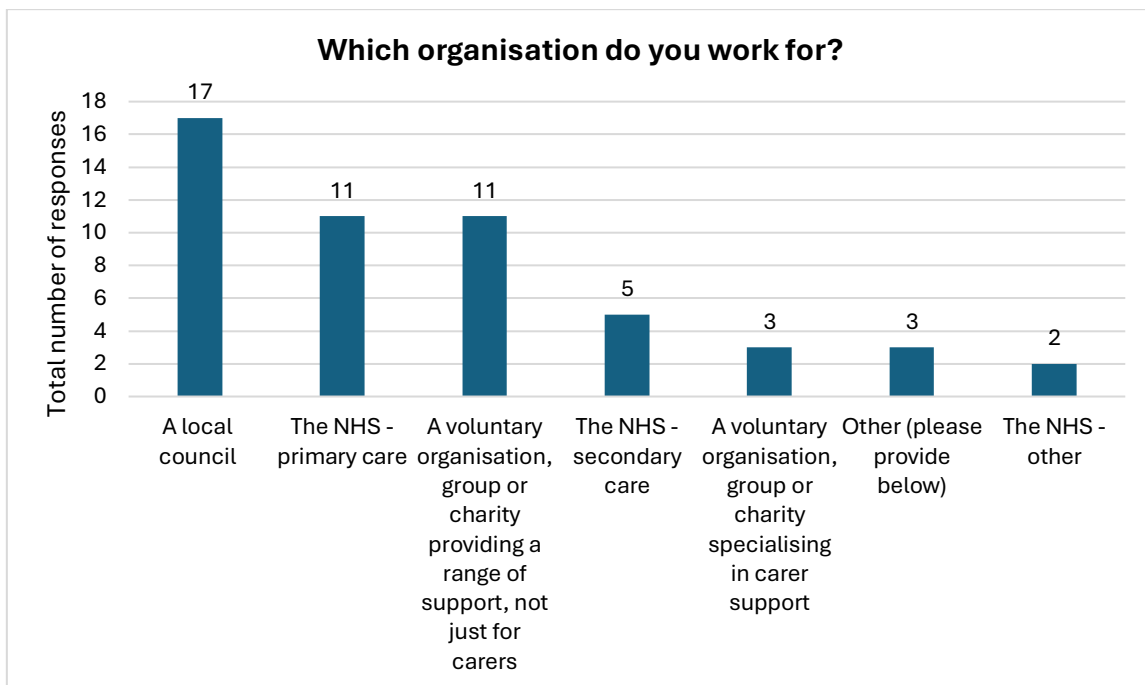
"One thing I think is massive, is how much money carers save the NHS and social services, massive amounts, you know. And that alone should give them some respect, you know. And that's not why carers do it, though. It's because they love whoever they're looking after."

9. DETAILED FINDINGS FROM THE ONLINE SURVEY OF PROFESSIONALS

This section incorporates detailed feedback on each questions in our survey of professionals working in health, care, and voluntary sector services who have regular contact with unpaid carers, or are involved in recording, using, or sharing information about carers and their needs.

Distribution of the survey, and survey communications, were co-ordinated by members of the project oversight group using their own networks. This was key to the good response rate and built ownership for the project from the outset. It also contributed to the rich and diverse range of responses from the local care and health sector.

Q1-What organisation do you work for?



Q2- Job roles

There were a wide variety of respondents to the survey, including Heads of Service, GPs, nurses, service managers, specialist carers workers, providers and champions, frontline workers, advocates and volunteers. Although the survey was intended to include data specialists who handle and report carer data, there were few respondents in this category though their views are represented through the 1-1 interviews.

Q3a. Organisational culture around sharing information about unpaid carers

As highlighted in the early part of this report, one of the main barriers to the sharing of information about people who draw on health and care services, both internally, and with external partners, is a risk averse culture within organisations. *“We do not share information about unpaid carers due to data protection and confidentiality policies and procedures.”*

This question in the survey was intended to get a ‘feel’ for whether there was supportive culture and environment for data sharing, both within the organisation, and with those outside it. One person said *“We are supportive, collaborative, and committed to raising awareness and sharing accurate,*

respectful information about unpaid carers externally” another described the culture as *“Organisation - Risk averse. Service - cautious.”*

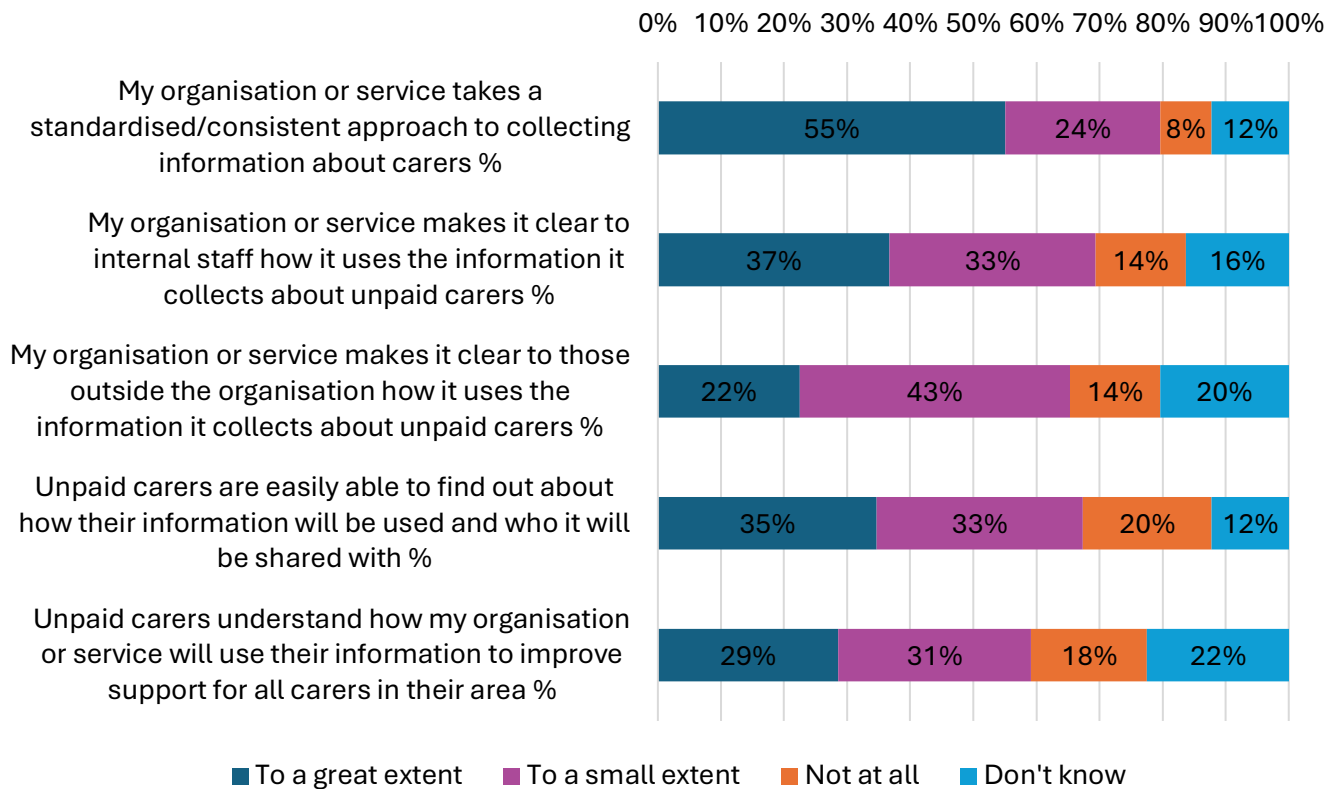
Most respondents to this question did not however describe their organisation’s culture. Answers centred instead on systems, processes or services for carers. Several respondents did mention issues of consent, GDPR, confidentiality and safeguarding impacting on data sharing, with one person saying data sharing would only happen *“...where safeguarding concerns are present and not sharing would place greater risk or harm to a person or other people.”* This reinforces the view that data sharing is an exception, and only happens to protect people from harm.

Overall, the responses indicate a culture which remains risk averse to sharing information both internally and externally, and suggests that staff, especially those on the front line, remain fearful of the consequences of them inadvertently breaching organisational rules, policies and procedures regarding data held by them about others. Few responses acknowledged or described the benefits of sharing information though one person said there needed to be *“...commitment to providing accurate, empathetic, and accessible information to support their [carers] essential role.”*

Q3b. Organisational approach to collecting and sharing information about unpaid carers

This question aimed to explore the extent to which there was clarity and consistency of approach across the local system in how carer information was collected and shared through a series of statements. The greatest levels of agreement centred on whether the person’s organisation took a standardised or consistent approach to collecting information about carers, with the lowest level of agreement with the statement that their organisation is clear with those outside their organisation how they use the information they collect about unpaid carers. The final two statements show a significant degree of optimism bias on the part of organisations participating in the survey as there was little or no evidence from discussions with the 24 carers taking part in the project that they knew how their information was being used or who it was shared with, or how it was used to improve services for carers in their area.

3b. Thinking about the approach your organisation or service takes to collecting and sharing the information it collects about unpaid carers, to what extent do you agree with the following statements:



3c. Concerns about sharing information about unpaid carers within professionals own organisation or service

Q3c.	Do you have any concerns about sharing information about unpaid carers <u>within</u> your own organisation or service? This might include with other teams or departments
Response	%
No	71%
Don't know	16%
Yes	12%
Total no of responses	49

Overall, levels of concern about sharing information internally were low. Where professionals did have concerns, this centred on a) lack of robust systems to ensure carers were clear how their information would be used b) inconsistent recording of who is a carer on individual records c) feeling unable to share information without carers consent and because of data protection and d) concern over how colleagues might use this information

“[Concerned] not from a legal perspective, but in terms of the kinds of conversations they would then go onto have with a person about the information they have seen. I am concerned that assumptions can be made based on a limited amount of information on a screen.”

3d. To what extent do you feel the information about unpaid carers directly collected by your organisation or service is:

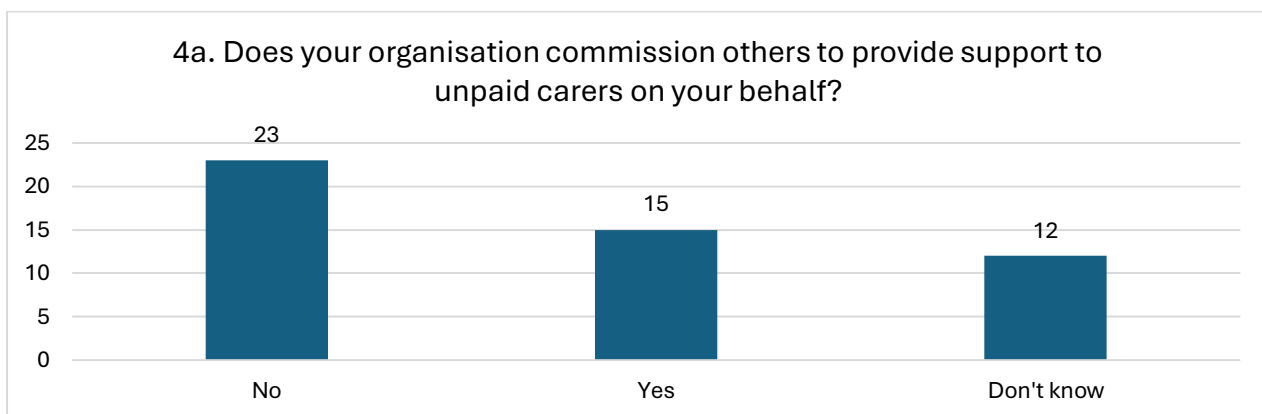
	High quality %	Reliable %
To a great extent	40%	50%
To a small extent	42%	36%
Not at all	8%	6%
Don't know	10%	8%
Total responses	50	50
Definitions	High quality = fit for purpose, complete, consistent, and accurate	Reliable = trustworthy and dependable

“We don't ask for a lot of information about unpaid carers, most of our recording is about services provided to the service user. Whether or not signposting to carer services is recorded consistently when a carer is identified, other than that, case notes may log further detail, but at staff discretion.”

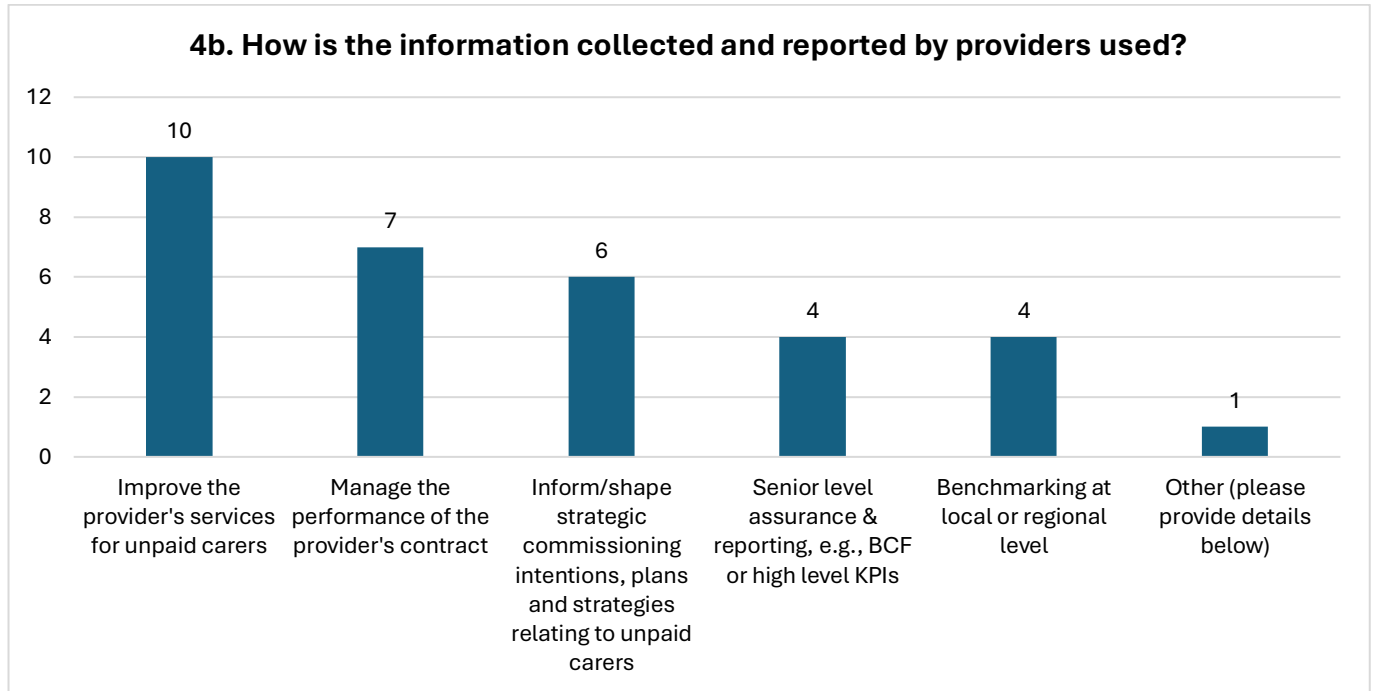
“I feel there is always room for improvement, but we work hard to try and ensure details are accurate. We have a dashboard which does give us some intelligence too with regard numbers and also which documents relating to carers have been completed, for example the number of carer contingency plans created. Our carer service collects a lot more accurate and detailed data on behalf of [the council] which informs a lot of our management information, due to the service being contracted to provide this.”

4a. Do organisations commission others to provide support to unpaid carers on their behalf?

This table of responses is included as its notable that of those responding (50), 12 (24%) didn't know if their organisation commissioned others to provide support to carers on their behalf.



4b. How is the information collected and reported by third party providers used? (More than one box could be ticked).



Q4c. To what extent do you feel the information about unpaid carers collected by commissioned providers is:

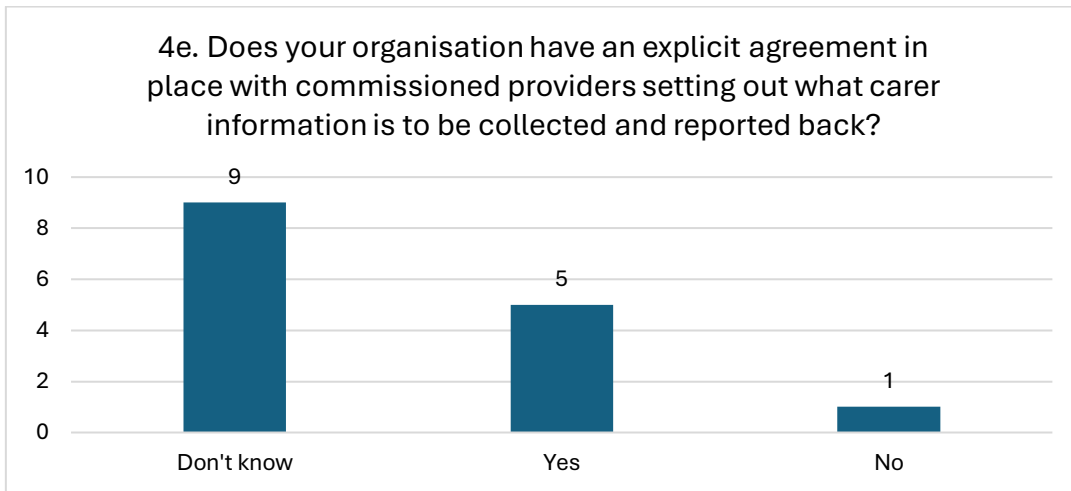
	High quality %	Reliable %
To a great extent	40%	40%
To a small extent	33%	33%
Not at all	0%	0%
Don't know	27%	27%
Total responses	15	15
Definitions	High quality = fit for purpose, complete, consistent, and accurate	Reliable = trustworthy and dependable

Q4d. Further comments on the quality and reliability of the information about unpaid carers collected by commissioned providers.

There were no relevant responses in this category.

Q4e. Does your organisation have an explicit agreement in place with commissioned providers setting out what carer information is to be collected and reported back?

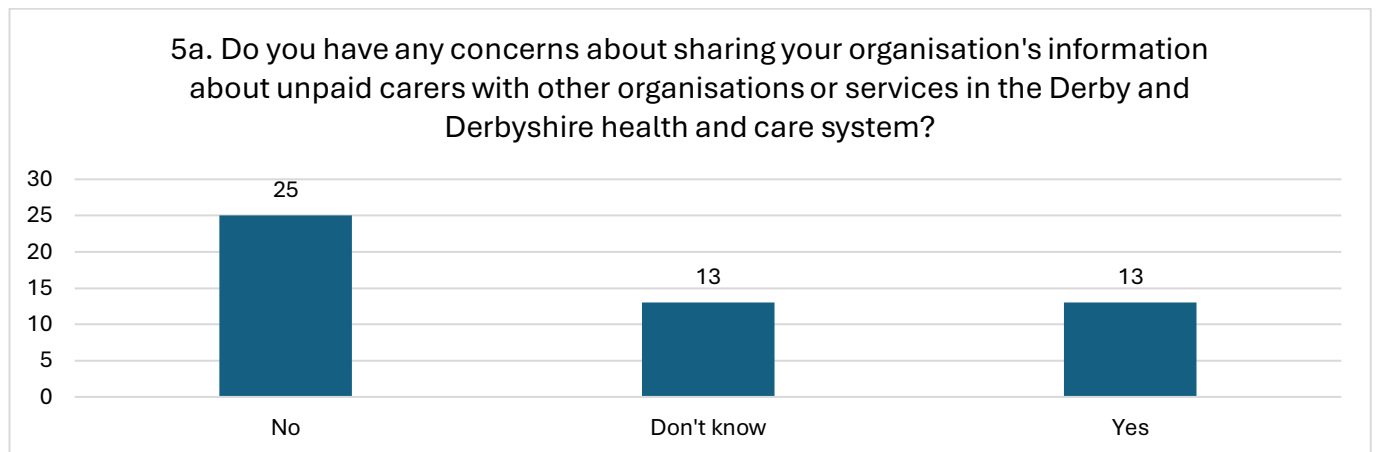
This table is notable because most respondents don't know if there was an explicit information sharing agreement in place with commissioned providers.



4f. Whether current agreement meet needs for good quality, reliable information about unpaid carers and any improvements professionals would like to see in third party data collection and sharing.

There were no relevant responses in this category.

5a. Concerns about sharing your organisation's information about unpaid carers with other organisations or services in the Derby and Derbyshire health and care system?

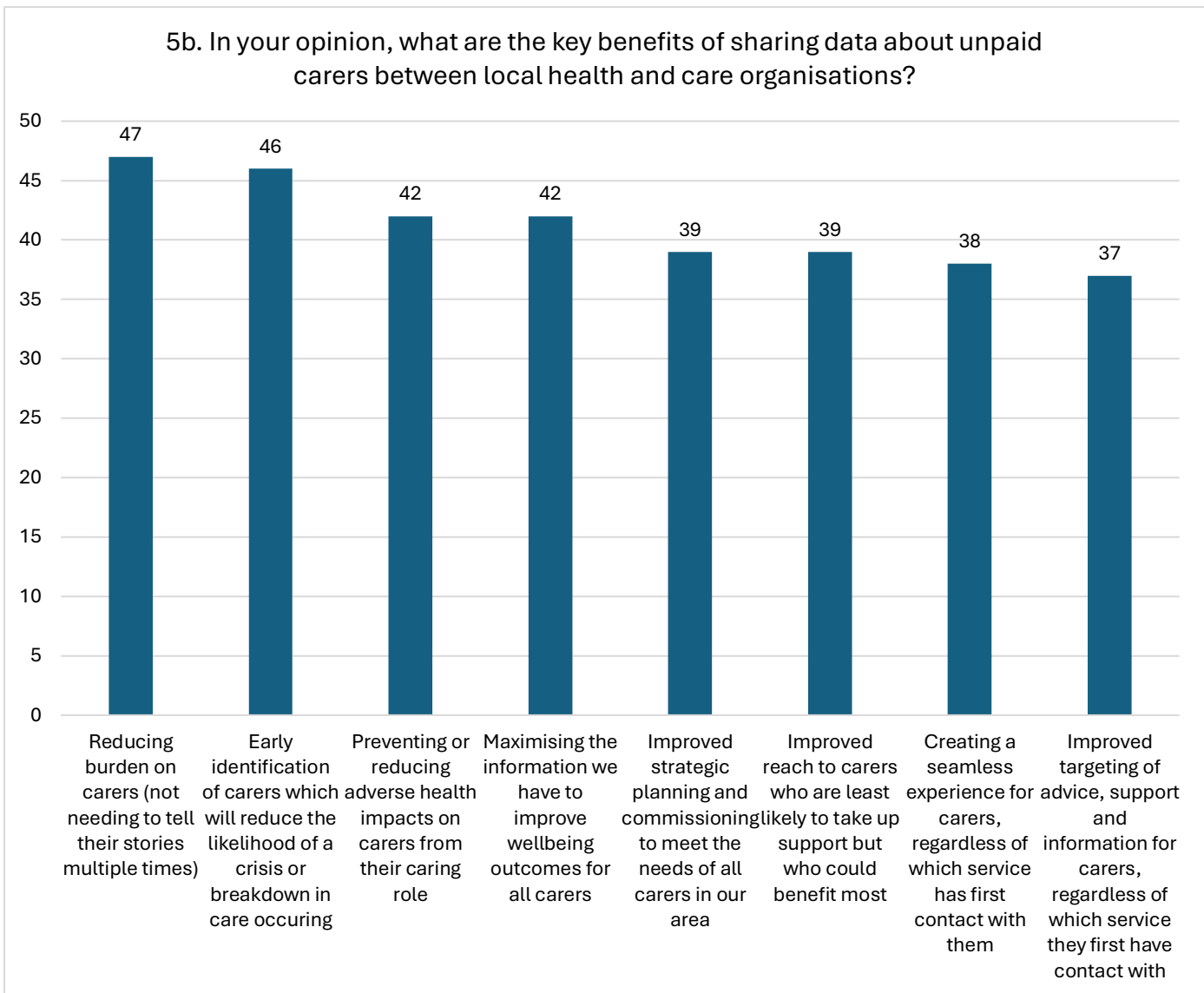


Where concerns were highlighted concerns, these centred on issue of consent to share, compliance with data protection rules, how information shared would be kept up to date, a risk averse culture, and lack of clarity about how the information would be used.

“On an individual basis, with the carer's consent, I would be comfortable sharing their information with services that might support them. Beyond this, I don't know what other information would be worth sharing with other systems? If it is about collecting the numbers of unpaid carers in our service, I don't think we currently have a way of collecting that data, and I would wonder about its accuracy since many people do not recognise themselves as a carer.”

“Currently we would only share information to external partners if we were concerned about someone's welfare- or the welfare of others around them. With the persons consent, we can and will share information more widely.”

5b. The key benefits of sharing data about unpaid carers between local health and care organisations. Respondents could choose as many options as they liked.



5c. Extent to which professionals felt supported to share information about unpaid carers with colleagues in other organisations or services as a way of improving carer support

Response	%
Fully supported	42%
Partially supported	46%
Not at all supported	13%
Responses	48

When asked to provide further detail such as the ways in which professionals did not feel supported, and what might help them feel more supported they said:

“It’s not about being supported; sharing information between partners must fit into current organisational policy and procedure and we are not really set up to do that; [we’d need to be] part of a consortium, [with] an expectation to signpost to other organisations if that would be beneficial to the person, and our data sharing policy [was] clearly explained to the client/carer.”

“Data from the VCSE isn’t always received or seen in the same way or trusted because we’re viewed as lay people. However, the staff on our social prescribing teams for example are highly professional, understand safeguarding and a range of issues and when they share info it is always with the best interests of the client at heart.”

“I feel fully supported through clear communication, leadership encouragement, and regular opportunities to share information and collaborate with other organisations.”

“Staff can always ask a service manager if it’s appropriate to share information.”

“Due to my particular role I often share concerns about a carer in crisis, or with carer stress...In all the years I have shared this (with consent) with ASC practitioners...they have always been responsive and grateful, despite the increased pressure ASC teams are under.”

6a. Confidence levels in understanding and following legal guidelines around sharing information about unpaid carers

	With others in your own organisation or service %	With those outside your organisation or service %
Fully confident	42%	34%
Mostly confident	32%	26%
Somewhat confident	18%	24%
Not at all confident	8%	16%
Total responses	50	50

One of the major barriers to sharing information with professionals in other organisations is a lack of confidence in the legal and policy framework surrounding the safe and lawful sharing of information, which leads to a culture of risk aversion. Many of the free text responses show that there is a reluctance to share information other than in exceptional circumstances such as where there is a safeguarding concern. Many carers in our focus groups believed that professionals often “hide behind” data protection, consent and confidentiality as a way of avoiding sharing information both with them (about the person they support), and with other services they have contact with, leading to them repeating their stories multiple times. Responses to this question show that less than 50% of respondents are “fully confident” they understand and can follow the legal guidelines

around sharing information about unpaid carers within their own organisation; this drops even further when the same question is asked about sharing information with those outside their organisation.

When asked for suggestions for how confidence could be improved, suggestions included: *“Clear guidance and policies to aid with this for everyone.”*

“Regular data governance training, and training around carers.”

“I feel fairly confident in understanding and following legal guidelines, but regular training and clear, simple resources would improve confidence.”

“We have training around sharing information to ensure this is being done legally, and when to share information around safeguarding when consent for this cannot be gained.”

7a. Good examples of unpaid carer data sharing between partners in the local health and care system

It’s interesting to note that there were no concrete examples offered of effective data sharing between partners in this free text section of the survey, other than that which forms part of statutory or contractual obligations between the council and their commissioned provider or which is recorded as part of individual referrals or assessments. There seems to be some sharing of information about individual carers between services, but it’s unclear how standardised this is or whether any mechanisms are in place for sharing aggregated information about carers. Where organisations had carers leads or champions, information sharing seemed to have a higher profile and priority, but this still focused on sharing individual rather than collective information.

Q7b. The key barriers to sharing information about unpaid carers with others in your local care and health system

Analysis of the responses to this question is covered in detail in section 4. of this report.

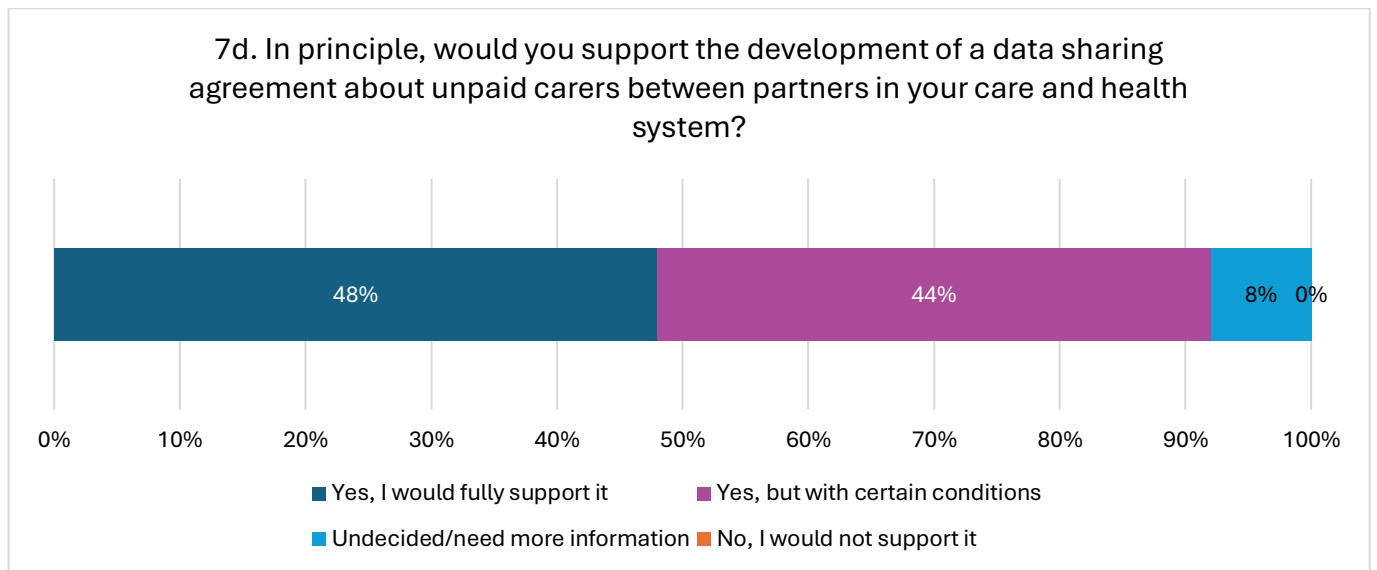
Q7c. Commitment of organisational leadership to overcoming barriers to sharing information with partners within the local care and health system

Response	%
Fully committed	51%
Mostly committed	18%
Somewhat committed	27%
Not at all committed	4%
Total responses	49

Q7d. Support in principle for the development of a data sharing agreement about unpaid carers between partners in your care and health system.

A data sharing agreement was defined as setting out the purpose, responsibilities and standards of data sharing, and covers what happens to the data at each stage of the sharing process.

It's encouraging that no-one felt unable to support the principle of a local data sharing agreement. A small number felt unable to commit themselves without more information but the majority either fully supported the idea or supported it with certain conditions.



APPENDICES

Appendix 1. Professional views about the benefits of a data sharing agreement from Q7 in the survey:

- Reducing duplication, ensuring a consistency of approach and equity of services for carers.
- Everyone understanding the importance of carer support.
- Reducing the times carers are offered the same information or signposting by multiple professionals which can increase the burden on them to pursue previously tried sources of help.
- Knowing what has been offered to carers, when, and what was helpful, as well as understanding a carers needs without them having to discuss it again with another professional.
- Easier to access and share information across multi-agencies.
- Providing clear guidelines, protecting privacy, building trust and improving collaboration between different organisations.
- Better support for patients if their carer is in hospital / unwell; carers would be able to prioritise their own health needs and not worry so much about the person they support.
- Organisations and staff would work more together and not repeat unnecessarily
- Better outcomes for the carer and the client.
- More joined up work, less time explaining the same story for various professionals, better whole-family approach.
- Ensuring carers are recognised and supported, and to provide accurate figures on unpaid carers which are likely currently underestimated.
- More confidence and an onus on workers to share information about the carers they work with. May increase chances of better support for the carer and individual they care for.

Appendix 2. Professionals in the survey who supported a data sharing agreement, but with conditions, said:

- As a manager, I have limited power to influence and change policies/procedures. However, if funding was tied to a service model that would allow more cross system signposting and data sharing, it is something that my employer would help and support.
- I would need to see internal support/investment/buy-in and robust systems and processes in place to assure carers their information was being shared appropriately.
- Conditions would be clarity and consistency around informed consent, confidentiality and risk.
- Happily share data but it would very much depend on the time required and whether or not our current systems would accommodate different reporting.
- GPs are responsible for data control, and we are at risk if we share data a patient doesn't want sharing. Are we protected if we share?
- [Carers] experiences to be shared, certain personal information to not be retained unless critical.
- My worry is that in a cash strapped system we will place more burden on unpaid carers. By identifying them across the system, I worry that patients may be risk stratified based on the availability of an unpaid carer rather than need.

- To develop a system whereby unpaid carers are known and appreciated, target resources to ensure that they are aware what help is out there for them and how they can access it without waiting for a crisis to happen first.
- I would want to think carefully about what gets shared with who, and the training of staff who would be party to this information.
- Clarity about how will the information be kept current on each carer.
- What will happen if a mistake is made and information is shared in the wrong way.
- Making the process clear to carers and what and why information is shared.
- Misunderstanding the guidelines for data sharing - could lead to complaints, misconduct, dismissal, possible court proceedings.
- As long as the information shared is proportionate and agreed with the carer (unless of course risk information needs to be shared) I support it.

Appendix 3. Professionals said that to make a data sharing agreement work, their organisations needed:

- A secure database.
- Clear pathway for signposting to other services (professionals who undertake the signposting have a clear idea of what other partners provide).
- Ability for partners to explain their service to other partners .
- Trust.
- Not to have a tick box exercise.
- Agreed format and help to align our current systems.
- An overarching agreement, combining policies and approach.
- Training, knowledge and understanding.
- IT improvements so that information feeds seamlessly between each service's system.
- Clear communication about who is expected to do what. Not having to repeat information in several different places, information should pull through where needed. Consideration of how risk to patients affects carers.
- Easy access to systems in local places to get the info.
- To be fully on board with the idea of a data sharing agreement.
- The agreement is safe, a lot of other organisations need to be involved to make it work effectively, should be easy to use.
- Clear guidelines, strong data protection measures, staff training and regular communication between partners would be needed for it to work.
- Co-production.
- Consistent information and guidance for all staff.
- Clarity on how information will be updated and reviewed.
- Indemnity for GPs risk of sharing patient data.
- Clarity how this would be shared with the carers - it's all very well different systems agreeing to share carer data, but do the carers agree?
- Clear protocols given to all staff
- Clear guidelines, examples that can be used across agencies during the roll out.
- Clear process for registering and updating carer details.

- Clear understanding of what will happen with the info (e.g. do carers automatically get added to a carers database?)"
- Consistent system which professionals can access to review any information relating to carer.
- Having main carer details linked to record for adult.
- Ensure that the unpaid carers are aware that we all have one system to input information with certain parameters on who can accessed what and at what level so as to ensure there is a level of confidentiality maintained and safeguard people's personal information.
- Clear guidance on how this is done and full consent from the carer.
- It has to work with the existing systems we have so it doesn't involve repetition of admin for staff.
- Clear consultation with carers and those who will be sharing this information.
- Ensuring all information is up to date and current on how a carer can be supported and who or how this support will be provided.
- To be clear that carers support is changing and promote positivity around this.
- To ensure as much as can be who will be involved in this, and why.
- Setting out time scales and goals within the organisations, and what is changing and when.
- Looking at current IT systems to see how this fits with the current ways of working/ assessment / financial processes.
- A clear, forward-thinking plan and documentation on how this will work for staff to read and have for reference.
- Have the new process rolled out to staff who deal with carers to see how this works and is recorded prior to a full roll out to all staff.
- Robust systems in place, training and examples of good and bad practice.

Appendix 4. Professionals in the survey offered other ideas to improve the sharing of information about unpaid carers:

- It would be helpful from a professional standpoint to have a carers promise: something which could tell us what we can expect from other services around supporting carers. If this was provided, it could mean we as another service could cater what we are offering to extend support when required.
- We do signpost to unpaid carer services, but often opportunities can't be taken up as the person is too busy or tied to their caring responsibility.
- The biggest thing that unpaid carers want is a break from their role... !
- An option on Mosaic to record further information?
- More social prescribers joining carers support groups
- Carer identification across different platforms eg cards , shared care records. Carers should be able to update their data eg no longer a carer
- Seek the opinions of unpaid carers - would they want their information shared in this way?
- That there is a flag or a mark to show that they are an unpaid carer so may require support as someone else relies on them
- Improved service and experience for unpaid carers.
- Improvement in carers feeling recognised and valued.
- We would still recommend self-referral. But their needs to a response provided at first contact, and not passed from one organisation and the another.

Appendix 5. Summary from the focus groups with unpaid carers of things they want to see happening:

- More initiatives around a 'Think Carer' approach such as work with Fire and Rescue Service and Housing Associations who go into settings where there may be vulnerable adults with carers who might not be known to the care and health system.
- More creative approaches to reaching carers who wouldn't necessarily talk to their GP or social care through activities such as shopping, going to a pharmacy, or hospital.
- Be more joined-up-we don't want the same information/leaflets multiple times.
- Much more investment in preventative support for carers.
- A carers register shared between health, social care and the voluntary sector, with clear benefits for joining this register, and which reduces the need to repeat stories.
- A consistent, pro-active approach by professionals and front line staff such as reception or call centre staff to identifying carers, and who have knowledge about 'what next?' when they do identify a carer.
- Clarity and consistency about what the right language to use is, what being a carer means, and how and when to get help, without feeling judgements will be made .
- Widening communications and marketing to reach carers who won't see themselves as a carer but who could benefit from support.
- Avoiding jargon, explaining terminology, and not hiding risk aversion behind issues of consent, confidentiality and GDPR which makes carers lives more difficult.
- Professionals recognising that people are not "just a carer" and have other identities which are equally important such as partner, spouse, parent, child, employee.
- People with specialist expertise in carers in each GP surgery as standard and a more universal approach & better signposting to sources of support.
- Primary Care Networks taking the lead on ensuring GPs are consistently identifying and registering carers, and can spot the signs of stress and burnout
- Specialist expertise in supporting carers helping people living with specific conditions such as mental health problems and younger age or working carers; carers are not a homogenous group.
- If asked to share information, please be clear what is being shared and who with to protect individual privacy.
- The 'use cases' of carer information should be much more explicit-this needs set out when carers are asked to share their information. Understanding uses and benefits is key to consent.
- Please don't put on 'carer consultation' events in health and care but still don't listen...a year passes and then asking the same questions again...
- Think about support for carers whose loved one may be in care, but still needs support, or who lives in another area; carers said they were unable to register with their GP if their loved one lived elsewhere or access other forms of local support.

Appendix 6. Useful resources & references

1. The Suffolk Office of Data & Analytics (SODA)

SODA have done significant work on the issue of data sharing with local partners including the NHS.

[Suffolk Information Sharing Charter](#)

[SODA Information Sharing Agreement](#)

[SODA Information Sharing Agreement Guidance](#)

[Other resources from SODA](#)

Suffolk Office of Data & Analytics - A guide to successful data sharing across public services - [webinar recording Sept 2025](#)

5. Pan-London Data Sharing Agreements Project

The London Office of Technology and Innovation (LOTI) have developed some [excellent resources](#) to support the design and development of data sharing agreements. Project Lead is victoria.blyth@loti.london

[Data sharing templates directory](#)

[Information Governance Hub](#)

2. Sheffield - example of data sharing agreement (not carer-specific)

[Sheffield Data Sharing Agreement](#) - Multi Agency Risk Assessment Conference

[‘GDPR Says Yes’](#)

Excellent website with a collection of resources designed to tackle the most common barrier cited by professionals to sharing information - fear of breaching GDPR and data protection rules.

3. Birmingham & Solihull Shared Care Records

<https://www.birminghamsolihullics.org.uk/our-initiatives/shared-care-record>

4. Multi-Agency Safeguarding Tracker (not carer-specific)

[Data driven digital approach enabling information from multiple safeguarding bodies to be easily and securely shared, matched and anonymised.](#) By limiting access to the necessary information to only authorised parties, this approach sits squarely within the GDPR regulations and wider requirements as demanded by the Data Protection Act 2018

OTHER USEFUL RESOURCES

[NHS England-call to action: Health and care staff must share information effectively to support individuals' care](#)

[Use and share information with confidence NHS England](#)

[NHS England Information governance guidance](#)

[Local government data maturity assessment tool](#)

[Demystifying data: An overview of common data terms](#)

[Data strategy and use Knowledge Hub group](#) - free online platform to allow groups of local government officers to come together in online groups. Aimed at officers with an interest in the strategic and/or practical aspects of the use of data in local authorities with opportunities to ask questions and share advice and good practice.

[GP Survey 2025-slide sets for individual ICS areas](#)

[Data Standards for Social Care](#)

ICO - [Data protection by design and default](#)

[Review of councils' online services for unpaid carers in the ADASS East region](#)

Office for Statistics Regulation (OSR) - [A UK-wide public dialogue exploring what the public perceive as 'public good' use of data for research and statistics](#)

Office for Statistics Regulation (OSR) - [Data Sharing and Linkage for the Public Good: Follow-Up Report](#)

The Health Foundation (2023) [Can you tell we care? Identifying unpaid carers using local authority and GP records](#)

The Kings Fund (2023) [Caring in a complex world Perspectives from unpaid carers and the organisations that support them](#)

Simpson E. et al (2021) [Understanding the Barriers and Facilitators to Sharing Patient-Generated Health Data Using Digital Technology for People Living With Long-Term Health Conditions: A Narrative Review.](#)

Seddon & Robinson (2015) [Carer assessment: continuing tensions and dilemmas for social care practice](#)

Busby et al (2020) [Motivations for and barriers to data sharing Identifying cultural and legal barriers to data sharing across government Report](#)

National Data Guardian (2020) [Survey report: Information sharing to support direct care](#)

Nuffield Trust (2022) [Falling short: How far have we come in improving support for unpaid carers in England?](#)