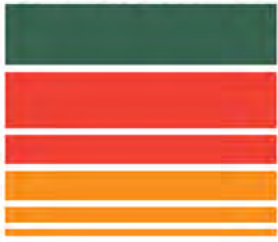


Brainbox Research



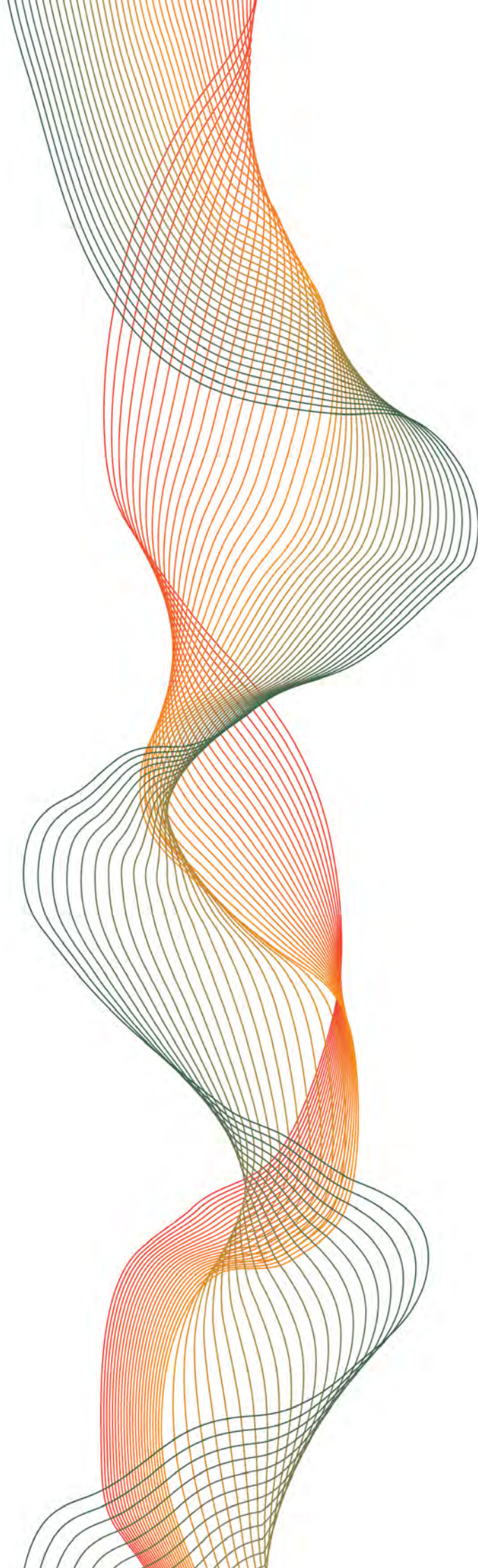
Joined Up Leads

Report for Rebecca Nichells,
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Insight and understanding



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Summary

Leeds has a vision to be the best city for health and wellbeing and to be a global leader for health innovation. Using and sharing information about citizens underpins this ambition yet there is often hesitancy around sharing information even where this may lead to improved health outcomes and reduced health inequalities. Joined Up Leeds was developed as a two-week period of conversations taking place across the city in which citizens discussed how their health and wellbeing data could and should be shared, the benefits of sharing, the concerns they have, and how information could be used for the benefit of people in Leeds.

Citizens could take part in Joined Up Leeds in four different ways. They could attend one of 17 “city conversations” taking place across Leeds in which researchers facilitated workshops around the key questions on sharing health and social care data. They could take part in a “network conversation” in which they used a “chat pack” to guide a conversation with people in their social, work, or community network about one of four case studies showing how people can benefit from information sharing. “Media conversations” took the form of Leeds citizens commenting on twitter using the hashtag #JoinedUpLeeds, viewing and commenting on a Joined Up Leeds Facebook page, and emailing. Finally, citizens could complete a survey, available in both online and paper formats or use an event card to record their views on the case studies. A total of 1,474 citizens participated in Joined Up Leeds. In addition, the Joined Up Leeds Facebook page received 111 likes, post promotions reached 8,084 people, and 492 tweets made 1,102,113 impressions.

What happens to information about me?

We identified three themes in participants’ conversations about what happens to information about them. The first - *Who sees information about me?* – describes how participants assume that information is shared more widely than is currently the case. While there were a few concerns, participants supported better information sharing as they believed that this would improve the quality of the care and services they receive. The second theme – *Who owns information about me?* – is about many different types of information, including financial information, employment records, purchases, internet browsing history, and health records. These conversations demonstrate variety in how people think about information ownership. Overall, participants are happy to take greater ownership of information about them. They believe it would reduce inaccuracies in their records and that greater involvement in and ownership of information would help ensure they get more appropriate services and care. The third theme – *Missed opportunities* – describes conversations about how greater sharing of, and more action upon, information collected could improve services, particularly for those with long-term health conditions and those who are vulnerable or elderly.

Who do I trust with information about me?

Survey respondents were asked how much they trust different organisations with information about them. The results show that GP practices are highly trusted, and more so than the NHS in general. Both of these are trusted more than banks or building society, the Council and Universities. All these organisations are trusted more than insurance companies, and in turn, all of these are trusted more than health apps, store loyalty cards, Amazon, Apple and Google. Facebook is trusted less than all other organisations listed. Respondents who considered

themselves to have a disability trusted universities and insurance companies with information about them less than people without a disability. Younger respondents had greater trust in banks, insurance companies, store loyalty cards, health apps and online organisations than older respondents.

Conversations about trust formed four different themes. The first – *Personal medical records* – reflects participants' mixed views about who should be able to access their individual medical records. They agree, however, that because people differ in the extent to which they would be willing to share information there should be a degree of personal choice. There are concerns about non-medical professionals accessing this information, and most people do not want employers to have access. Younger participants are more accepting of wider access. The second theme – *Control* – includes conversations about participants wanting to know who can see information about them and to retain some control over who has access to it. Participants do not like the idea of their personal information being sold to other organisations, especially if it means they will receive sales calls. The third theme – *Security* – reflects concerns about the security of systems used to store information about them. The fourth theme – *Trust-benefit ratio* – reflects how the amount of personal benefit an individual receives from sharing their information influences the extent to which they are prepared to trust an organisation with their information

What might the future look like?

Survey respondents were asked what they would be prepared to allow information anonymised from their health and social care records to be used for. The results showed clear support for this information to be used, with 93% supporting it being used for one or more reasons.

- 89% believed it should be used to plan the best services for people in Leeds;
- 74% believed it should be used to help people stay healthy;
- 74% believed it should be used to help find cures for diseases;
- 65% believed it should be available for general research for the public good;
- 18% believed it should be available for commercial research.

There were no differences based on age, disability and where people live (inner or outer Leeds). Despite this support, respondents had concerns about their information being used. The most common concerns are that information might be sold to private companies (71%) and it might not be stored securely (61%).

There was interest in greater use of technology in the future of healthcare, although older respondents were less interested in using apps and mobile internet than younger respondents. There was support for the way in which health information was shared in the four case studies, and while respondents of all ages agreed, support was greater in the younger age groups (91%) than the older (76%).

We identified four different conversations about what information sharing might be like in the future. The first – *Greater sharing of personal records* – is about participants wanted wider sharing of their records. They believe that this would lead to better more seamless healthcare, with fewer mistakes and omissions and one that would be more cost-effective. The second – *Citizen-owned, IT-enabled information* – is about a vision of a future in which citizens own their own information and grant access to professionals whose services they want. The third – *Open data* – is about citizens being bemused about why this would be useful and their pragmatic approach to accepting it being unlikely, rather than impossible, that they would be identified. The fourth – *Resources where they are needed* – reflects beliefs that better use of information means that resources can become more flexible and can move to

areas where they are needed most. This could shorten waiting times for healthcare, and by anticipating people's needs, services could become proactive rather than reactive.

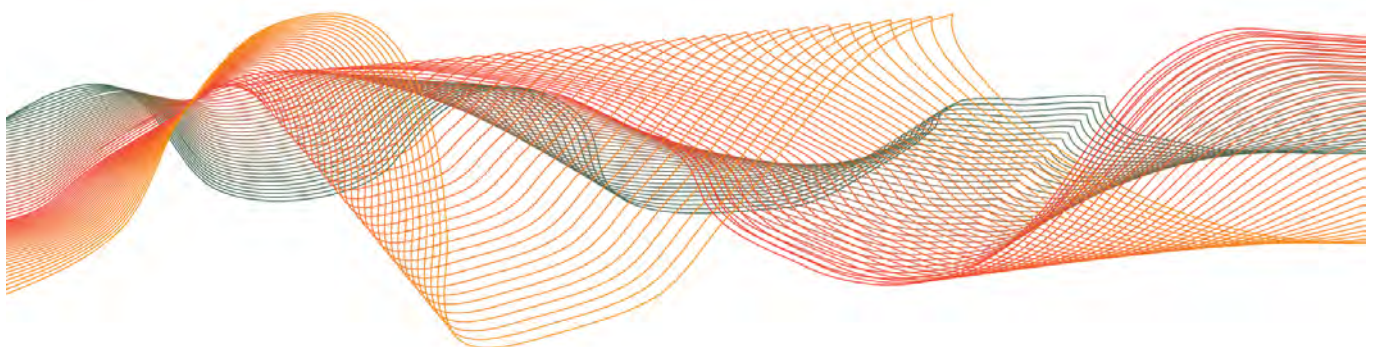
Our research leads to the following conclusions.

- Citizens trust the NHS, and in particular their GP practice, with their information more than other organisations because they believe the NHS has better motives for wanting access to it.
- Most citizens are willing for information about them to be used to improve health and wellbeing and to plan services. This includes granting wider access to personal medical records, publishing information on the number of people with different conditions and situations (aggregated data) and releasing datasets that contain anonymous information about them (open data).
- There is less support for releasing information for commercial research purposes as citizens are concerned that organisations using information in this way are solely motivated by increasing their profits. They are also concerned that if private organisations were to have access to this information they would use it to gain a competitive advantage, which would adversely affect the NHS.
- Younger citizens are more likely to allow wider access to their individual healthcare records for the purpose of direct care and they are less concerned over information about them being sold.
- Individual citizens should not be readily identifiable from information released about them. They do not want to be contacted or marketed to as a consequence of their information being released. This is of particular concern for citizens with disabilities.
- Citizens want to feel in control of who has access to their information, particularly their individual medical records. They need to trust people who see their information about them.
- Citizens are puzzled by the concept of open data and what it could be used for. They are concerned about sensationalised, inaccurate or misleading stories that could be reported by the media.
- The trust-benefit ratio is central to increasing the number of citizens who support and advocate information sharing. People need to understand how access to their information can help learn more about, treat, cure and prevent illness and increase quality of life. They need concrete examples of how aggregated data and open data has or could make this happen.
- There is interest in using technology to send and access health information. Benefits include gaining personalised health recommendations and guidance in managing long-term conditions. At present citizens feel most comfortable with using a computer for this purpose but there will be increasing interest in using health apps, and this will be driven by younger people who rely substantially on their smartphones for communication and internet access.

- Giving citizens greater control over their own healthcare records is likely to change the clinician patient relationship, particularly around trust and citizens taking greater responsibility for their own health.
- The cost of making datasets available should be less than the financial savings made from better and more efficient services.
- People using information to make decisions about citizens should remember that they are people, not numbers.

We make the following recommendations.

1. Let citizens know – in easy-to-understand terms – what information collected from them is being used for. This should not be hidden in terms and conditions.
2. Help citizens to understand the value of information about them by developing clear examples of how it has been used to improve services. The Health and Social Care Information Centre could play an important role in this.
3. When information is requested from citizens, for example on application forms, surveys or Equality monitoring forms, it should be clear why it is being asked and what it will be used for.
4. Reassure citizens about the ethical principles that guide professionals on confidentiality and protect their privacy.
5. It should be possible for citizens to opt out of information sharing, although they need to understand the implications for themselves and others of doing so.
6. Produce an audit trail, open to citizens, showing the information that was used to reach policy and planning decisions.



1. Background

Leeds has a vision to be the best city for health and wellbeing and to be a global leader for health innovation. Using information appropriately is an important component to support this ambition but until now little was known about what citizens of Leeds think about how information about them could and should be used. This can lead to hesitancy around sharing information even where this may lead to improved health outcomes. Missed opportunities to make use of information might hinder the city's ability to improve health outcomes and reduce inequalities.

Residents of Leeds have access to health and social care services provided by organisations such as GP practices, local hospitals, community nurses and local social care services teams. To deliver services, these organisations collect information about the people they treat. They also share this information with each other as deemed appropriate by the health and social care professionals involved in care. Greater integration of care between the NHS and the Council will mean that information sharing becomes even more important. Innovations in IT mean that there are increasing opportunities for citizens to input into their own healthcare records. Yet again, we were not aware of how much support there is for these new ways of working.

Citizens know that the world of data and information is changing. They may choose to interact with services and bank online. They may sign up for 'Google' or 'Apple' services and access their account from any number of devices. They see online adverts targeted at them because of a shopping web site they may have been browsing. Alongside this there are worrying headlines about security systems being breached. They hear about information being used for research and are unsure whether their personal data can be identified.

In Leeds, we want residents to be given the best possible health and social care and this involves services being improved over time by learning from the past and anticipating the future. To do this we need to analyse information about our citizens and the services they use. But people differ in how much they want to engage in information sharing. Organisations in Leeds that currently handle health and social care data would like to understand how citizens feel about how their information is used now and might be used in the future and how residents of Leeds can be involved and engaged with this.

Brainbox Research, a health and social research organisation in Leeds, was commissioned to undertake a project that both engaged citizens in Leeds in a conversation about information sharing in the city and explored their beliefs about how information about them could be used.

There has been some previous research on information sharing in the healthcare setting. For example, qualitative research with patients in Ireland explored their views on using their GP records for health research.¹ This study, with 35 patients in six focus groups, identified that participants were supportive of both identifiable and anonymised

¹Clerkin, P., Buckley, B.S., Murphy, A.W., MacFarlane, A.E. (2013) Patients' views about the use of their personal information from general practice medical records in health research: a qualitative study in Ireland. *Family Practice*, 30:105–112.

records being used for health research purposes. While they believed the risks to be low, participants wanted to be informed how their information would be used. There were some concerns about the consequences of information being leaked, with males more concerned about financial and employment impact and females more about potential social embarrassment. This study clearly supports the use of information for research for the public good, although as, despite their efforts, the researchers were unable to recruit young males (age 18-35) to the study, this is a demographic that needs particular attention.

Survey research in London² has provided further evidence of public support for sharing information across health and social care and for using health records for health research and to inform policy and planning. This study examined support for the use of electronic healthcare records and concluded that most people (90%) support having a single electronic health record and most of these would want their entire medical record to be included for direct healthcare purposes rather than a summary. There was also substantial support for using their information for health research (81%) and policy and planning (80%), although most respondents wanted personal identifiers to be removed if their information were to be used for these purposes. The strength of this research is that it was a large-scale (n=2857) cluster randomised study that examined support for electronic health records for a variety of purposes. This allowed multivariate analysis which showed that younger people and those who do not identify as White British are less likely to support their records being used for health research and policy and planning purposes. While the size and the diverse sample recruited make this a strong study, no open responses were reported so we do not gain insight into the concerns that people have about their information being used.

Some previous work on information sharing has been undertaken in Leeds. A consultation delivered in collaboration with the Leeds and York Partnership NHS Foundation Trust³ highlighted that data privacy was a key public concern. This consultation was successful in engaging stakeholders working in the health sector but less so in engaging the general public. It provides a good foundation for the current research, enabling us to move beyond the concerns that people have on data security to discuss what citizens believe and expect for the future of information sharing. To enable future initiatives to be truly collaborative and citizen-led, as recommended by the Smart Cities project⁴, the current research required broad and in-depth public engagement.

Joined Up Leeds was developed as a two-week period of conversations taking place across the city in which citizens discuss how their health and wellbeing data could and should be shared, the benefits of sharing, the concerns they have, and how information could be used for the benefit of people in Leeds. These conversations aimed to provide insight into which information people think should be shared and between which organisations, why people would be willing to share their information with some organisations and not others, which organisations they would trust with their information, differences in how people think and feel about data sharing with public and private sector organisations, concerns that people might have about sharing their data, why people might feel differently about their data being shared using paper or electronic files, and their ideas for how else technology could enable data to be shared in a way that benefits Leeds citizens. It aimed to involve a wide range of people, and accordingly, there were several different ways in which people could take part, including:

² Luchenski, S.A., Papoutsi, C., Bell, D. (2013) Patient and Public Views on Electronic Health Records and Their Uses in the United Kingdom: Cross-Sectional Survey. *Journal of Medical Internet Research*, 15(8):e160

³ <http://www.leedsdatathing.co.uk/wp-content/uploads/2013/12/AboutMeLeeds.pdf>

⁴ <http://leedssmartcities.wordpress.com/smart-cities-health-and-wellbeing-discussion-draft-nov-2014/>

1. **Have a chat:** Get a small group of people together to talk about how information could be used. A chat pack was provided to guide people through a 20-minute conversation and groups could post back the completed pack for free.
2. **Go online:** Visit the Joined Up Leeds Facebook page www.facebook.com/joinedupleeds or blog <https://joinedupleeds.wordpress.com> and post your comments, tweet with #joinedupleeds, or visit the online survey at <http://tinyurl.com/joinedupleeds>
3. **Invite us to host a workshop:** If people were able to get 10 or more interested parties together at one venue, the Joined Up Leeds team were able to facilitate a discussion..
4. **Come to an event:** Various small and large events were held across Leeds for anyone to attend.

Having many different ways for people to contribute encouraged people who would not normally consider attending events to get involved, talk about their experiences and their views, and share their ideas for the future.

2. Methods

The project had three stages. The first was to interview key thinkers on data sharing in the city and to use this to develop materials to help citizens understand how information could be used, and the risks and benefits of doing so. The second stage was to hold a variety of conversations with people in Leeds and to encourage them to contribute their views. The third was to analyse the data collected and to develop recommendations for how information sharing in the city should develop. A project steering group was set up, involving NHS and Leeds City Council personnel. This group advised on methods and facilitated communication about Joined Up Leeds during the run up to the conversation and during the conversation period itself.

2.1 Interviews

Interviews with 18 people viewed as key thinkers on information sharing in the city were undertaken, along with one interview with a citizen who talked about their experiences from a patient perspective. During the interviews their views and experiences of information sharing were explored, together with how they use information currently, the challenges they face, and their ideas for the future of information sharing. An unstructured approach was taken so that the topic of the interview was free flowing depending on the experiences and interests of each participant. The key thinkers were identified primarily by the steering group, with some additions suggested by the initial key thinkers interviewed. Each interview lasted between 15 and 45 minutes and field notes were taken. The insight gained was used to develop a set of materials that could be used to help citizens understand some of the potential benefits and risks of information sharing and to get them talking about how information is used in their day-to-day lives and how it could be better used for health and wellbeing in the future.

2.2 Conversations

To enable a wide range of Leeds citizens to take part we developed three types of conversations: city-based; network-based; and media-based.

City-based conversations

These conversations took place in 17 different locations (Table 1) around Leeds and involved focus group activity workshops around the key questions on sharing health and social care data. The city events used three different types of activities.

- **Journey Mapping:** participants create a life events map in which they chart significant events in their life so far, and explore the role that shared data did or could have played in these events. This approach enabled people to explain what is important to them in a way they would find difficult to articulate in traditional focus groups or interviews.
- **I Like, I Wish, What If:** participants described what they like about how information about their health and wellbeing is being shared, what they wish could happen differently, and how information sharing would be different if the data sharing or technical environment were fundamentally different. It helped participants to imagine how their health and wellbeing might be affected by better information sharing.
- **Why-How Trees:** participants discussed the people and organisations they give their information to, the benefits that information sharing can bring, and any concerns they have about information sharing. Participants discussed both why and how information is shared currently and how they would like information sharing to work in the future. This activity helped participants to visualise how they feel about information sharing and what reassurance they would like about how their information is used.

Network-based conversations

These conversations are between people within their networks. These were social networks (e.g. groups of friends or leisure groups), work networks (e.g. groups of colleagues) and community networks (e.g. people who live in the community, use a resource in the community such as a pub or children's centre). A resource was developed – a “chat pack” that guided people through a conversation. It included four case studies (see Section 2.4), based on real-life experiences of how people can benefit from information sharing. Participants chose one to discuss in detail and they explored what they like about how information was used, any concerns they have, and if they would be happy for their information to be used in that way. Participants returned the chat packs in reply-paid envelopes.

Media-based conversations

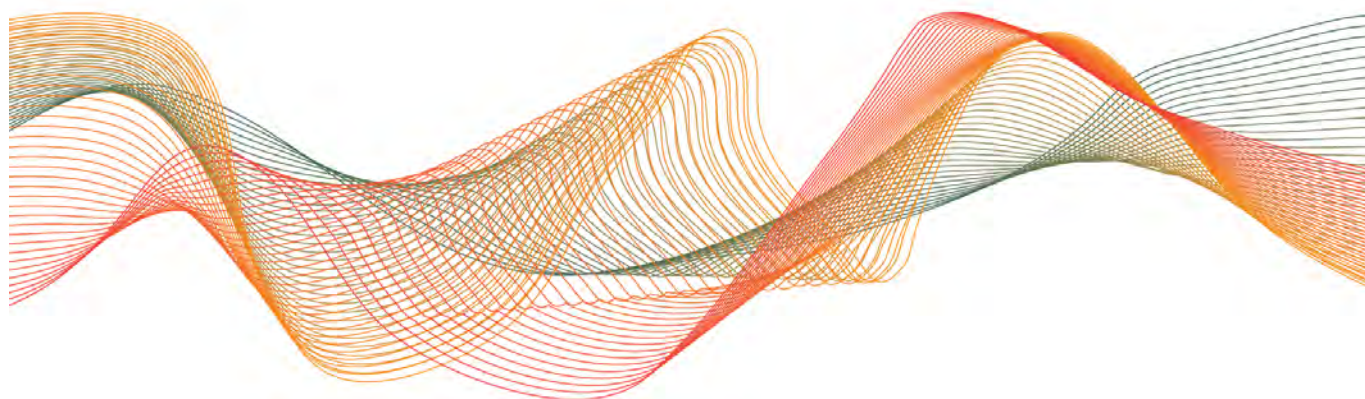
These conversations took the form of Leeds citizens commenting on twitter using the hashtag #JoinedUpLeeds, and viewing and commenting on a Joined Up Leeds Facebook page. This helped engage people who were unable to commit to a city- or network-based conversation but who nevertheless wanted their views to be heard. It also provided a mechanism by which professionals could raise awareness of Joined Up Leeds.

2.3 Survey

A survey was developed that included questions about what information should be used for, how much different organisations are trusted with personal information and preferences for using IT to share information with GPs. We wanted to make the survey brief enough so that potential respondents were not deterred from taking part, yet explore more potential uses of information than has been asked in previous research. We also wanted to identify how much people trust different organisations with information about them. Both open and closed questions were included to allow for more insight to be gained into people's views on information use. The survey items are shown in Appendix 1. Respondents were asked how anonymised information, where it is not possible to identify individual people, should be used. As such this could include both aggregated data and anonymised data, but to keep the survey brief by avoiding long explanations and examples of these uses, separate questions were not asked about these two different forms. It was simply stated that it would not be possible to identify individuals from the information. The survey was available both online and in paper format.

2.4 Case study event cards

To engage citizens who were not able to commit much time to Joined Up Leeds the team developed case study event cards that could be completed in only two-three minutes. Four different versions were produced, each containing a different fictional case study. Each were based on typical ways in which information sharing could benefit patients in the future, and each addresses a different potential concern. Sarah's story addresses sharing mental health records. Ali's story addresses sharing information between the NHS and social services. Sheila's story involves sharing personal and healthcare information with a private company. Neil's story involves both citizen-controlled information and sharing information with voluntary workers using a system currently being piloted by Leeds City Council. Respondents were asked to answer two questions: Is this a good use of information? and Would you be happy for your information to be used in this way? Because previous research indicates age is a factor that might affect views on information sharing, respondents were also asked to indicate their age group. The case studies are shown on the following page.

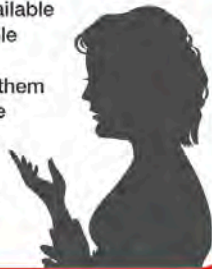


Sarah's story

Sarah is 21 years old and has suffered from alcohol abuse and mental health issues for some time. She regularly sees her psychiatrist who has prescribed Lithium to help. At her most recent appointment her psychiatrist checked her Leeds Care Record, which allows doctors from different hospitals and GP practices in Leeds to see a patient's medical records. The psychiatrist could see that Sarah had gone to A&E twice after drinking a lot of alcohol and noticed that as well as having high levels of alcohol in her blood, Sarah also had Lithium poisoning. He prescribed a different medication for her.

"Thank goodness, my psychiatrist was able to see my hospital test results at my last appointment, because I'm now taking a different medication which is suiting me better."

Before the Leeds Care Record was available her psychiatrist wouldn't have been able to see the A&E test results during her appointment – he could only have got them by phone or letter, which wouldn't have happened during the appointment, if at all. Because Sarah is no longer ill from the Lithium she had been taking, both her physical and her mental health have improved.



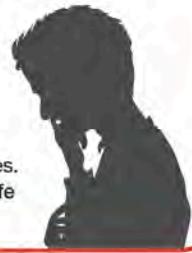
Ali's story

Ali is a happy, lively ten year old who loves football, and because he plays so often he usually has lots of bruises. One Saturday morning, though, Ali fell over while playing and knocked himself out for a couple of minutes. His arm was cut and bleeding and he couldn't move it. Ali's friends went to fetch his Dad, who took him to A&E.

When they arrived at A&E the hospital staff said that Ali's arm was broken and so they would set and stitch it and give him some antibiotics to make sure it wouldn't get infected. They asked Ali's Dad about any allergies but he didn't know.

"It's my wife who takes care of all of the family. I just don't know if he's allergic to any medicines. I don't think so, but I don't know."

The hospital checked Ali's GP records and found that he was allergic to the antibiotic they were going to give him, which would have made him ill. Instead they gave him a different one. The hospital doctor was worried about all of Ali's bruises and checked Ali's council records to make sure that there were no concerns about violence at home logged by social services. Once they were reassured that Ali was safe and well Ali's Dad took him home.



Sheila's Story

Sheila is 83 years old and lives alone. Her daughter – Claire – has been worried about her for a few years and would like her to move to a care home but Sheila doesn't want to. She has carers who visit every day and this gives her the help she needs to stay independent.

"I've lived in this house for nearly 50 years and I'm comfortable here. I know Claire worries about me but I want to stay here for as long as I can."

Sheila had a system installed that monitors movement around her property and uses a "lifeline" unit that allows her to talk to a helpline operator 24/7 if she needs help. One night Sheila couldn't sleep so decided to go downstairs and make herself a hot drink, but tripped coming down the stairs and was lying unconscious in the hall. The operators at Tunstall Healthcare were alerted automatically that Sheila had left her room but was not moving around her house. They used the lifeline unit to call out Sheila's name to ask if she was ok. This roused her and she shouted that she had fallen and couldn't move. The operators called an ambulance, told them about Sheila's fall, her address and how they could get in without breaking down the door. They called Claire and told her what had happened. They were able to provide further personal details to the health professionals and they informed her GP and her care workers. Because people were alerted she got to hospital quickly and made a much better recovery. While Claire would still like her to move into a care home, she knows her Mum has an extra layer of safety to enable her to stay in her own home.

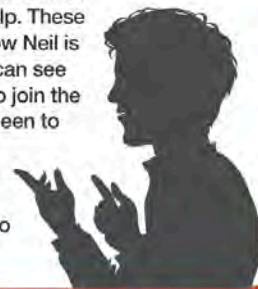


Neil's story

Neil is 42 years old and until recently lived with his wife and son. Within the last year Neil and his wife separated and his son, Matt, left home to go to University. Neil has multiple sclerosis and uses a wheelchair. Even though he is struggling to live alone, Neil tries to do most things himself.

"The council said I could have a carer to come to help every day but most of the time I can manage. I've been bad with depression in the past and I think it's important that I stay positive and part of that is doing things for myself – I don't want to rely on other people just yet."

The council set Neil up with a Circle of Care – a group of people who he can call on for help if he needs it. He uses a tablet (a mini computer) to go online and keep in touch with the people in his circle of care. People in Neil's circle include his community care worker, his mental health worker, the community meals service, and a contact from his local voluntary group. Neil doesn't have regular visits from these people but he lets them know how he is and can ask them to visit if he needs help. These people keep electronic notes on how Neil is doing, and everybody in the circle can see these notes. Neil has invited Matt to join the circle so that he can see who has been to visit, and can ask them questions. This is a big reassurance for Matt, who often worries that he should leave University and stay at home to care for his Dad.



2.4 Participants

Participants for city conversations were recruited both directly and through community organisations. The number of participants taking part in each city event is shown in Table 1. Events took place across different locations in Leeds and included city centre bars, community centres, business centres and leisure centres. These venues were selected to provide events around different areas of the city, and to encourage a wide range of people to take part, including males age 18-35 as they have been absent from previous research in this area.² The most successful method was to attend existing community groups. Also effective was holding an event in a venue that attracts people for leisure purposes, e.g. bars and leisure centres and to encourage people and passers by to take part. One participant had read about the work on Better Lives Leeds, and one on Event Brite. Nobody attended as a result of the Facebook page or tweets.

Table 1: Participants taking part in City conversations at each venue.

Black Swan (LS1) A city centre bar and restaurant, popular with students and young professionals. The Reliance tweeted and posted the event on their Facebook page.	11	HEART (LS6) Headingley Enterprise and Arts Centre is a community centre that provides workspaces, classes, events and a café.	4
Armley Library and One-Stop Centre (LS12) A busy Council building attracting both young parents (especially to the library) and a range of residents from Armley seeking advice and support from the One-Stop Centre.	5	Dragons Health Club (LS19) The event took place in the gym café, which is open to the public. Dragons is an LA Fitness centre located in Yeadon.	3
Leafield House, (LS17) The Headquarters of Leeds North CCT, located in Moortown.	7	Civic Hall (LS1) Two events took place at the Civic Hall.	5
Roundhay Park Lakeside Café (LS8) The cafe attracts people using the park for a variety of reasons, including walking, exercising and visiting the playground. The event was timed to coincide with Parkrun runners as well as visitors to the park.	14	Richmond Hill Community Centre (LS9) This community centre serves Richmond Hill, East End Park, Cross Green, Saxton Gardens and Osmondthorpe. The event took place at lunchtime when people drop in to have lunch.	20
Trinity Shopping Centre (LS1) The event took place in the customer service lounge where people call in to sit down, ask for directions, charge their phones or use the computers.	7	Heydays (LS2) This is a community project for the over 55s that helps people develop and share creative skills. It is based at the West Yorkshire Playhouse and attracts people from across Leeds.	31
Inkwell (LS7) Inkwell is a space where people can be creative, come to a class, take part in an activity, visit the café, or come to an event. It is run by and for people with mental health problems and is open to everybody in the community.	4	John Charles Centre (LS11) Based in Middleton, the John Charles Centre is a large sports centre. The event took part in the café bar area where people meet for post-work and post-activity refreshments.	6
McCarthy's Business Centre (LS7) Based in Sheepscar, the business centre provides serviced offices for small businesses across Leeds.	3	Horsforth Children's Centre (LS18) The event took place with a group of young parents who attend parenting classes at the Children's Centre.	11

Reliance (LS2) A city centre bar and restaurant, popular with students and young professionals. The Reliance posted the event on their Facebook page.	11	Bramley Elderly Action (LS13) This is a neighbourhood network scheme that promotes the independence, health and wellbeing of older people throughout the city. It includes people from Bramley, Swinnow and Stanningley. The event took place over lunchtime, during when older people were calling in for their lunch.	6
LS14 Trust, Seacroft (LS14) This is a community organisation that provides an informal space where local residents can ask for help and advice and use the computers and the internet.	10	John Smeaton Leisure centre (LS15) The researchers were based in the reception area of the leisure centre and invited people to complete and event card or survey while they were passing by.	Event cards and surveys only

Chat packs, surveys and case study event cards were left in community and leisure areas, including pubs, shopping centres and one stop centres. The chat pack was downloaded from the Brainbox Research website 185 times.

Survey respondents were recruited both through the Leeds Citizens Panel and also through community organisations and workplaces. A total of 1,100 respondents fully completed the survey, with another 116 partial completions (91% completion rate). This high completion rate indicates that the questions within the survey did not deter respondents from taking part. Most responses (85%) were from the Leeds Citizens Panels, and accordingly, were from a representative range of locations across Leeds and good balance of genders, although younger adults were less well represented. Just over half were female (53%) and the majority were white/white British (93%). Most were age 25-64 (26%), 46-64 (46%) or 65-84 (25%). Efforts were made to include more young people by contacting the Universities but as this work coincided with Student Union elections and the National Student Satisfaction Survey, they were unable to circulate the survey link. However, Youth Watch circulated information about the survey.

A total of 189 citizens completed case study event cards. Most were 18-24 (15%), 25-45 (35%), 46-64 (20%) or 65-84 (22%). We received 111 likes on the Joined Up Leeds Facebook page. Post promotions reached 8,084 people. There were 492 tweets using #joinedupleeds from 167 participants, averaging 1 tweet/hour and 3 tweets/participants. There were a total of 1,102,113 impressions.

2.5 Ethics

Brainbox Research Consultants are Chartered Psychologists and members of the British Psychological Society (BPS) and the Social Research Association. As such they conform to each society's codes of conduct, ethical principles and guidelines. The project and its materials were reviewed internally to ensure that the research is ethical, and the information about the project easy to understand and enabled potential participants to make an informed choice about taking part. Participants were made aware of how the information they provided would be used. They were given the opportunity to ask questions about the research and were assured of their anonymity.

3. Results

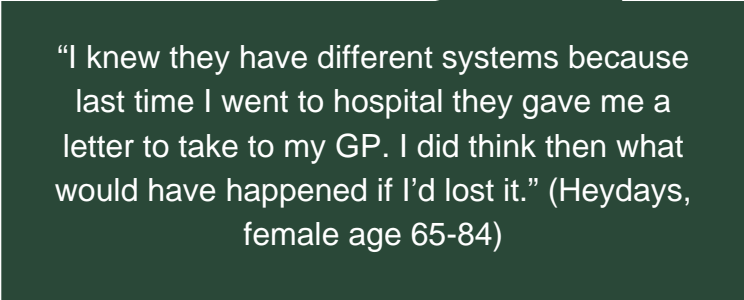
The results are presented in three sections. The first explores citizens' beliefs about what currently happens to their information, who it is shared with and what it is used for and who owns their information. The second section explores who citizens trust with information about them and examines their beliefs about their personal medical records, and what influences their feelings about who they are prepared to share their information with. The third section explores what the future might look like, including the role of IT and what information might be used for. Each section is illustrated by quotes from participants attending city events. The event venue is shown in brackets.

3.1 What happens to information about me?

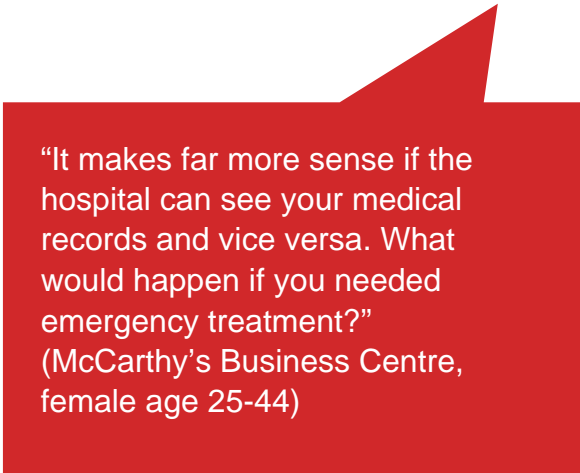
We identified three themes in participants' conversations about what happens to information about them: Who sees information about me? Who owns information about me? Missed opportunities for sharing information. These are described below.

3.1.1 Who sees information about me?

A recurrent topic of conversation was that participants assume that information is shared more widely than is currently the case. They were surprised that GP practices and hospitals don't share the same record system and cannot, generally, access one another's records. A few were aware of current information-sharing initiatives such as the Leeds Care Record and all saw benefits in this.



"I knew they have different systems because last time I went to hospital they gave me a letter to take to my GP. I did think then what would have happened if I'd lost it." (Heydays, female age 65-84)



"It makes far more sense if the hospital can see your medical records and vice versa. What would happen if you needed emergency treatment?" (McCarthy's Business Centre, female age 25-44)

Similarly participants were surprised that information collected by the Council isn't stored on a central record: that different departments keep different records. As they talked about information sharing within the Council, however, they could think of several situations in which they had to give the same information to different departments and realised that the Council is likely to have multiple systems and that information is not necessarily shared across them. They saw many advantages to both their medical and Council records being more widely shared. For example, if they informed the Council that they had moved house this could change their Council tax records and could trigger sending them an information pack about their new area, or information on saving energy.

Participants' conversations framed information sharing within the Council as being more complex than within the NHS as there are so many different Council departments and it would not always be appropriate for everybody at the Council to be able to see everything about you.

“You wouldn’t want everybody in the Council to be able to see everything about you. You wouldn’t want them to be able to see who lives in your home.” (HEART, male age 25-44)

Conversations explored what happens when the lines between NHS and Council employees blurred, for example care workers who are directly involved in providing healthcare. With greater thought, many participants commented that this is an area that becomes more complex. Their discussions suggested that being an NHS employee conveys privileged status, with citizens being more inclined to trust the motivation for information sharing from the NHS than the Council.

Participants also assumed that information about them – in some aggregated form – is used to help plan services. A few were aware of data such as the Hospital Episode Statistics, but most had not given this much thought previously and simply assumed their information would be used in some way to help identify current and future demand for services. They were happy for this to happen. Although unaware that their GP records are not currently used for this purpose, nobody disagreed that this should happen. They thought this information is or should be used to help identify trends in conditions and so improve access to services.

In contrast, some participants talked about how they are asked to give too much information and about feeling sceptical as to why this information is obtained and what it is used for. One example discussed was the equality monitoring information that is gathered when people apply for housing. They suspected that the Council uses this information when deciding on whether a bid for a home has been successful and they talked about how it should have no bearing on whether or not somebody is deemed suitable for a home.

“They share too much information at the moment. You have to give your age, your sexual orientation – and does it matter if you’re gay, straight, or you like cows? It shouldn’t be relevant! Your ethnicity too, it shouldn’t be an issue. It’s not relevant. There shouldn’t be any favouritism. Get rid of that box ticking.”
(Armley, male age 45-64)

3.1.2 Who owns information about me?

Conversations covered many different types of information, including financial information, employment records, purchases, internet browsing history, and health records. These conversations demonstrated a lot of variety in how people think about information ownership. Some participants had not thought much about the issue previously and were more likely to think that information belongs to the person who collects it. They became aware that

information about them had been shared or sold when they receive sales communications. Others were clear that information about them collected by different organisations belongs to them and it should not be used and shared without their permission.

Conversations about health records again indicated differences in both beliefs about and experiences of information ownership. Many participants had not considered this question expressly before. Some firmly believed that individuals own their own records and described how if they change their GP, their health record goes with them. Others believed that their GP, or the NHS in general, owns their records and described how you can request access to your records, which indicates that you are not entitled to see them. One participant described a case in which access to medical records was denied because it was thought not to be in the person's best interests to see their own records.

“It’s me you’re talking about! I’d like to be see what is written about me.” (John Charles Centre for Sport, female age 25-44)

A few participants talked about GPs being able to charge for a letter confirming some aspect of your medical records, for example following a request from an insurance company. Others talked about what happens when you don't want professionals to see some aspect of your medical records, for example a previous drug addiction, or a diagnosis you didn't agree with. One participant talked about how you can't ask for parts of your record to be deleted. This supported the view that individuals do not own their own records.

“I don't think you do own your medical records because I've asked my GP for a letter about my condition and I had to pay for it. If you owned your records they couldn't charge you. I've seen my own records and there are some things on there I don't agree with. Somebody put things on my record and years later it's still affecting me because people read it and they get a certain impression of you. And there's nothing you can do. You can't take it off.” (Dragons Health Club, female age 45-64)

Some participants were unclear about where ownership lies and considered it a co-produced and co-owned document in which they choose to tell their healthcare professional about their health, and the professional enters observations, test results, diagnoses and treatments.

Participants agreed that it should be possible to see your own medical records, although a few did not think they would want to as they wouldn't be able to understand what is in them. Several participants discussed how owning your own medical records might change the professional-patient dynamic. They talked about how if people owned their own information they might take greater responsibility for their own health and wellbeing. They would feel more empowered. A few participants discussed how they think that doctors can find it difficult to raise issues with

patients, for example about obesity, alcohol or exercise, and that if a patient could see on their own records that they are obese, or their alcohol consumption is a health risk, they may be willing to raise this issue themselves.

“If we were given our own medical records we would have more responsibility for our health. Anything that means people take more interest in their health is good.” (Reliance, male age 25-44)

They discussed how if professionals had to request access to information, rather than being automatically entitled to it, they might do more to earn the trust of individual patients. This was viewed as a positive outcome for patients.

“People will withhold information unless they trust their doctor. It could mean that increasing trust becomes more of a priority for doctors.”
(Leaffield House, female age 45-64)

One participant discussed whether having greater access to your own medical records might mean that you start to know more than your doctors, and wondered what that might mean for the doctor-patient dynamic. They thought it possible that doctors might start to get defensive, or it might mean that doctors and patients could have more in-depth and meaningful conversations about their health conditions, their expectations and aspirations.

People were happy to take greater ownership of information about them. Many gave examples of how the information kept about them is inaccurate. They thought greater involvement in and ownership of information would help ensure they get more appropriate services and care. Some suggested an annual sign-off of records where people are asked to go online to review and update their records.

“They should trust us with our own information.” (Leaffield House, male age 65-84)

The case studies sparked several interesting conversations around ownership of medical records and responsibility for care. Several different groups identified that in Sarah's story a test result from in A&E should have been acted upon immediately, rather than waiting for the clinician who prescribed the drug to take action. One group believed that Sarah herself should have taken responsibility for contacting her psychiatrist. Another group discussed where the duty of care lies when no single professional owns medical records. A concern was raised that if lots of different professionals can access your medical records, would there be any one person who would be responsible for

monitoring your health? This could lead to a situation in which nobody takes action because everybody believes the responsibility lies elsewhere or assumes that another professional would already have responded.

“Who was prescribing and what checks were or should have been made? Who was monitoring? (Heydays, female age 65-84)

Neil's story also generated lively conversations. People identified many benefits of the Circle of Care in Neil's story, in which an individual invites people to join a closed group that can view and record notes about them. They discussed that a key aspect is that Neil has control over who joins the group. This generated discussion over whether everybody should control their own care notes or whether some conditions may make this unsafe. Some participants discussed that people with learning difficulties may not always make choices that are in their best interest.

“Would you need a key worker for people with mental health difficulties? If they refuse treatment, you need somebody with oversight and responsibility. It would be to protect them. An advocate.” (Inkwell, male age 25-44)

“People with learning difficulties have control over their own money at the moment but they need help. Like if somebody decided to spend their whole year's money on going on a 60-day cruise. Is this a good use of money? They need somebody to oversee it.”
“And with sexual relationships in people with learning disabilities. They need some advice, but when does advice become control?” (Inkwell, female age 25-44)

One participant who had been in a situation in which several professionals were providing support and guidance for mental health problems and addiction praised the Circle of Care. He believed that having trusted individuals in the circle would mean that people take advice when their health or behaviour is starting to deteriorate, and that this would mean there is less need for mental health sections to be imposed.

3.1.3 Missed opportunities

These conversations were around how the NHS should share information more widely between different departments and units. Participants would like NHS staff to be able to see relevant medical information about them. For example, one citizen with diabetes would like more people to know about their condition and would be prepared for a range of health and fitness professionals to see information about them.

“I would like people to know that I am diabetic in case I have a hypo. They could help me manage my diabetes and this would help me to live a normal life. It should be shared with the walk-in centres so they give me more appropriate treatment. Paramedics, dentists, opticians and the gym. More professionals would know how to help me quicker.” (Black Swan, female age 18-24)

Participants thought that better sharing of information between professionals could help provide better services for vulnerable people, especially the elderly. They thought that this would become increasingly important in the future as more of the population will be living with long-term health conditions, more of the population will be elderly, and more people will be living with dementia. Their conversations highlighted that it is important to share information between healthcare professionals and also with the families. Several participants talked about how they had been frustrated that GPs are unwilling to discuss their elderly parents' health with them, even when this would help provide better support. They also talked about how better sharing of information between NHS and Council social care professionals might help prevent child abuse.

“Dementia is going to be the new mental health. There's going to be a lot of people living with it and there is going to be stigma. GPs should understand that we need to know what is happening, things to be aware of now and what we can expect to happen so we can help and plan ahead.” (McCarthy's Business Centre, male age 25-44)

Many participants held similar beliefs about the benefits of the Council sharing more information between different departments. They thought that the Council should have a single digital record that contains all the information the Council might need. They discussed how they already supply information on who lives in their home, and this record should allow them access to all Council services without completing separate application forms. For example, one participant described how he had to complete an application form for a “tip permit” to use the Council recycling centre yet the Council should have the information necessary to do this automatically. Some participants discussed all the information that is supplied to the Council when they move home, and how better use could be made of this, for example sending information about the nearest leisure centres and GP and dental practices.

Several participants talked about a one-way flow of information, in that the Council and the NHS repeatedly ask for information but it is not acted upon, or they never feed back what they have changed as a consequence of receiving that information. A common example participants gave was giving information about their needs or disabilities, for example a visual impairment. Even though this is reported on various Council and NHS forms, none of the communication from either organisation arrives in large-print format.

“It’s a tick-box exercise to ask disabled people if they have a disability. They don’t do anything with that information. It makes you very cynical.” (Dragons Health Club, male age 45-64)

Many participants suspected that nothing happens to all the information that is collected and that it is simply stored somewhere, not analysed, and certainly not acted upon. They thought that this is a waste of time and resources. They believed that if the Council and the NHS take the time to ask us for information, and that individuals take the time to provide that information, it should be used. They thought that these organisations shouldn’t collect information for no purpose. They did not want a lot of money spent on collecting and releasing datasets for no clear purpose. They highlighted how much this might cost and believed money would be better spent on delivering services.

“Collecting information is a job creation scheme.” (Dragons Health Club, female age 45-64)

“Is this the best use of public resources? Wouldn’t the money be better spent on the front line?” (Heydays, male age 65-84)

Other participants discussed how analysing information does not, in itself, solve any problems. They agreed that it is useful to know about problems with services or health inequalities, but that knowing about a problem is only the first step to solving it. They believed that it is another thing entirely to act upon problems, and several were cynical that the Council, and to a lesser extent the NHS, would take any action.

“Numbers on their own will not do anything. It needs to be used for a purpose.” (McCarthy’s Business Centre, male age 25-44)

“Data is only useful if it is read, used, and acted upon.” (Leaffield House, female age 65-84)

Some people talked about how more information about a community could help benefit that community – it would enable people to work together to improve quality of life for everybody who lives there. They were interested in the idea of being able to access information about the problems in an area but thought they would need help and guidance in taking action.

3.2 Who do I trust with information about me?

3.2.1 Survey responses

Survey participants were asked how much they trust different organisations with information about them. They were asked to use a scale from 1 to 10 where higher scores indicate greater trust. The mean score for each organisation is shown in Figure 1.

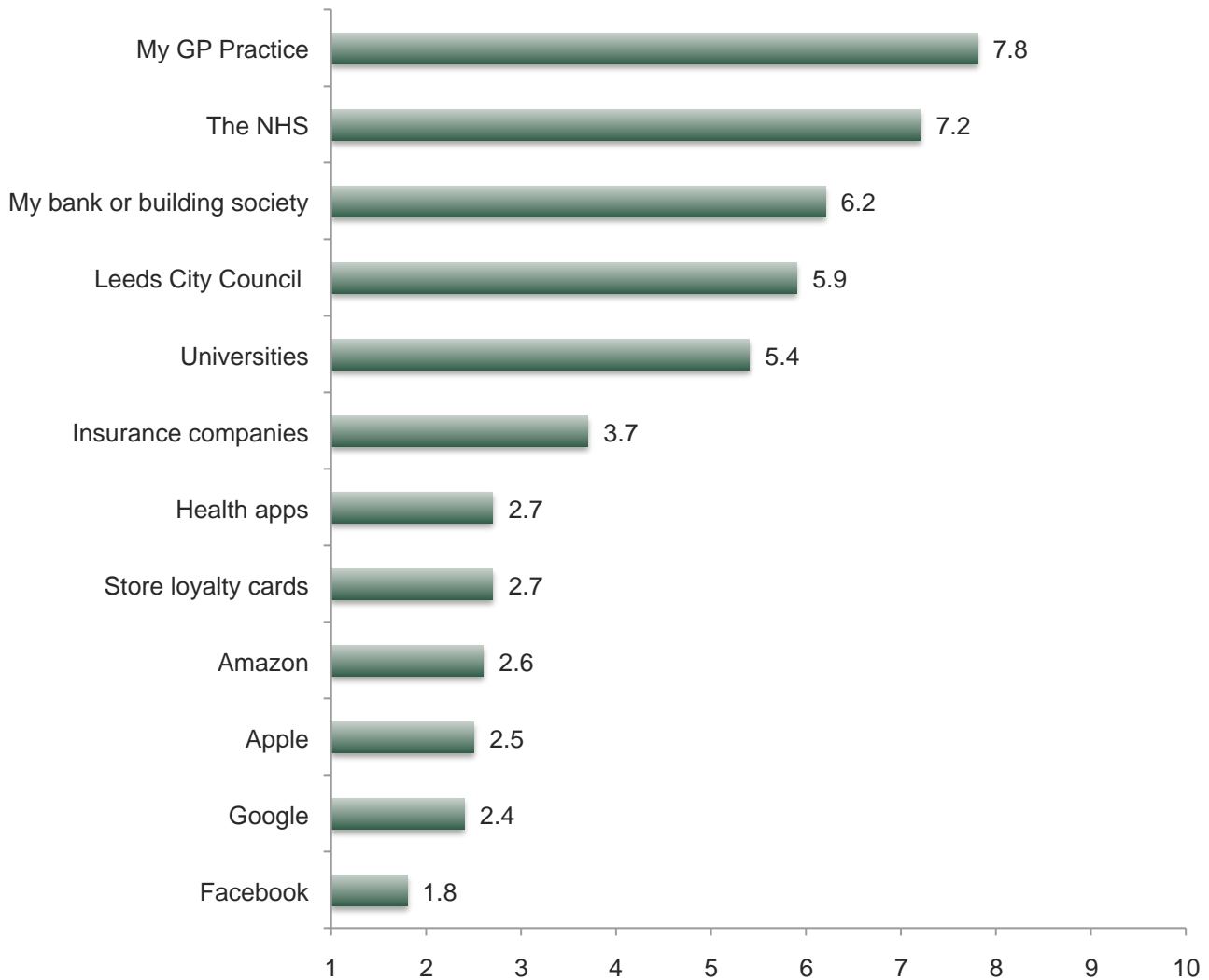


Figure 1: How much respondents trust different organizations (n=1,100).

There are statistically significant differences between these organisations, with GPs trusted significantly more than the NHS in general, and both of these are trusted significantly more than banks or building society, the Council and Universities. All these organisations are trusted significantly more than insurance companies, and all of these are trusted more than health apps, store loyalty cards, Amazon, Apple and Google. Facebook is trusted significantly less than all other organisations listed.

We undertook some additional analyses to explore whether different resident groups trusted some organisations more than others. People who considered themselves to have a disability trusted universities (M=4.8) and

insurance companies (M=3.2) with information about them significantly less than people without a disability (M=5.5, $p=0.001$ and M=3.6, $p<0.05$, respectively). People living in inner Leeds areas trust universities with their information (M=5.5) significantly more than people living in outer areas (M=5.0, $p<0.02$).

There were a few significant differences in trust between different age groups. We compared three age groups: <18-24, 25-64 and 65-85+ and found that younger respondents have greater trust:

- Younger respondents (<18-24 and 25-64) trust banks and building societies more than older respondents;
 - Younger respondents (<18-24 and 25-64) trust universities more than older respondents;
 - Younger respondents (<18-24) trust insurance companies more than respondents aged 25-64 and 65-85+;
 - Younger respondents (<18-24 and 25-64) trust health apps more than older respondents;
 - Younger respondents (<18-24) trust store loyalty cards more than respondents aged 25-64 and 65-85+;
 - Older respondents (65-85+) trust Google, Apple, Amazon and Facebook less than younger respondents.
- The youngest residents trust these online organisations the most.

3.2.2 Conversations about trust

Conversations about trust formed four different themes. These were about trusting people with personal medical information, about having control over your own information, about the security of information, and about a trust-benefit ratio.

Personal medical information

Participants had mixed views about who should be able to access their individual medical records. Some talked about information being shared on a “need to know” basis. Others were happy for anybody involved in their care to see their records. There was agreement, however, that people differ in the extent to which they would be willing to share information with and there should be a degree of personal choice.

Mental health was an area that generated a lot of different beliefs. There was a lot of discussion around the impact of greater access to records on stigma, with many people believing greater awareness of the number of people with a history of mental health problems would decrease the stigma associated with these conditions. However, people also discussed how some people would nevertheless experience stigma, and would be treated differently by professionals because of their current or previous mental health problems.

“Professionals treat you differently when they know you have bipolar so you don’t disclose. You need to trust people. They need to break down the barriers for you to trust them.” (Leaffield House, male age 65-84)

Participants were most concerned about non-medical professionals, as they believed they would not have a good understanding of mental health problems and are not bound by the same ethical codes as healthcare

professionals. This could lead to them discriminating against people by treating them differently because of their diagnosis and disclosing medical details.

Most people did not want their employer to be able to access their personal medical records. They thought that there was no need for this to happen and it could lead to discrimination. Some, however, saw benefits of greater sharing. For example, if their employer were signposted to advice about their condition and reasonable adjustments that would help them in the workplace.

“Tailored support could be provided to employers about medical adjustments they need to make.” (Black Swan, male age 18-24)

Many participants believed that younger people would be more accepting of the idea of open records and wider access to health information, and indeed, our younger participants (age under 20) only saw advantages from employers or university knowing about their health issues. They discussed how if they were taken ill at work they would want their employer to make better choices about what actions to take. Some participants highlighted that you become more sensitive about your records if you have medical conditions or a history that you would prefer others not to know about.

“Unless you have a criminal history you shouldn’t have anything to hide.” (Reliance, female age 18-24)

“Why be embarrassed?” (Reliance, male age 16-18)

Overall there was support for a core set of medical details, relevant to a person’s current health status, that is accessible beyond your GP practice. Most participants were happy for these to be available for healthcare professionals, particularly those who undertake assessments or deliver care face-to-face. This included care workers and mental health workers. There was mixed support for social work professionals being able to access this core record. Some participants talked about situations in which this would be useful and others were suspicious that because social work professionals don’t have medical training they would not understand the content of the records. They were concerned that what they read might allow what they read to prejudice their professional decisions. Voluntary workers also received mixed support, with participants concerned both by their lack of medical training and also that their role might be transient. There little support overall for employers being able to access records, especially prospective employers, and for the police having access.

In contrast, one participant discussed how he would like the police to have access to information about his health. He described how he has mental health condition and has been arrested on many occasions and believes that if the police had been able to access health information about him he would have been taken to hospital rather than a police station. He was very positive about the Circle of Care and believed it would help to reduce social isolation

for people with mental health difficulties. Some participants disagreed, however, and viewed non-medical professionals with more suspicion.

“Police and social services often abuse their position of authority and can sometimes be manipulative in order to gain what they want.” (LS14 Trust, female age 45-64)

Control

Many of the conversations discussed the importance of control over what happens to their information. Participants discussed how each individual is likely to have a different group of people they are likely to benefit from sharing their information with. This may change over time and according to their life and health situation. They therefore believed that access should ideally be tailored to each individual person and adaptable at different time points. An important aspect for participants was that they wanted to know who can see information about them and to retain some control over who has access to information about them. This was very apparent in responses to Neil's story, in which Neil invited people to join his circle of care.

“I liked the idea of a sharing circle amongst different professionals involved with Neil's care and how things were only put into place if he decided he needed help.” (Horsforth Children's Centre, female age 18-24)

Participants did not want people with access to their information to share it with third parties without their knowledge. They may not trust these third parties and they don't want their information to be sold. The following quotes come from conversations arising from the case studies. Participants talked about the importance of controlling who information about you is released to and they perceive a difference between choosing to grant access to information about you and the NHS or Council selling it to a third party that does not have your own interests at heart.

“I would need to give permission for people to see the things about me. They shouldn't be able to sell information.” (Armley, male age 45-64)

“The older lady with care needs. She chose to have that company helping. It's helping her. It's her choice.” (HEART, female age 25-44)

“It’s good that Sarah’s information is kept together, it’s not in different bits and it doesn’t take long to obtain. But certain stuff should stay confidential. They should ask if you’d like it shared with others. (Horsforth Children’s Centre, female age 18-24)

There was very strong agreement that people did not like the idea of their personal information being sold to other organisations. Many participants talked about situations in which they believe it has happened without their consent. For example, registering with recruitment agencies has led to contacts about loans. Participants wanted to feel in control of who sees information about them. They are also aware that once information is released about them it cannot be recalled.

In Sarah’s story participants talked about the way the information was used as being good, but Sarah should still have control over who has access to it. Similarly for Sheila’s story, participants talked about a key factor being that Sheila chose to release her information to a private company because she received greater support that enabled her to retain greater independence. The concern remained, however, that the company may sell her information to third parties, which may result in Sheila receiving sales calls. Participants were particularly concerned that Sheila’s age may make her vulnerable to sales calls. Some participants suggested that people with early dementia might be targeted with sales calls, should companies be able to access information about who has this condition.

“This is a good use of information in Neil’s case. But individual rights should be respected. I’d be concerned about nuisance phone calls, e.g. insurance companies, stairlifts, if information about me is widely accessible. Vulnerability of people needs to be considered if their information is widely available, we could even be rung up by funeral planners and PPI accident claim firms. How much control will we have over our data?” (Heydays, male age 65-84)

“I would worry about commercial interests coming in here. I don’t want to be bombarded with phone calls.” (Civic Hall, female age 25-44)

“Could we be pursued by funeral planners or ambulance chasers. People don’t want nuisance phone calls.” (Bramley Elderly Action, female age 65-84)

Security

Another aspect of information sharing that participants discussed was the security of systems used to store information about them. People were concerned about the security of their information and questioned how possible it is to develop a system that is completely secure. They talked about how different organisations are likely to have different standards of security. Many conversations drew on examples of international companies having been hacked, particularly as at the time of the research Sony had recently been hacked. Participants talked about how creating a secure system is expensive, and for that reason, they trusted central government more than local government. They believed that central government have the resources to develop sophisticated security systems whereas local government was talked about as having fewer resources and therefore less secure systems.

Participants also made the distinction between protecting their information from external access and from unwanted internal use. For example, banks were thought to have very safe systems, but this trust was tempered by an awareness that banks are commercial organisations that need to make money from people. People discussed how it is more important for banks to keep their personal financial information secure than it is for other public sector organisations to keep their medical records secure, as the consequences of financial records being leaked or lost is much greater.

“Banks won’t maliciously harm you but they are out to gain.” (Richmond Hill Community Centre, male age 25-44)

Some participants talked about electronic records being less secure than paper records. They thought that people would not be bothered looking through paper records to find out information but that searching an electronic record would be faster. People also talked about computers and memory sticks being left in public places, so electronic records are vulnerable in this way. They drew on their own experience of using computer file systems and wondered if information could be erased by mistake. They had further concerns about using mobile internet to exchange information.

“Personal health records are now on the computer so I don’t feel they’re as safe.”
(McCarthy’s Business Centre, female age 25-44)

“I wouldn’t like to use apps, it’s not secure, the mobile internet isn’t secure.”
(McCarthy’s Business Centre, male age 25-44)

People discussed how big organisations are scrutinised and accountable. They have terms and conditions that need to be adhered to. They questioned whether the Council and the NHS are accountable to the same extent.

Trust-benefit ratio

These conversations were about how the amount of personal benefit influences the extent to which citizens are prepared to trust an organisation with their information. A simple example used was giving your financial information to a bank so they can make a decision about whether to offer you a credit card. Another was giving financial and family information to a letting agent so they can decide whether you can rent a flat. Participants also talked about giving employers contact details for their next of kin so that should anything happen at work employers would be able to contact them. Passports were another example used: you give information on your name, address, place and date of birth, and in return you have a credible form of identification and you are able to travel to different countries. Similarly, providing information for the electoral roll can improve your credit score. All these conversations highlighted that information is exchanged rather than given: a benefit is expected in return.

Opening an account with organisations like Amazon was also a conversation point, as participants were willing to provide their details when they open an account in exchange for being able to save money. Store loyalty cards were discussed as having a more complex relationship as participants were aware that while the cards are promoted as benefiting the shopper, their information is used to increase the store's profit.

“We give our ID to Amazon even though we don't know what they're doing with it. But the benefit is greater than the risk so we are willing to take the risk.”
(Civic Hall, male age 45-64)

“Nectar cards, they offer you discounts but they're really there to control stock and for market research.” (Reliance, male age 25-44)

Participants were generally happy for their information to be used in this way, and see discounts from the store as a reasonable trade off. However, their conversations indicated they don't like it when their contact details are sold on to other organisations. Many talked about the amount of spam emails they receive and link this directly to their information having been sold on by an organisation they have shopped with.

“Don't shower me with PPI messages, credit card applications or insurance letters. Most of my nuisance calls are from PPI companies. Who sold my number on?” (Dragons Health Club, male age 45-64)

Participants were aware that information about them is often sold, and this was tolerated to varying degrees. They are aware of pop-up advertising and the use of cookies to track which websites people visit. Some appreciated that this can save time entering information into web forms while others would prefer this not to happen. However,

participants did not like to be tricked into ticking a box to say their information can be shared. They believed that questions about privacy are often written to confuse them into giving permission for their information to be shared.

“Trust depends on the benefit you’re going to get back. Retail organisations put adverts on the screen but the service is beneficial so you’re prepared to take the risk.”
(Leaffield House, male age 65-84)

Some of the conversations explored the benefits that might arise should the NHS and the Council sell information about us to commercial organisations. Some participants fundamentally disagreed while others were happy for the NHS and the Council to sell information as long as the revenue generated directly funded services. This would directly benefit them and other people and they talked about this being an acceptable trade off. Several conversations included the cost of the health and social care and how this cost is likely to increase in the future. There was a concern about being able to afford care for elderly parents, and for oneself in the future, especially if social care services are increasingly withdrawn. Some participants suggested selling information in order to fund services. Not everybody agreed, however, as some were sceptical about whether or not services would actually receive the money generated.

“The NHS provides a service, and selling information could help fund it in the future.” (McCarthy’s Business Centre, male age 25-44)
“If it means we don’t have to save to pay for our care homes, I’d be happy for them to sell my information.” (McCarthy’s Business Centre, female age 25-44)

“I’m sceptical about the revenue being re-invested.”
(Reliance, female age 18-24)

“If the money is used for good causes that would be good but there is no trust.”
(McCarthy’s Business Centre, male age 25-44)

3.3 What might the future look like?

3.3.1 Survey responses

What should anonymous information be used for?

To explore what citizens were prepared to allow their information to be used for in the future, survey participants

asked to think about if information were anonymised from their health and social care records and combined with everybody else's, so that people could see THE NUMBER of people with different conditions or situations but NOT WHO has them. They were asked what this anonymous information should be used for. They were given five options and could choose as many as they thought applied. They were also given the option that their information should not be used for any purpose. The results show clear support for information to be used, with 93% supporting it being used for one or more reasons. The percentage agreeing with each use is shown in Figure 2.

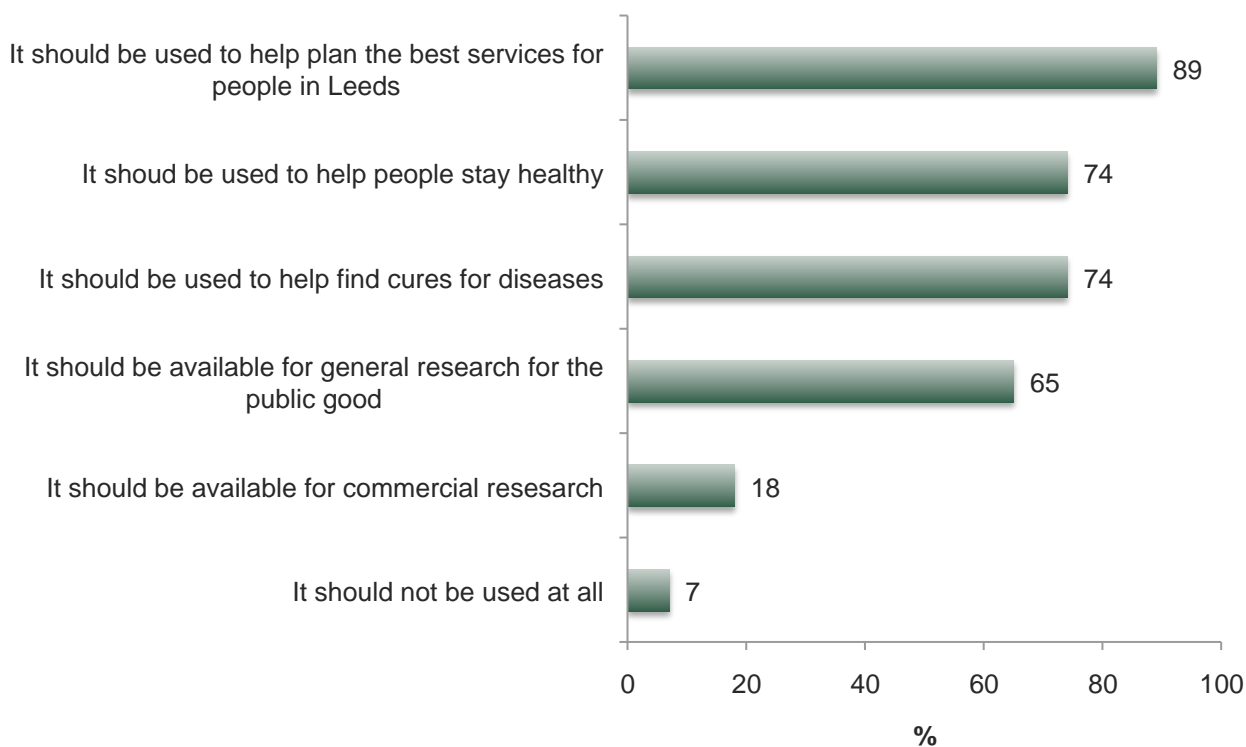


Figure 2: What should anonymised information be used for? (n=1,100)

We analysed the results statistically to identify any differences in respondents' views about anonymous information based on age, disability and where people live (inner or outer Leeds). There was only one significant association, and this was between age and beliefs about how anonymous information should be used ($\chi^2 (2) = 6.322, p = .042$). Fewer people aged under 25 (47%) think that anonymous information should be used for general research than people in older age groups – both 25-64 (64%) and 65-85+ (69%). The effect size is small.

What concerns do people have?

Survey respondents were asked about any concerns they might have about anonymous information being used to improve services in Leeds. We provided a list of potential concerns and respondents were able to add their own. The percentage of respondents reporting each concern is shown in Figure 3.

The most common concerns are that information might be sold to private companies and it might not be stored securely.

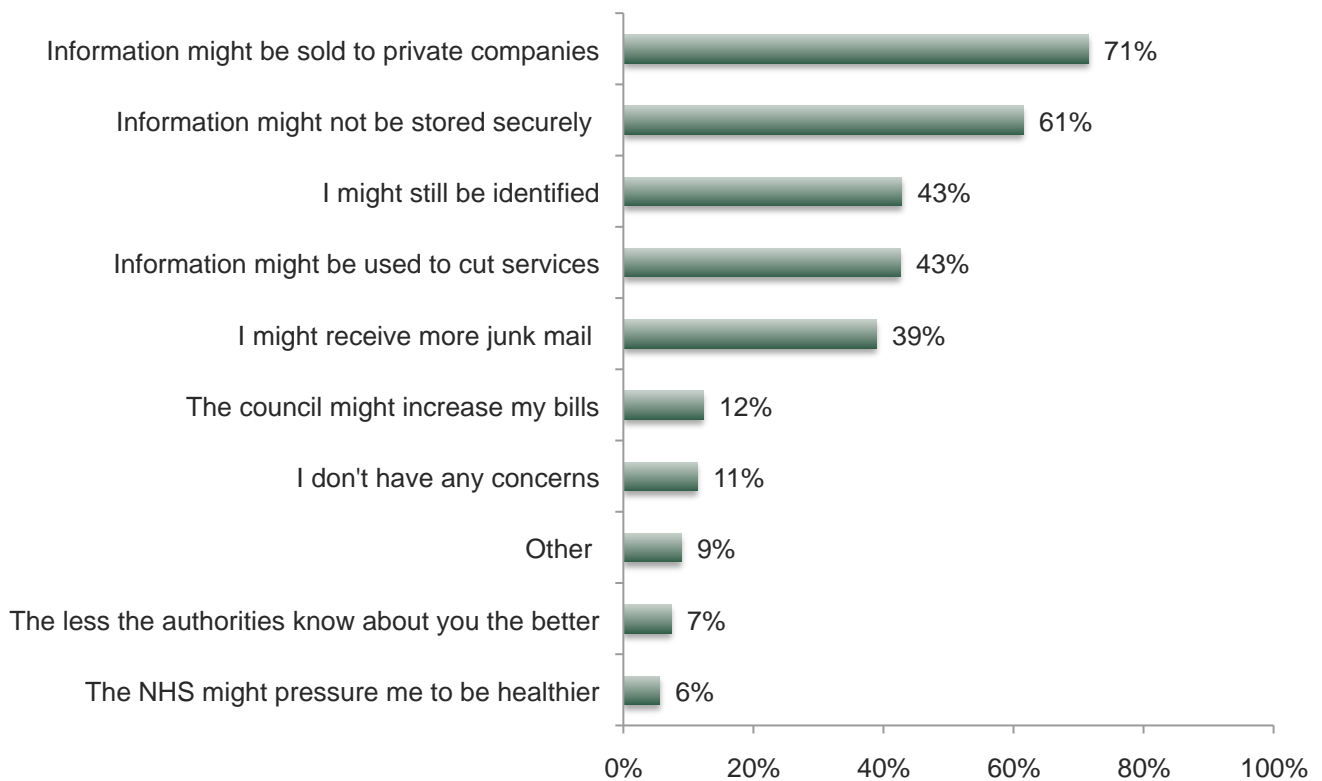


Figure 3: Concerns that respondents had about anonymous information being used to improve services (n=1,100).

We explored whether there were any statistically significant associations between different groups or respondents and the concerns they have about anonymous information being used to improve services in Leeds. All of the associations found have a small effect size.

The information might be sold to private companies

- There is a statistically significant association between having a disability and a concern that anonymous information might be sold to private companies ($\chi^2 (1) = 4.064, p = .044$). More residents who have a disability (76%) are concerned that information might be sold than those who don't have a disability (70%).
- There is also a statistically significant association between age and having a concern about anonymous data being sold ($\chi^2 (2) = 7.377, p = .025$). Fewer younger residents (<18-24, 50%) have this concern than older residents (25-64, 72% and 65-85+, 71%).

Even though my name and address aren't there, I might still be identified

- There is a statistically significant association between age and a concern that they might personally be identified through anonymous information ($\chi^2 (2) = 6.425, p = .04$). More 25-64 year olds (44%) have this concern than other residents (<18-24, 31% and 65-85+, 36%).

I might receive more junk mail

- There is a statistically significant association between having a disability and a concern about receiving more junk mail ($\chi^2 (1) = 5.712, p = .017$). More residents who have a disability (45%) have this concern than people who don't have a disability (37%).

The NHS might pressure me to be healthier

- There is a statistically significant association between having a disability and a concern that the NHS will pressure individuals to be healthier ($\chi^2 (1) = 5.712, p = .017$). This concern isn't common overall, though more residents who have a disability (8%) have this concern than people who don't have a disability (5%).
- There is also a statistically significant association between living in inner or outer areas of Leeds and a concern about pressure from the NHS to be healthier ($\chi^2 (1) = 5.654, p = .017$). More residents living in outer areas of Leeds (7%) have this concern than residents living in inner areas of Leeds (3%).

We content analysed the "Other" concerns volunteered by respondents and found three categories of concerns. These are described below.

How would it be governed? (41% of other responses)

This category is about concerns around how information would be governed and the extent to which citizens would have control over their information. It includes concern about how data would be collected, documented and stored to ensure that it is accurate, meaningful and secure. It also includes concerns that inadequate control over the information and who it is shared with could lead to discrimination and questionable use, for example, for political purposes. A few comments were around a lack of trust in the NHS or Council to maintain and protect the data. This category also includes questions about whether individuals would have control over which information about them is released, who has access to it, what it is used for, and whether people could opt out of having their information is shared.

Would it be used for commercial gain rather than public benefit (33% of responses)

This category is about concerns that information would be sold to private organisations and used for commercial gain rather than for the benefit of citizens individually and the wider public. Respondents' comments drew on examples such as insurance companies using information to increase premiums and make people financially worse off.

Could people be identified? (25% of responses)

This category is about concerns about anonymity. It includes concerns that mistakes could be made or linked datasets published that would lead to people being identifiable. Of particular concern was if individuals or groups (including criminal groups) used this information for unethical purposes. It also includes concerns that details of rare conditions could be released that makes individuals identifiable.

We also asked respondents about whether anonymous information, for example the number of people accessing A&E, should be released. They were asked to select from three different categories, or to give their own answer. The three fixed categories were that: it's a good idea and I'd like to see this information; it's a good idea although I

wouldn't look at this information; and it's a bad idea, this information shouldn't be released. The percentage of respondents selecting each category is shown in Figure 4.

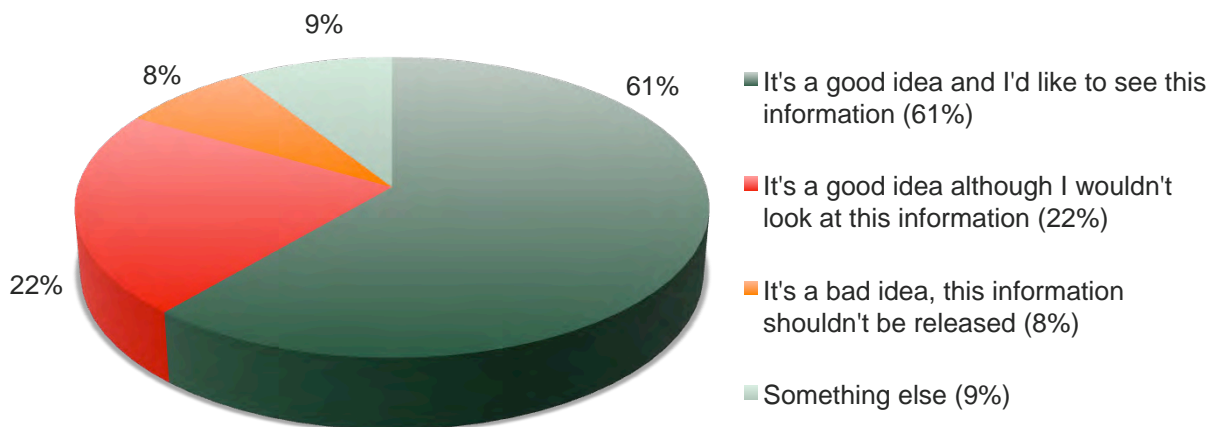


Figure 4: Respondents' support of and interest in aggregated data.

There is no difference across different demographic groups or by inner/outer areas of Leeds in relation to whether people think aggregated data should be available and whether they would look at it.

Responses to the fourth option "something else" were content analysed. We identified five categories of response, which are described below, together with the proportion of responses in each category.

This could be useful (23% of responses)

This category is about it being valuable to use anonymous information to improve services or identify where they could be streamlined to give people better care, as long as information is acted upon rather than just being reported. It also includes beliefs that information should be used to identify groups who misuse services, and how many people are "wasting resources" and "using services unnecessarily" but with the aim of improving services by changing how they are accessed. Respondents thought it important to be able to see how service decisions were made from information.

It would be useful to know who is repeatedly using services and why i.e. are they not getting the treatment or support that would resolve their issue/condition? (Female, age 45-64)

I don't trust this (22% of responses)

This category is about worries that information could be used to blame or victimise vulnerable groups or used by the media or politicians for their own gain. Others were concerned that private companies could

use the information to charge more for their services or make themselves more competitive which might adversely affect services provided by the NHS.

I would be concerned that this may be used in ways that increase prejudice or serve dodgy politicians. I don't trust our media not to use the information to create misleading sensationalised articles. (Female, age 45-64)

I'm just not sure (22% of responses)

This category is about residents' lack of understanding of what anonymous information is and how it can be used to inform policy and planning. Some comments question what the information will be used for and how it will be beneficial. Others question how useful anonymous information can be as they assume it doesn't include any demographic information. Some indicate uncertainty and not knowing enough to make a firm decision about whether having anonymous information available is a good or bad idea.

What's the purpose of releasing those figures? Need to explain why people might need them before spending resources gathering them. (Female, 45-64)

An incomplete picture (18% of responses)

This category questions how useful anonymous information can be without contextual details or qualitative information about how and why people are using services in the way that they do. It contains concerns that without knowing about individual people's lives, health and motives for accessing services in a particular way, anonymous data might be used to draw incorrect conclusions. It also includes concerns that certain groups of citizens might be absent or under-represented from datasets and so policies based on that information that may exclude them further.

Anonymous information doesn't account for everyone - not everyone is registered with a GP or people go in the evening because they are afraid of losing their jobs. It's not telling you about the underlying story of people. (Female, 46-64)

Anonymous information shouldn't be public (15% of responses)

This category questions the value of the general public having access to anonymous information about service use as they would not know what to do with it. As such, there were concerns about whether making these datasets publicly available is money well spent.

What good will it do if Joe Soap knows that 20% of AE cases on Saturday night are related to drink? What can he do about it - nothing. It is confidential data for doctors to use as they see fit. It is sufficient for us to be told that drink is a major problem - why do we need the numbers? (Gender withheld, age 65-84)

Using technology

Survey respondents were asked about the computer and internet technologies they use and whether they would like to use these to receive health information and send it to their GP. The percentage who report regularly using each technology is shown in Figure 5. Nearly all respondents (92%) reported using a computer, but as a large proportion of responses were generated from the online citizen panel, this is not surprising. Over half (60%) access the internet on their mobile phone, and slightly fewer reported using a tablet (55%) or apps on their smartphone (51%).

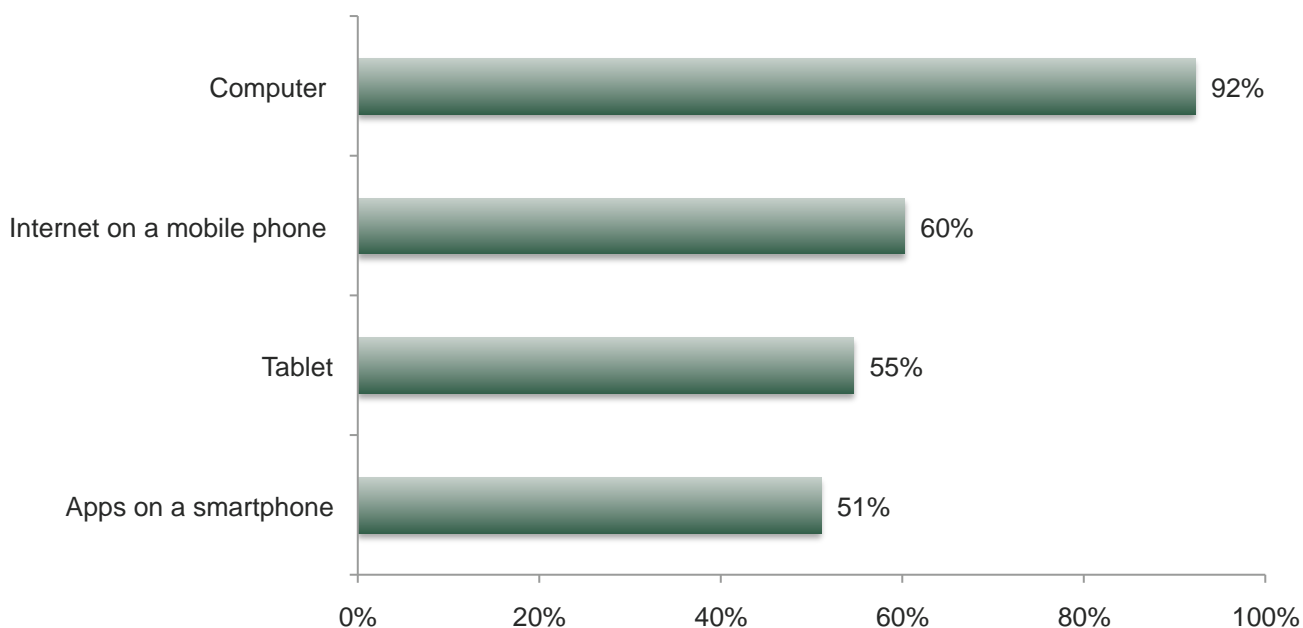


Figure 5: The percentage of survey respondents who regularly use technologies.

Respondents were asked whether they would like to use these technologies to send information to their GP and to receive health information. The proportion of those who regularly use these technologies who would like to use them in this way is shown in Figure 6. Computers and tablets were the most popular options, followed by the internet on a mobile phone and least popular, apps on a smartphone. Just less than half of respondents who regularly use apps would like to send or receive health information in this way. Across all the options, respondents were more willing to access health information than to send it to their GPs.

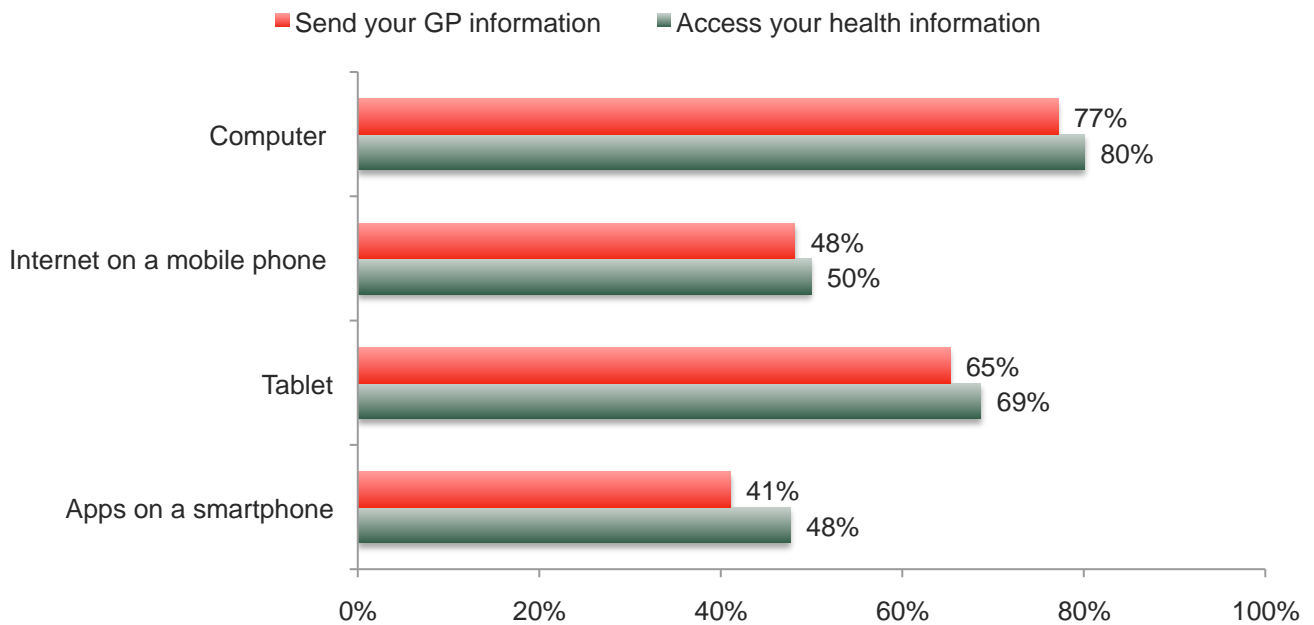


Figure 6: The proportion of respondents who use these technologies who would like to use them to send or receive health information.

There were some significant associations between age and whether residents wanted to use technology to access or send health information. This analysis included only those residents who told us that they regularly use these technologies. The effect sizes were small-medium. The key differences across groups are:

- Fewer older residents aged 65-85+ would like to use mobile internet (34%) or health apps to access their health information (27%) than younger residents aged <18-24 (mobile internet, 58% and health apps, 74%) and aged 25-64 (mobile internet, 53% and health apps, 50%).
- Fewer older residents aged 65-85+ would like to use health apps to send information to their GP (26%) than young residents (<18-24, 52% and 25-64, 44%).

To make sure the sample wasn't biased by respondents being primarily those who use the internet, we asked them to categorise themselves into one of four groups. The categories, and the percentage in each group, are:

- If I can do it online, I will (47%);
- I do things online only when it's convenient (47%);
- I avoid doing things online (6%);
- I never use the internet (1%).

This gives us confidence that the survey sample is not biased by being primarily made up of people who always prefer the internet. There were no significant associations between different demographic groups and preference for interacting online.

3.3.2 Case study event cards

Residents were presented with four different stories describing different fictional characters in different scenarios where their information is shared. In brief, the stories were about:

- Neil, 42, who has multiple sclerosis and uses a wheelchair. The Council helps set Neil up with an online Circle of Care that includes his health workers and his son. He can go online, let people know how he is and ask them to visit if he needs help.
- Sarah, 21, who suffers with alcohol abuse and mental health issues. Her psychiatrist is able to access her Leeds Care Record to see which medication she was taking and help select one that suits her better.
- Ali, a ten-year-old, who is taken to A&E by his father after he got injured whilst playing. As his medical and Council records can be seen by hospital staff they can identify his medication allergies and follow-up on child safeguarding concerns they have.
- Sheila, 83, lives alone and has a “lifeline” unit installed in her house with a helpline operator available 24/7 in case she needs help. After a fall whilst alone at home, Sheila is helped by getting quick medical attention through the helpline operator.

Respondents were asked whether this is a good use of information and the majority of respondents agreed that it is (86%). Over three-quarters (78%) said that they would be happy for their information to be used in the way described in the story they read, as shown in Figure 7. Slightly fewer would like their information used in this way, and from conversations with respondents, we interpreted this as previous negative experiences resulting in individuals preferring not to share their information in this way. For example believing the Circle of Care to be like Facebook and having a previous bad experience with Facebook, or a previous encounter with children’s services.

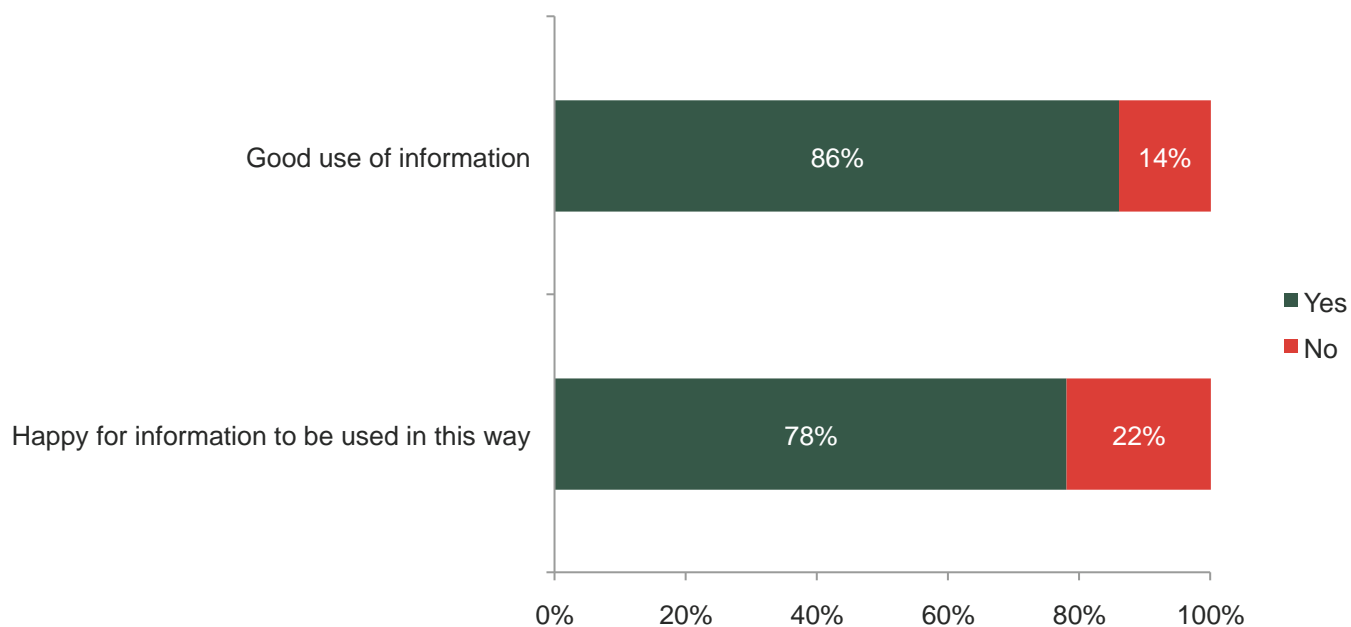


Figure 7: The percentage of respondents who think the case studies are a good use of information and who would like their information to be used in this way (n=189).

There were no significant associations between the story that participants responded to and whether they thought it described a good use of information or they are happy for their information to be used in the way described. There are, however, some significant associations between age groups.

Good use of information

- There is a statistically significant association between age and whether respondents think the stories show a good use of information ($\chi^2 (2) = 6.192, p = .045$). More residents in the 25-64 age bracket (91%) think the stories show a good use of information than residents aged 65-85+ (76%).

Happy for information to be used in this way

- There is a statistically significant association between age and whether residents think they would be happy for their information to be used as it is in the stories ($\chi^2 (2) = 9.907, p = .007$). More residents in the 25-64 age bracket (87%) are happy for their information to be shared in the way depicted in the stories than residents aged 65-85+ (66%).

3.3.3 Conversations about the future

We identified four different conversations about what information sharing might be like in the future. These are: greater sharing of personal records; citizen-owned, IT-enabled information; using open data; and resources where they are needed. These are described below.

Greater sharing of personal records

Participants wanted wider sharing of their records. They believe that this would lead to better more seamless healthcare, with fewer mistakes and omissions that would be more cost-effective. Some participants talked about their own experiences of being in hospital when doctors did not have the information they needed from their GP medical records and this had led to uncertainty and delay. They thought that having a single central record could mean that decisions are made faster, and there is less need to provide lots of different organisations with information. They talked about several different examples of the advantages this would bring, such as if you have to claim benefits, where a central record could instantly show entitlement rather than having to complete several lengthy forms. However, many were sceptical about whether they would personally gain by receiving better, faster or more seamless service.

“If they had all this information will it be used to help you? If you fall on hard times is going to be easier to claim? I don't think so.”
(McCarthy's Business Centre, male age 25-44)

Participants often talked about a future in which lots of different organisations could access their health records and there were mixed views of whether this would be positive or negative. They thought there could be lots of benefits, for example better support for people managing a health condition and more appropriate advice. They also talked about where responsibility lies if lots of people can access healthcare records. For example, if a professional working in a University became aware that an employee or student has a drug problem, should there be a responsibility to make an entry on their medical record? These conversations drew lots of different opinions, and through their discussion, participants recognised that wider sharing of healthcare records brings many questions.

There were mixed views of employers being able to access information on medical records. Some participants believed the advantages would outweigh the disadvantages. Advantages included better support at work, especially for people managing a chronic health condition, and employees not being allocated a job role or task they are not suited to, or put into a situation they are uncomfortable with. There was a great deal of discussion around the impact on stigma. Participants talked about the possibility of fewer misperceptions and less stigma if more people were aware of the physical and mental health conditions that people they meet in everyday life have. Others were concerned that employers may be able to search people's medical history in a way similar to a financial organisation searching a credit history. They talked about a future in which an employer could refuse an individual a job on the basis of a condition that may no longer be current, or one that should have no bearing on their ability to perform the job role.

“You could have somebody who used to take drugs but they've turned their life around. The past should be the past but the employer could just turn round and say: You can't have this job.” (Black Swan, male age 18-24)

Citizen-owned, IT-enabled information

Participants described a future in which citizens own their own information and grant access to professionals whose services they want. Some talked about how records of a previous diagnosis or situation, both from the NHS and Social Services, influences the way they are currently treated by professionals, even when the diagnosis or situation is not or is no longer relevant. They wanted the ability to decide which aspects of their previous records remain relevant, and to restrict access to some parts of their previous history. They believed that this would give them better treatment with less prejudice.

“Just because of how I was brought up, when I was having my child I was surrounded by Social Services because they thought I would mistreat my child.” (Horsforth Children's Centre, female ag 18-24)

Some talked about having an ID card that provided access to their medical details and they would be able to authorise a professional to access a specific part of their records. Some participants talked about more advanced security protection, for instance cards unlocked by retinal scans or DNA. People thought that if professionals have access to more information about somebody's life they might understand their situation better. This would enable professionals to deliver more tailored care and support.

“There should be an ID card with your National Insurance number and medical number on, like a driving licence with a photo so you can’t abuse it. It could have a SIM card with a chip and PIN to provide access and some security questions. The card would open a medical file. You’d have control over what goes onto the card – operations and illnesses. You’d carry the card with you and in an accident they could see information like blood group, allergies, donor card conditions.” (Armley, male age 45-64)

They talked about how if you owned your own records you would identify any errors and correct them. Many of the citizens who took part described situations in which they had become aware of errors on their medical records and they believed that by owning their own records the errors would be reduced.

Participants talked about how better IT could more personalised healthcare. They described how information on the exercise they do, their diet, and their alcohol intake could all be uploaded and enable tailored healthcare decisions based on their own lifestyle and metabolism. For example, they talked about how people have different tolerances to alcohol and different nutritional needs. By providing individual personal information about health, wellbeing, fitness and behaviour they could receive individual personal health advice, rather than generic guidelines. They also thought the capacity to exchange personalised information would be useful to manage long-term conditions. While only around half of respondents were interested in using apps to exchange health information at the moment, using technology featured much more in conversations about the future. Participants talked about apps being able to provide a mechanism by which health records could include how much activity you engage in. Younger people in particular welcomed using apps when managing their healthcare. They believed installing and using an app is quick and easy to do and they would engage with healthcare apps.

“It would be very convenient, being able to get an app quickly.” (Reliance, female age 18-24)

“If it were on my phone I’d track my own health information. I do everything on my phone.” (Reliance, male age 16-18)

People of all ages, however, appreciated the benefits that health apps could bring. However, not all participants had a smartphone, and indeed, not all had their own computer, although everybody who took part in the events was able to access a computer, e.g. in a local college or at a shopping centre or library.

“Apps could give you detailed feedback. A smoking app could show you the percentage of normal lung function you have. You could see how well you’re doing. It would help you to keep going if you were trying to give up smoking.” (Roundhay Park, male age 45-64)

Participants also talked about potential negative consequences of an IT-driven health service. They discussed how if we rely increasingly on IT to exchange information it might become more difficult to talk to somebody about your health. They wanted to retain the facility to see your doctor face-to-face and talk about your health.

Open data

While none of the participants spontaneously talked about open data as part of the future, when prompted they were able to think about how it might be used. Some participants discussed potential disadvantages of datasets being released, including if insurance premiums increased as a result of insurers becoming aware of certain areas being more at risk of crime or medical conditions. However, everybody who took part believed that insurers are likely to already have access to this information. They talked about how it is necessary to disclose any medical conditions to insurers or you may not be covered, e.g. when purchasing travel insurance.

Participants talked about it being important that individuals shouldn’t be identifiable from any open dataset that is released. For example, if details of visible or rare medical or conditions were included in a dataset, if information on geographic area were also included, people could guess who that individual is. While some survey respondents were concerned about the theoretical risk of being identified, participants at the events were more pragmatic. They were more concerned about whether it would be likely (rather than possible) that by releasing a dataset you could find out a lot of personal details about an identified individual. However, some participants, particularly the younger ones, were more relaxed about this and couldn’t see any problem if they were identified.

“What’s somebody going to do with your records?” (Reliance, female age 18-24)

Most people were puzzled about possible advantages that might arise from open data. They accepted that it might be possible to advance medical knowledge if medical details were available for analysis. They were bemused about how other types of data might be useful.

“That would ring alarm bells: why would you want to do that? (release open data) What is the benefit? Would they make a profit? I wouldn’t be interested in looking at that.” (HEART, male age 18-24)

Some participants were concerned that releasing open data would mean that people with little or no statistical expertise would scrutinise the data and draw inaccurate conclusions about it. The media might access the data in order to search for a news story that, once again, is inaccurate but nevertheless makes good headlines.

“The media sensationalise stories, they misrepresent research findings. It would be worse if people release findings when they don’t know what they’re doing.” (Reliance, male age 25-44)

They would like to see examples of how open data had been used, and the benefits it brought people whose information had been used. The most commonly held concern was around commercial organisations using open data to increase their profits and to gain a competitive advantage over the NHS. There were many conversations around the NHS being vulnerable, a concern that open data might be used more effectively by private companies, and that the NHS might ultimately be undermined if it allows information it collects to be used by commercial organisations.

Another big concern was the cost associated with producing open datasets, and who would pay for this. Many participants were sceptical of how the cost could outweigh the benefits. They believed that the benefits would primarily go to commercial organisations, such as pharmaceutical companies who would increase profits. They did not usually talk about how profits arise from producing drugs that benefit people. There were several conversations around open data being collected at the expense of the public sector and exploited by the private sector.

“Do your own research!” (John Charles Centre for Sport, female age 25-44)

“What’s the point of open data? It’s only big companies like pharmaceutical companies that would use it.” (Inkwell, female age 25-44)

Resources where they are needed.

Participants believed that better use of information would mean that resources can become more flexible and can move to areas where they are needed most. It could shorten waiting times for healthcare, and by anticipating people’s needs, services could become proactive rather than “fire fighting”. They also discussed how better use of information could demonstrate services provide value for money.

However, some people talked about how information could be used to reduce or remove services. They thought that in times of increasing pressure on budgets Council and NHS could use information on lack of use of services to close them down. Some participants were fearful that services could be targeted exclusively in areas of highest deprivation and those living in “the leafy suburbs” could lose out.

“It could lead to decreased funding in less needy areas. Would it lead to fewer services for some? Would some people lose out?” (Dragons Health Club, female age 45-64)

4. Strengths and limitations

The Joined Up Leeds conversation is, as far as we are aware, the first collaborative project between the NHS and the Council to engage citizens in a conversation about how their health and wellbeing data could and should be shared, the benefits of sharing, the concerns they have, and how data could be used for the benefit of people in Leeds. It involved awareness-raising activities (based on presenting case studies) to generate interest and to enable people to have an informed discussion about data sharing. The Joined Up Leeds team developed materials to engage citizens in conversation, hosted 17 events and provided Chat Packs across the city and completed a large-scale survey. This was a remarkable achievement given the requirement for data collection to be completed within two-months of the project being commissioned. Care was taken to host events across different areas of Leeds, in both the affluent suburbs and areas where deprivation is more widespread. Extra efforts were taken to involve people living in the Inner East, West and Inner South areas of Leeds where life expectancy is lower. Joined Up Leeds has been praised for taking the conversation to where people talk rather than relying on NHS buildings and Councils buildings to host events. Pubs, cafes, care homes, and piggybacking on community events proved that we could reach a wider community instead of speaking to the usual faces that are already engaged in public service debates.

One of the limitations of the research was the relative low numbers of young adults who took part. This was despite many attempts to engage with the Universities and Colleges in the city. However, as the research indicates that younger people are more trusting of organisations and more willing to grant access to their personal information, this is less of a concern than if older people or those with disabilities had been under-represented.

If additional Joined Up Leeds conversations take place in the future, we recommend that press releases are approved well in advance and sufficient time is given to generate press interest to help raise public awareness of the events.

5. Conclusions and recommendations

Our research leads to the following conclusions.

- Citizens trust the NHS, and in particular their GP practice, with their information more than other organisations because they believe the NHS has better motives for wanting access to it.
- Most citizens are willing for information about them to be used to improve health and wellbeing and to plan services. This includes granting wider access to personal medical records, publishing information on the number of people with different conditions and situations (aggregated data) and releasing datasets that contain anonymous information about them (open data).
- There is less support for releasing information for commercial research purposes as citizens are concerned that organisations using information in this way are solely motivated by increasing their profits. They are also concerned that if private organisations were to have access to this information they would use it to gain a competitive advantage, which would adversely affect the NHS.
- Younger citizens are more likely to allow wider access to their individual healthcare records for the purpose of direct care and they are less concerned over information about them being sold.
- Individual citizens should not be readily identifiable from information released about them. They do not want to be contacted or marketed to as a consequence of their information being released. This is of particular concern for citizens with disabilities.
- Citizens want to feel in control of who has access to their information, particularly their individual medical records. They need to trust people who see their information about them.
- Citizens are puzzled by the concept of open data and what it could be used for. They are concerned about sensationalised, inaccurate or misleading stories that could be reported by the media.
- The trust-benefit ratio is central to increasing the number of citizens who support and advocate information sharing. People need to understand how access to their information can help learn more about, treat, cure and prevent illness and increase quality of life. They need concrete examples of how aggregated data and open data has or could make this happen.
- There is interest in using technology to send and access health information. Benefits include gaining personalised health recommendations and guidance in managing long-term conditions. At present citizens feel most comfortable with using a computer for this purpose but there will be increasing interest in using health apps, and this will be driven by younger people who rely substantially on their smartphones for communication and internet access.

- Giving citizens greater control over their own healthcare records is likely to change the clinician patient relationship, particularly around trust and citizens taking greater responsibility for their own health.
- The cost of making datasets available should be less than the financial savings made from better and more efficient services.
- People using information to make decisions about citizens should remember that they are people, not numbers.

We make the following recommendations.

7. Let citizens know – in easy-to-understand terms – what information collected from them is being used for. This should not be hidden in terms and conditions.
8. Help citizens to understand the value of information about them by developing clear examples of how it has been used to improve services. The Health and Social Care Information Centre could play an important role in this.
9. When information is requested from citizens, for example on application forms, surveys or Equality monitoring forms, it should be clear why it is being asked and what it will be used for.
10. Reassure citizens about the ethical principles that guide professionals on confidentiality and protect their privacy.
11. It should be possible for citizens to opt out of information sharing, although they need to understand the implications for themselves and others of doing so.
12. Produce an audit trail, open to citizens, showing the information that was used to reach policy and planning decisions.

Appendix 1

If information were anonymised from your health and social care records and combined with everybody else's, so that people could see THE NUMBER of people with different conditions or situations but NOT WHO has them.

1. What should this anonymous information be used for? (please tick all that apply)

- It should be used to help plan the best services for people in Leeds
- It should be used to help people stay healthy
- It should be used to help find cures for diseases
- It should be available for general research for the public good
- It should be available for commercial research
- It should NOT be used at all

2. Do you have any concerns about anonymous information being used to improve services in Leeds? (please tick all that apply)

- The information might not be stored securely
- Even though my name and address aren't there I might still be identified
- The information might be sold to private companies
- I might receive more junk mail
- The Council might increase my bills
- The NHS might pressure me to be healthier
- The information might be used to cut services
- The less the authorities know about you the better
- Any others? (open question)

The NHS and Leeds City Council are thinking about letting the public see anonymous information on how many people use NHS and Council services, such as how many people have used A&E. This would show THE NUMBER of people who use services, NOT WHO have used them.

3. What do you think of this? (please tick one)

- It's a good idea and I'd like to see this information
- It's a good idea although I wouldn't look at this information
- It's a bad idea, this information shouldn't be released
- Something else - please tell us what It's a good

4. How much do you trust these different organisations with information about you?

(Use a scale from 1 to 10 where 1 is you don't trust them at all and 10 is you trust them completely)

- My GP practice
- The NHS
- Leeds City Council
- Universities
- My bank or building society
- Insurance companies
- Store loyalty cards
- Health apps
- Google
- Apple
- Amazon
- Facebook

5. Which of these do you use regularly?

Computer Tablet Internet on a mobile phone Apps on a smartphone

6. Which of these would you like to use to access your health information?

Computer Tablet Internet on a mobile phone Apps on a smartphone

7. Which of these would you like to use to send your GP information?

Computer Tablet Internet on a mobile phone Apps on a smartphone

Please tell us a bit about you

Which age group are you in? <18 18-24 25-45 46-64 65-84 85+

Which of these best describes you?

If I can do it online I will

I do things online when it's convenient

I avoid doing things online

I never use the internet.

Which area of Leeds do you live in?

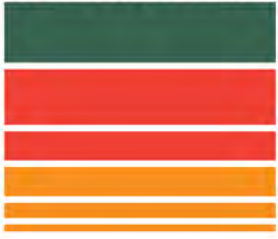
What is your gender?

Do you consider yourself to have a disability?

What is your ethnic origin?

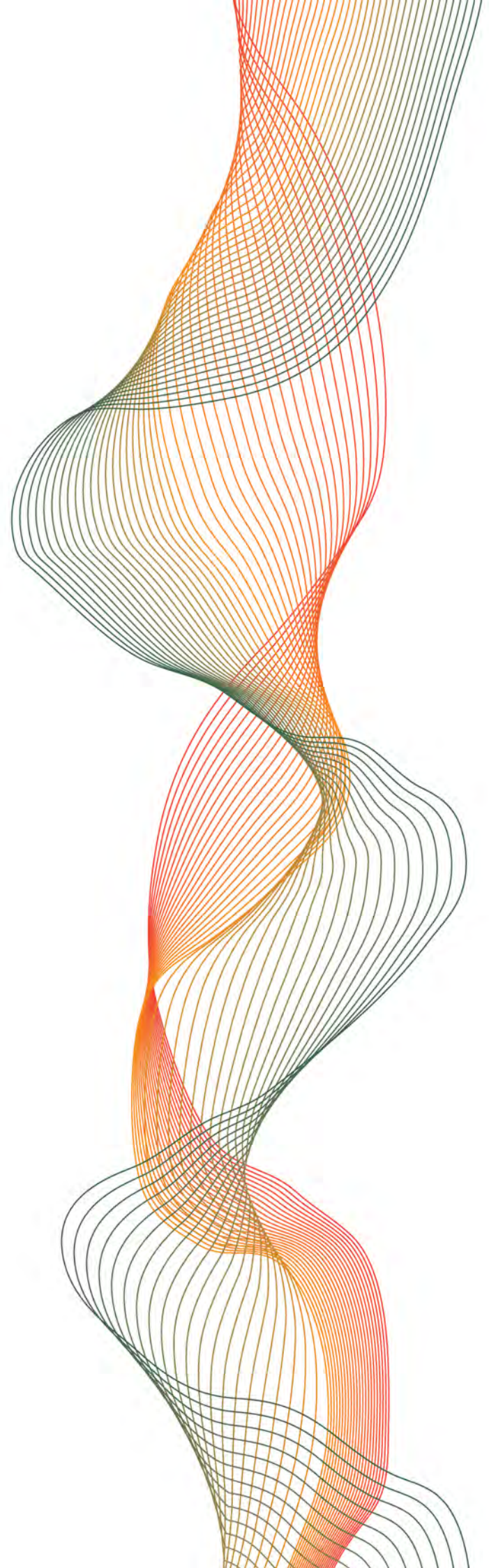
What nationality are you?

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