



Yorkshire & Humber
Care Record

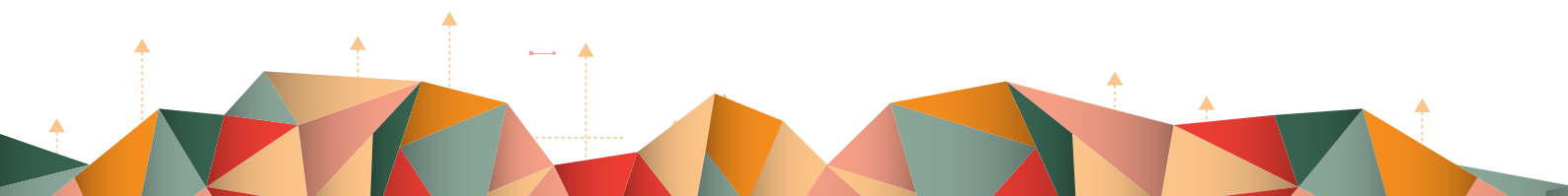
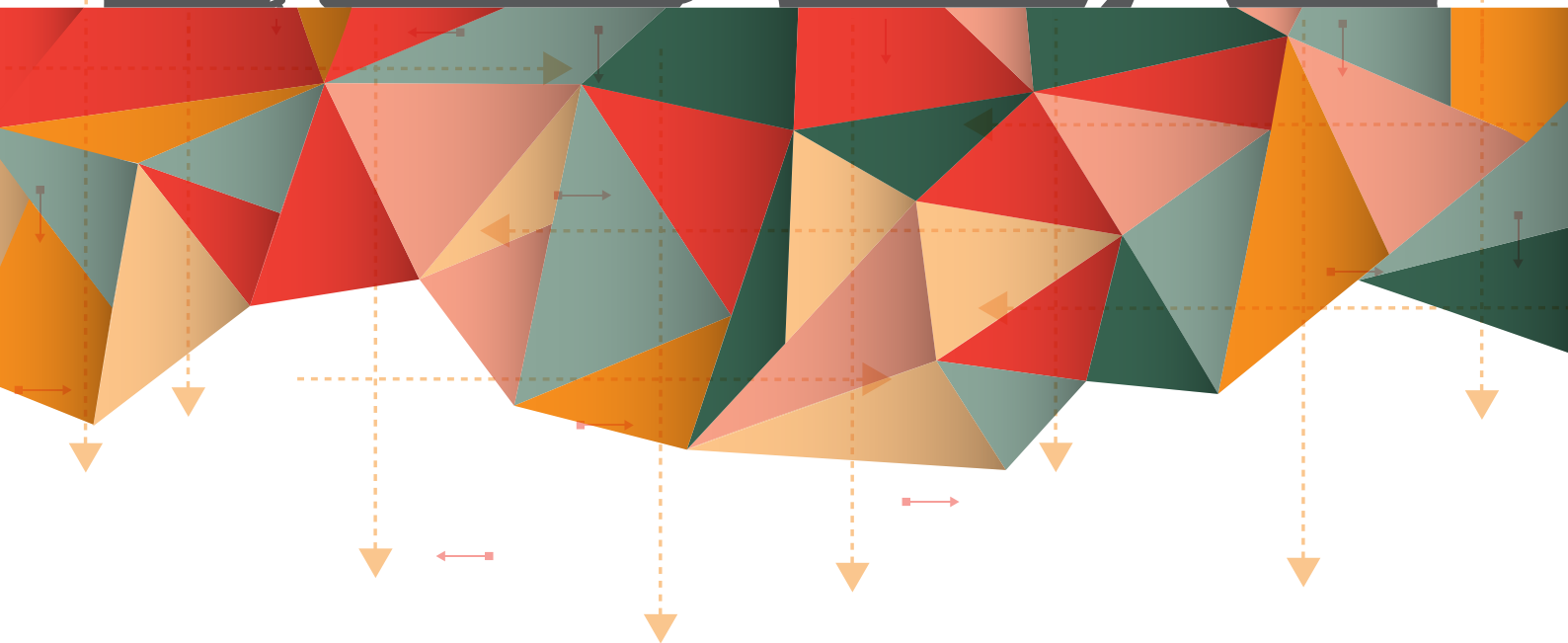
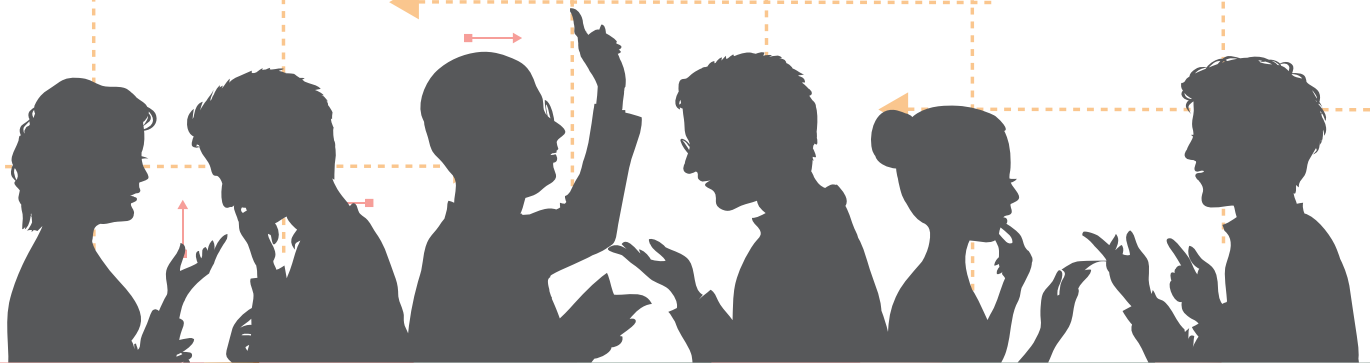
Joined Up

Yorkshire & Humber

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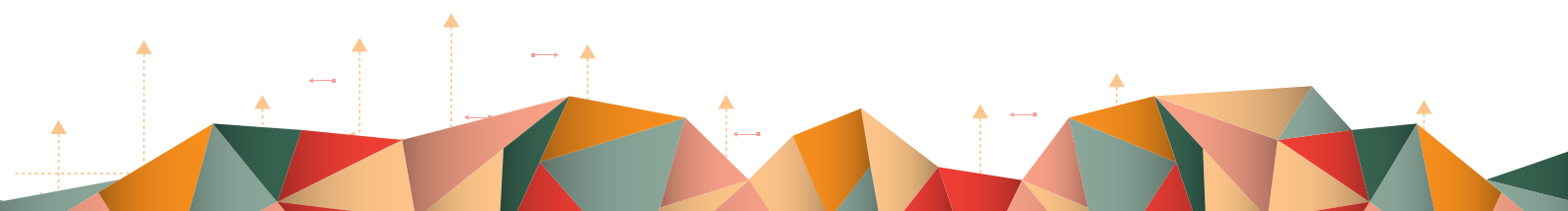
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Yorkshire & Humber Care Record

JoinedUp Yorkshire & Humber



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Summary

This report summarises insight research commissioned to inform the Yorkshire and Humber Care Record. It aims to explore the beliefs that people have about how their health and care records could and should be used, their boundaries for what they are willing for their data to be used for, their concerns around how their data could be used, and the reassurances they want about how their data is safe.

The research uses mixed methods, based on a survey, focus groups, case studies and workshops that ran across Yorkshire and Humber. Nearly 2000 people took part in the research.

The results show that there is strong support for the Yorkshire and Humber Care Record as people believe it will improve patient-centred care, improve continuity of care, improve communication between different health and care teams, improve the accuracy of diagnosis and prescribing, and generally lead to a more efficient and cost-effective service. However, they wanted access to be restricted to current and relevant information.

The research shows that many people are unaware of the role that local councils play in providing and planning care services and believe that only the NHS has this responsibility. Because of this, many have concerns about why the local councils would need to access their health and care records. The Yorkshire and Humber Care Record team should therefore raise awareness of the role of local councils in direct care and in planning health and care services.

Nearly all (95%) of the survey participants supported their data being used beyond their direct care, most commonly to plan services, to help people stay healthy and for research into understanding, diagnosing and treating diseases. There was also support for using health and care records to intervene *before* people develop a health condition, which may include contacting people at risk in order to offer screening or healthcare advice, and engaging them in managing their own health. Nevertheless, participants had concerns about data sharing, primarily their data being sold to third parties, or there being a data security breach. They were concerned that the NHS and local authorities use outdated IT systems, which places their information at risk. GDPR has made people more aware of the data that is collected about them and of the control they have over that data.

The results show that people have the most trust in their GP practices, followed by the NHS in general, then banks or building societies, the local council and universities. Accordingly, they prefer any contact about future health risks and managing their health to come from their GP.

The report presents a series of fictitious personas, based on participant discussions, that summarises clusters of beliefs and experiences about data sharing. Finally, we have produced a set of challenges that the Yorkshire and Humber Health and Care Record will need to overcome in order to reassure people about how their data will be used.



1. Background

The Yorkshire and Humber Care Record is an innovative programme that has the potential to produce a transformational change in healthcare in the region. Currently, patient data is not shared between the NHS and other organisations that play a role in health and social care, such as care homes, social services, and private clinical care organisations. Furthermore, relatively little patient data is shared *within* the NHS. For example, if an individual attends one hospital for a cardiac condition and another hospital for a neurological condition, information on their diagnosis, condition, test results and treatments for their cardiac condition is not accessible for staff involved in managing their neurological condition, and vice versa. This situation is inconvenient for patients and clinicians, leads to additional costs and delays with care, and is also potentially dangerous.

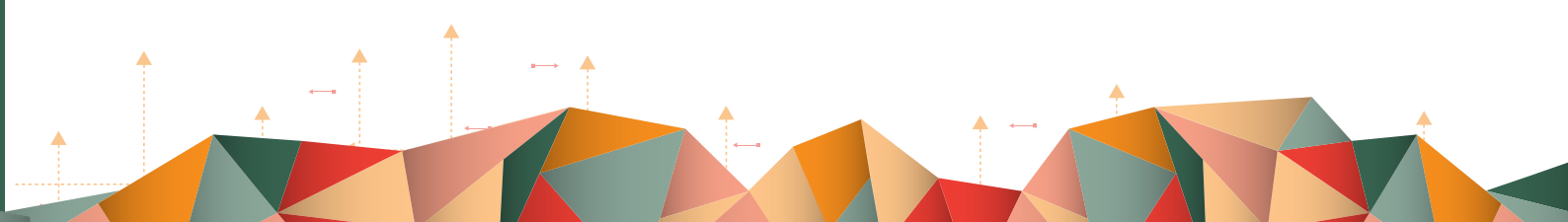
The Yorkshire and Humber Care Record is being developed to address the problem of data sharing. It is a digital care record which enables clinical and care staff to access real-time health and care information across health and social care providers and between different systems. It brings together a core of information about patients who have used services provided by their GP, local hospitals, community healthcare, social services or mental health teams. This information is stored on a secure computer system and so can be accessed by different care providers regardless of the computer system they use.

Better data sharing also has the potential to improve preventative health services and to help vulnerable people in our communities to remain living independently at home for as long as possible by providing appropriate support. There are also potential applications for using intelligence from large scale data sets to improve population health. Centralised data on patient health and wellbeing and on the services they use could enable better planning of services and a preventative approach by identifying and acting on trends in pre-conditions.

The Yorkshire and Humber Care Record team commissioned this research in Autumn 2018 to provide insight into people's beliefs about their health and care record being shared. This report presents the research findings and lists recommendations for the Yorkshire and Humber Care Record team.



Yorkshire & Humber
Care Record



2. Methods

There were two stages to the research. The first involved exploring people's views about whether their health and care data should be shared with different professional groups and used for different purposes. People could take part in three ways, described below.

2.1 Community conversations: focus groups and case studies

Community conversations took place in various locations around the region and involved group discussions of some of the key questions on sharing health and wellbeing data. A total of 12 of these community events were run: three in South Yorkshire and Bassetlaw; three in Humber Coast and Vale; and five in West Yorkshire and Harrogate. They were hosted by community groups or arranged by a member of the community. A financial donation was made to each group to acknowledge the help they provided in setting up the group. One group was arranged by a fieldwork agency. Table 1 provides further details of these conversations.



Table 1: Details of the community discussion events

Location	Participants
Barton	Men who work in the local area.
Bradford	People from the black and ethnic minority community.
Cottingham	People who attend Fitmums and Friends community group, which helps people to stay active.
Doncaster	Parents who attend the Central Family Hub. Parents were a mix of nationalities, reflecting the ethnic diversity of the local area.
Harrogate	People who attend the Multiple Sclerosis Society support group.
Hoyland	People at the Woolly Wednesdays social craft group, organised by women who live in this small community.
Huddersfield	People with long-term conditions who attend the Physical Activity and Leisure Scheme run by Kirklees Council.
Hull	People who work in or live near the Preston Road Estate.
Morley	Members of Morley Elderly Action, a charity that supports people over the age of 60 to live independently.
Ripon	People who live or work in the local community. Many of the group worked in the third sector.
Scunthorpe	Parents and carers who attend a local Children's Centre.
Sheffield	Young people attending Sheffield Futures, a charity that provides mentoring and specialist support to young people, especially the most vulnerable and disadvantaged.

Pop-up case study events took place in several locations across the region. These involved people recording their views on a series of case studies that described a short fictional story of how an individual's data was used to improve their care.

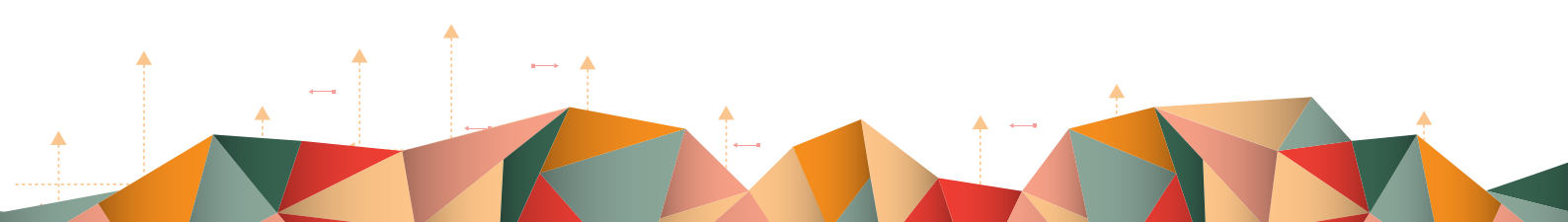
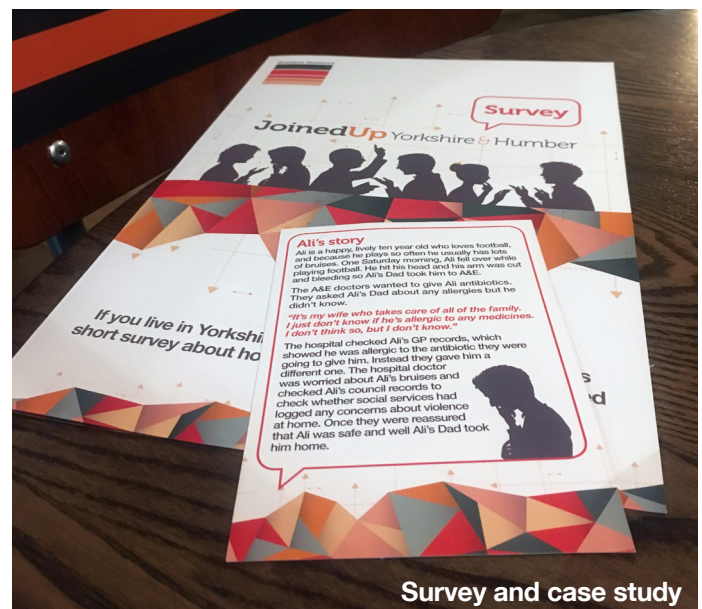
- **Ali:** A&E accessing social care records.
- **Neil:** Health information shared with a community care team.
- **Sheila:** Health information shared with the voluntary sector.
- **Mohammed:** Data used to plan services.
- **Saffi:** Identified as being at high risk and contacted with an offer of screening and lifestyle advice.

Details are shown in Appendix 1. Participants indicated if they think that this is a good use of information and whether they would be happy for their own information to be used in this way. They also indicated their gender and age group. A total of 415 case study cards were completed. Table 2 shows where these pop-up events took place.

Table 2: Details of the pop-up case study events

Location	Participants
Barnsley	Passengers on trains that run between Barnsley and Sheffield.
Batley	Passengers on buses running between Batley and Leeds.
Bradford	People in various cafes and bars in the city centre.
Hornsea	Various locations across the town, including the Freeport.
Hull	People using the Freedom Centre.
Leeds	People in various bars in the city centre.
Leeds	People using the Dewsbury Road Community Hub.
Sheffield	People using various cafes in the city centre.
Sheffield	Young people attending Sheffield Futures.
Wakefield	Passengers on buses running between Wakefield and Bradford.
Whitwell	People who attend the Whitwell Community Centre, which includes older adults and people with learning disabilities.
Yeadon	People using cafes in the area.

In addition, we ran a workshop at the UseMyData conference in Leeds. UseMyData is a movement that involves patients, carers and relatives in promoting the use of data to improve patient treatment and outcomes. The conference was attended by a mix of professionals and the public. After a presentation on the Yorkshire and Humber Care record, delegates took part in a series of small-group discussions on the benefits of data sharing described in the case studies, concerns that they have, and the rules they think should apply to using data in this way.



2. Methods cont.

2.2 Media conversations: survey

Media conversations took the form of a survey, available in both online and paper formats. Survey questions asked who should be able to see your health and care records, what the NHS and local councils should be able to do with anonymous health and care records, how much you trust different organisations with your information, and any concerns that you have about your health and care records being used to improve services. The survey included the same questions as the Joined Up Leeds research, which took place in 2015. While comparisons between the results sets should be made with caution because of differences in the samples, they can indicate where people's views may have changed.

A total of 1,031 people completed the survey. Most (86%) were completed online. More were female (63%) than male (37%), 10% reported having a disability, 18% reported having a long-standing illness or health condition and 11% a mental health condition. In terms of ethnicity, the survey respondents were mainly white (91%), which is higher than the 2011 census data for the region (86%). A third (33%) of survey respondents were based in Humber Coast and Vale, 21% were based in South Yorkshire and Bassetlaw and the remaining 46% were based in West Yorkshire and Harrogate. The higher number of respondents from West Yorkshire and Harrogate is to be expected: this area comprises 47% of the 5.5 million people who live in Yorkshire and Humber. The remaining 2.9 million are split approximately equally between Humber Coast and Vale and South Yorkshire and Bassetlaw.

2.3 Review workshops

The second stage of the research involved a series of workshops during which participants reviewed and discussed the challenges raised in the previous stages. Four workshops took place in Halifax, Sheffield, Grimsby and Leeds, each lasting 90 minutes. To ensure that we focused on views held by the general public rather than people who are already involved in health and care consultations, we used a mix of recruitment methods and participants received a financial incentive for taking part. Details of these workshops are shown in Table 3.

Table 3: Details of the workshops

Location and details	
Halifax	Nine participants, including two action researchers from the Yorkshire and Humber Health Record team and from public health. Three males, six females and a mix of ages. Participants lived in both urban and rural areas. Four had long-term conditions, which meant that they discussed their own health experiences in more detail than other groups.
Sheffield	Ten participants including one from Healthwatch. Six females, four males and a mix of ages. The group contained one participant who was a member of a Healthwatch Test Bed project, two who worked in health technology research, two who had worked in health and social care settings and one who was a Sheffield Futures young advisor. Participants' experiences meant that they discussed research processes and data security in more detail than the other groups.
Grimsby	Eight participants, including one from Healthwatch. Five males, three females recruited by a local fieldwork agency to be representative of the local population.
Leeds	Seven participants including one from Healthwatch and an action researcher from public health. Four males, three females, recruited by a local fieldwork agency to be representative of the local population. One worked as a nurse, another in a digital NHS capacity and a third as an interpreter. Participants' experiences meant they discussed access to health records by non-clinical staff more than other groups.





Sheffield Young Advisors

Working in pairs and trios, workshop participants completed a series of activities:

- Answering and commenting on a series of questions to assess affective attitudes (feelings) towards their health and care records being used and shared.
- Commenting on a series of five personas that were identified from the focus groups.
- Producing a map of the different people or organisations that have access to their health and care records.
- Identifying concerns they have about their health and care data being accessed by commercial organisations, including private hospitals and clinics that treat them; organisations that develop new equipment and treatments; companies that help the NHS function, such as providing IT systems, mail services, accounts software or staff training. They also identified rules that these organisations should comply with if they are going to access their data.

At the end of these activities participants took part in a facilitated discussion during which they reflected on the activities and their views on data sharing. Discussions were audio recorded, with the permission of participants.

2.4 Ethics

Brainbox Research Consultants are Chartered Psychologists and members of the British Psychological Society (BPS). As such they conform to the BPS Code of Ethics and Conduct. The project and its materials were reviewed 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

We report the results in six sections. The first reports on the extent to which people believe that health and care information should be shared. The second explores people's beliefs about what their health and care information should be used for, specifically using aggregated data for planning future services, and anonymised data for research. Section three reports the results on how much people trust different organisations with their data. The fourth section summarises the findings on involving people in managing their health. Section five explores the concerns that people have about their data being used and shared. Finally, the sixth section presents five fictional personas that could be used when planning future communication about the Yorkshire and Humber Health and Care Record.

3.1 Should health and care information be shared?

Overall, there was tremendous support for sharing health and care information for direct care, with participants believing that it will improve patient-centred care, improve continuity of care, improve communication between different health and care teams, improve the accuracy of diagnoses and prescribing, and generally lead to a more efficient and cost-effective service.

"I am going through all sorts of tests again because Wakefield can't access my records from Leeds, which I am really mad about. I wish it was all one system and I wouldn't have to go through all of this all over again."
(Female, WY & H)

Participants nevertheless discussed potential disadvantages of greater data sharing. They talked about how not all the information in their records is current or relevant and so professionals could be making decisions based on information that is no longer accurate. They were particularly aware that a previous diagnosis of a mental health condition could mean that they experience prejudice or stigma. However, some talked about how more openness around mental health could lead to reduced stigma as it becomes clearer just how many people experience mental health problems. This represents a change from the previous Joined Up research and may reflect work over recent years to reduce the stigma associated with mental health conditions, encourage people to talk about their mental health, and to give mental health conditions same priority as physical health conditions.

Several groups discussed how it would be useful to have the facility to flag some elements of your records as private, although they were aware that there may be technical and practical difficulties around doing this. Some also talked about how their health and care records could contain errors, so that greater sharing could lead to more inappropriate decisions.

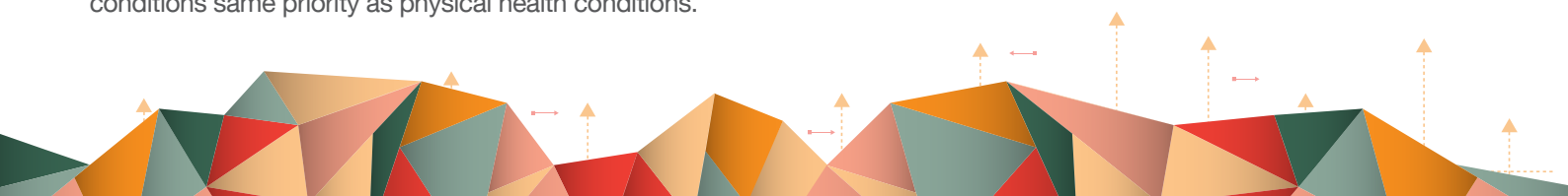
As in the previous Joined Up research (Joined Up Leeds, 2015), many people were surprised that their health and care records are not already shared across the NHS. There was support for health professionals being able to access health and care records no matter where in the country you are, with some participants discussing how your records should be available internationally.

The situation was not so clear cut when it came to social care professionals accessing records. Many people did not recognise social care as an important element of health care and there was low awareness of the role that local councils play in planning and providing health and care services. Many were puzzled as to why the local council would have any reason to access health and care records.

In the workshops people were asked to draw a map of who has access to their health and care records. The results show a wide variation in how extensive people believe data sharing to be. Some participants' maps contained just their GP, hospital doctors, and midwives. Others contained wider groups providing direct care, such as pharmacist, dentists and opticians. Others also included government bodies, such as the Department for Work and Pensions, the DVLA, the police, and the ambulance service, or commercial organisations such as private hospitals, and private therapists. Very few included social care or public health professionals. This indicates a need for raising awareness of the role of the local council in providing direct care and in planning services.

Discussions around sharing data with local councils revealed participants' concerns that care workers, social workers, etc. do not have sufficient medical training to be able to understand health records, and so could misunderstand the information they contain.

However, many participants held similar concerns about GP receptionists asking about their symptoms. They recognised that this was to direct them to alternative sources of help if a GP appointment is unnecessary but many were concerned that receptionists are not qualified to do this. Participants also raised concerns about whether administrative staff have the same confidentiality requirements as clinical staff and so may access and talk about the medical records of people they know.





“At our doctors, our receptionist can ask you questions so they can find out what is wrong with you – well I am not sure about that – it’s dangerous because they are only receptionists. They are not medically trained at all.”
(Female, WY & H)

“How would you be sure that people have accessed it for a legitimate reason not just thought yes, she lives down the street?” **(Female, WY & H)**

Participants from small communities were particularly concerned about this element of data sharing. They gave examples of people travelling to nearby towns or cities to collect prescriptions so that pharmacy staff would not find out about their condition. They talked about how there would be greater potential for rumours spreading if more health and care staff could see their medical records. Several participants suggested having an audit trail that would allow them to track who had accessed their information.

Survey respondents were given a list of professionals and asked which should be able to see their health and care records so that they can help care for them. The list included professionals that would have greater and lesser input into an individual’s direct care. The results are shown in Figure 1. Nearly everybody agreed that their GP (98%) and hospital doctors and nurses (93%) should be able to see their health and care records. Most people agreed that practice nurses (76%) and clinical staff (61%) should do so. These results clearly demonstrate that people support NHS healthcare professionals being able to access their records. There is more limited support for pharmacists (37%), care staff (36%), social workers (24%) and researchers (24%). Very few believed housing officers (7%), employers (4%), or insurers (4%) should have access.

During the community events, several participants noted that there are some elements of their records that employers should be able to access, for example if they drive for work their employer should be able to see any information that means they can no longer drive. Some talked about how they are required to have medicals for work and it makes sense to share employer and NHS health data.

3. Results cont.

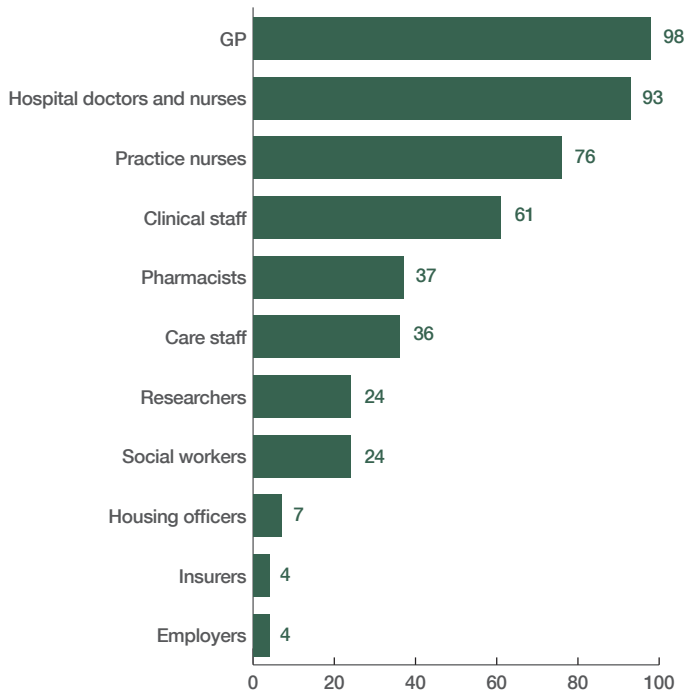


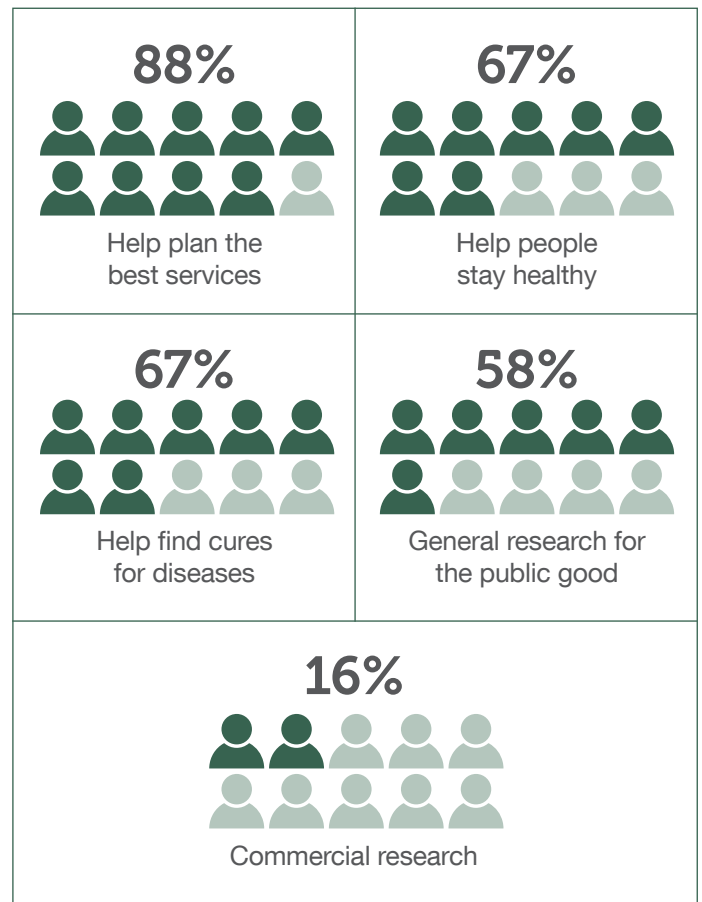
Figure 1: The percentage of respondents who believe different professionals should be able to access their health and care records (n=1031).

There were some age differences in the pattern of responses¹. People in the 25-64 age group were less likely to believe that practice nurses should be able to access records than those in the younger (<25) or older (>64) age groups ($\chi^2 (2)=25, p<0.001$). People in the older age group were less likely to believe that social workers should be able to access their records than the other groups ($\chi^2 (2) = 24, p<0.001$). There were no gender differences. People with a disability were more likely to believe that housing officers should be able to access their records ($\chi^2 (1)=15, p<0.001$).



3.2 What should health and care information be used for?

Survey respondents were asked what they would be prepared to allow anonymous information from their health and social care records to be used for. The results show clear support for making greater use of health and care information, with 95% supporting it being used for one or more reasons. The percentage supporting each reason is shown below. While people support the use of anonymous records for a wide range of topics, there is very little support for using health and care records for commercial research. These figures are very similar to those seen in Joined Up Leeds.

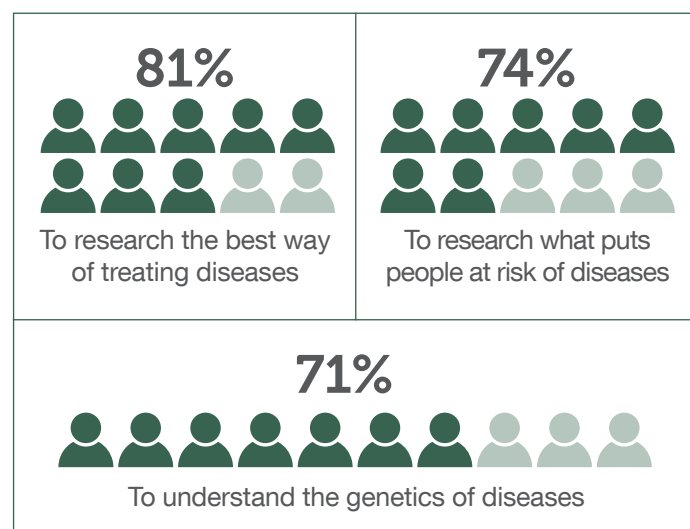
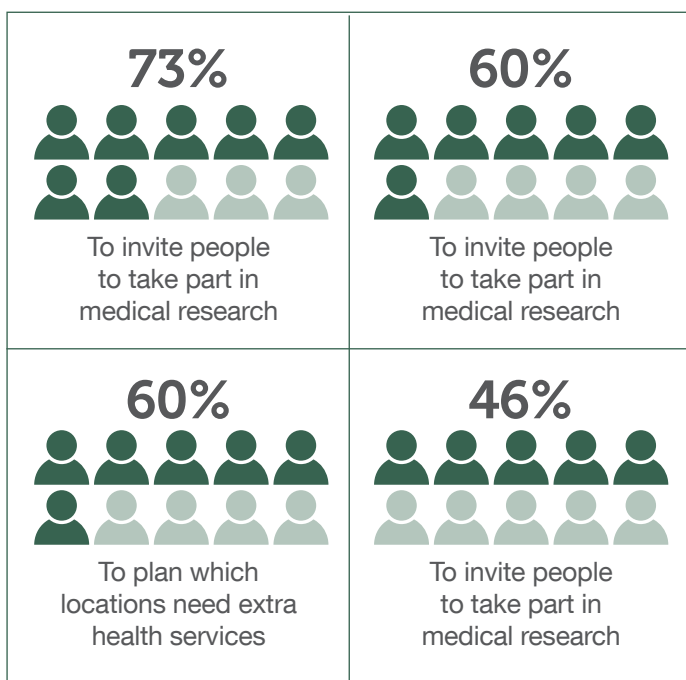




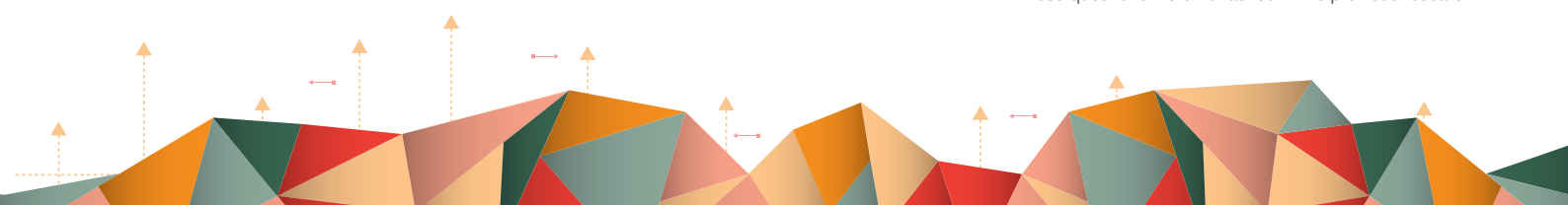
Respondents were told that the NHS could search everybody’s health and care records to find people at risk of a disease and were given a series of options about how this information should be used. Nearly all (92%) believed that this information should be used in some way. The percentage who agreed with each use is shown below².

These results provide support to potential future uses of data beyond direct care and for population health management. Indeed, the results show support for individuals being identified and contacted if they are at risk.

The results also show support for using health data for medical research. Respondents were told that the NHS could analyse everybody’s health and care records for medical research and were given a series of options about what research should be done. Even though this question did not specify that the records would be anonymous, nearly all (93%) believed that this information should be used for at least one research purpose. The percentage who agreed with each use is shown below¹.



1. A conservative significance value of 0.005 was used in all age, gender and disability analyses to control for multiple comparisons.
 2. These questions were not asked in the previous research.



3. Results cont.

Very few age- and gender-related differences were seen in the results. Males were more likely than females to believe that people should be contacted if they are at risk of a disease ($\chi^2 (2) = 11.8, p=0.003$) whereas females were more likely to believe that data should be used to plan services ($\chi^2 (2) = 13.7, p=0.001$). There were no differences based on disability.

During the pop-up events people were asked their view on six different case studies, each describing how a different form of data sharing was used to achieve a positive outcome. Participants were asked to decide whether or not it is a good use of information and whether or not they would like their data to be used in this way. The results are summarised in Table 3. There is support for data use across all the case studies, although less support for Saffi's story in which research on medical records was used to identify risk factors and Saffi was contacted as she is at higher risk. Nevertheless, 84% of participants believed this is a good use of information and would be happy for their information to be used in this way. Differences between the case studies were not statistically significant for it being a good use of data ($\chi^2 (5) = 3.98, p = 0.11$) or for their information to be used in this way ($\chi^2 (5) = 4.55, p = 0.47$). There were no differences in the pattern of responses based on age for it being a good use of data ($\chi^2 (5) = 8.99, p = 0.55$) or for their information to be used in this way ($\chi^2 (5) = 3.71, p = 0.59$).

Table 3: The percentage of people who agree with each data use.

	Good use of information	Use my information this way
Sarah (consultant accessed A&E data)	96%	93%
Ali (A&E accessed social care data)	94%	92%
Neil (data shared with community care)	94%	90%
Sheila (data shared with voluntary sector)	89%	87%
Mohammed (data used to plan services)	95%	93%
Saffi (identified as higher risk and contacted)	84%	84%



During focus group discussions and conversations about the case studies, participants talked about whether the NHS should use anonymous records to help plan services. There was agreement that this is a positive thing to do as it will help to ensure that services run efficiently and are sufficiently resourced to meet projected demand. A small number, however, highlighted that this could lead to a cut in services.

3.3 How much do people trust organisations with their information?

Survey respondents were asked how much they trust different organisations with information about them. They used a scale from 1 to 10, with higher scores indicating greater trust. The results are shown in Figure 2.

There are statistically significant differences in how much these organisations are trusted, with GPs trusted more than the NHS in general, and both of these trusted significantly more than banks or building societies, the local council and Universities. All these organisations are trusted more than insurance companies, and 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.

While comparison of these results with those from Joined Up Leeds should be made with caution, trust has increased slightly in GP practices (from 7.8 to 8.1) and the NHS (7.2 to 7.7). In contrast, there has been a fall in trust in banks and building societies (from 6.2 to 5.6), local councils (5.9 to 4.8) and universities (5.4 to 4.8).

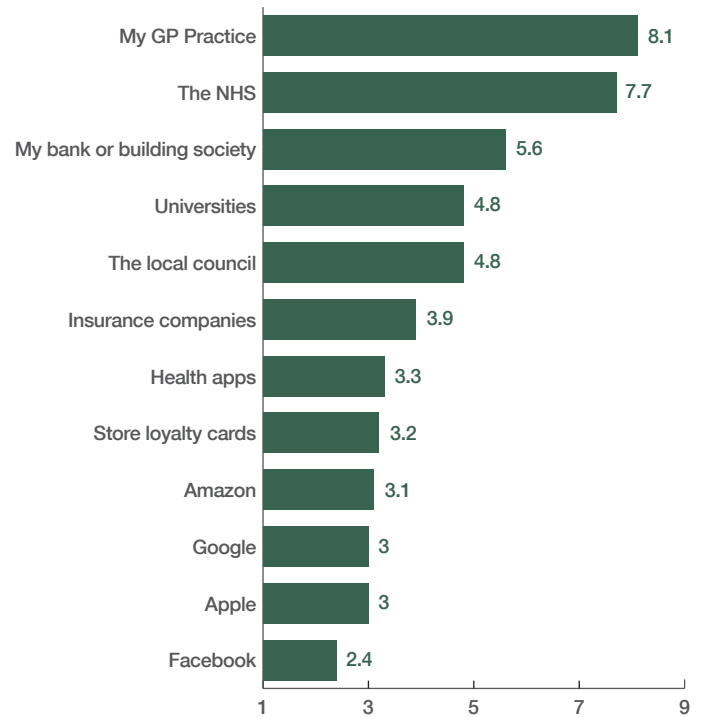


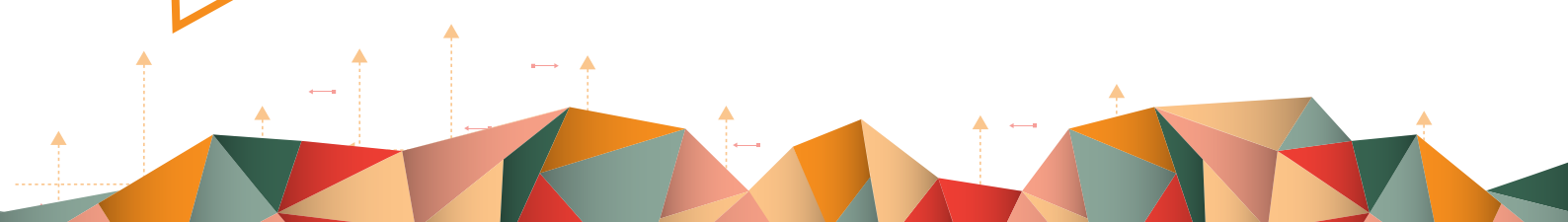
Figure 2: How much people trust different organisations with their information (n=995)

In the survey, respondents were asked if they had any concerns about anonymous information being used to help improve services. They were given a series of options and could also volunteer additional concerns. Most (79%) had at least one concern. The percentage of people having each concern is shown below. These results are broadly similar to those obtained from the previous research, although there is slightly less concern now about information being sold to private companies.

- The information might be sold to private companies: 56%
- The information might not be stored securely: 53%
- The information might be used to cut services: 41%
- I might receive more junk mail: 33%
- Even though my name and address aren't there I might still be identified: 31%
- The council might increase my bills: 21%
- The NHS might pressure me to be healthier: 8%
- The less the authorities know about you the better: 7%

“I don’t mind anyone sharing my information within the NHS or within the local authority, but I would be extremely unhappy to find it been sold to third parties or even given to third parties because of the potential abuse.” (Male, SY & B)

“If the NHS tells a private company, like a care home, where beds are needed, that is ok. But they shouldn’t get a commercial advantage.” (Male, WY & H)



3. Results cont.

While people in the focus groups were happy that their information be used to help the NHS and local councils to plan services, they were less certain about whether this information should be released to help private health organisations plan services. While they agreed that it is beneficial for the NHS to co-operate with private organisations to plan services, they did not want commercial organisations to profit from their health and care records. They were also concerned that a private organisation might identify them and contact them directly with the aim of selling products and services.

As in the previous Joined Up Leeds research, we found evidence of a trust-benefit ratio. This describes 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. If an individual perceives more benefit, they are willing to lend more trust and to provide more data. This suggests that if people were more aware of the advances in diagnosis and treatments that arise from research they would be more willing for their data to be used for research purposes.

3.4 Are people willing to be engaged in their own health management?

Participants in the focus groups and workshops discussed whether they would want to be informed if analysis of health records showed they were at risk of a condition. People held different opinions about this and the topics they discussed included whether you would be anxious and the implications for insurance and employment. They talked about how knowledge of their risk could have negative psychological and financial implications. All, however, agreed that their views could change depending on the health condition concerned and depending on their life stage and context.

Most people were keen to be told about any preventable or treatable health conditions because they wanted to take action to reduce the risk. For example, if they were flagged as being at risk of diabetes, they would want to engage with health services to change their diet to reduce that risk. One participant talked about how a healthcare assistant mentioned to him during a routine blood test that he was developing diabetes, but he was not offered any advice about what action he could take. He used the internet to find out about what changes to his diet he could make but was aware that other people might need more support to make these changes.

People discussed the practicalities of how those at risk could be contacted. They talked about who should make contact and most believed that this should be the GP practice: ideally the GP, but if not, a member of the clinical team at the practice.

“Your GP should be the one to tell you if you are at risk. They know you, they know your history.”
(Female, HC & V)

They thought that it would be important to be able to opt in or out of being told. Some talked about how it is usual to be asked to review and update privacy settings on apps and websites, so that it should be straightforward to ask people to do the same for notifications from their health and care records.

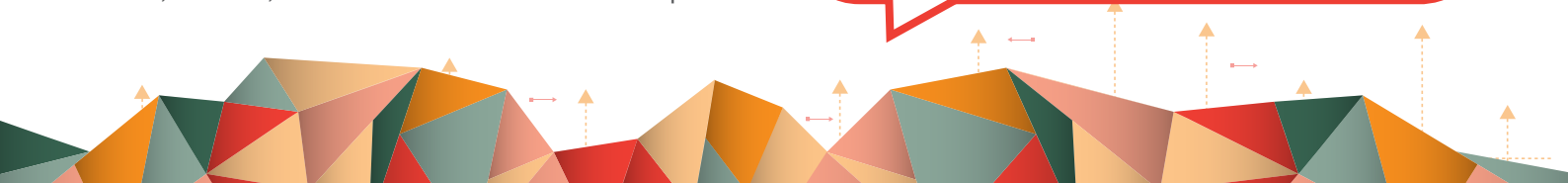
“Every time you install or update an app you’re asked to agree to privacy settings so I don’t see why we can’t do the same each year for our health record.” ***(Female, WY & H)***

3.5 What concerns do people have about their information being used?

There were three main reasons why people had reservations about their individual records being analysed and used for planning services or for research.

First, they were concerned that they could be identified. Some found it difficult to understand how their individual records could generate aggregated data, which reports only the number of people with specific conditions or who have used a service. Most were happy for aggregated data to be analysed but were more cautious about individual records being analysed, even when their name and other identifiable information is removed. They were concerned that it might still be possible to identify them.

“If pharmaceutical companies find out that you have got a heart condition and you are on a certain type of beta blocker before you know it you could be getting all sorts of leaflets, try this drug change to this drug, you could end up being targeted.” ***(Female HC & V)***





“Will all hospitals have to sign the same kind of GDPR requirements that we are doing at the moment with cookies every time we go onto a website?” (Male WY & H)

“It’s all changed now and we have to accept all these conditions on websites and we have more say over what they use our data for.” (Female HC & V)

Being identified was believed to be problematic because people were aware that data is valuable, and that there are organisations that would want to access their data. This concern was much more prevalent than in the previous Joined Up research. The Facebook and Cambridge Analytica incident was raised in many of the focus groups and workshops and participants were much more wary of what organisations might want to do with their data. While many people in the previous research were puzzled as to why being identified would be a problem, many in the current research talked about identity theft. Concerns about being targeted by commercial companies trying to sell them products related to their health condition were similar to those identified in the previous research.

The second main reason is that participants were more aware of cyber security limitations. They talked about data leaks in large organisations in many different sectors, and how data held by the NHS and local authorities can never be entirely secure. They also talked about how computer viruses might affect NHS and local authority data, with several pointing to the “WannaCry” cybersecurity incident as an example of how their data is vulnerable to hackers and malicious attacks. Some also highlighted how staff members themselves may be the source of data leaks, either intentionally or unintentionally.

“If you are going to share it across the country you are opening up the potential to misuse, blackmail, you know people down south who don’t give a toss about people up north all of a sudden selling that information to third parties, to Russia, to whoever it may be for them to use it for their own personal gain.” (Male WY & H)

“The NHS cannot afford to upgrade their security to the latest because they haven’t got the money to do so, so potentially it is at risk because they are using out of date technology which is more prone to be hacked than the latest operating systems.” (Male SY & B)

Changes to the Data Protection Act and GDPR were, of course, a new topic of discussion. Participants talked about how organisations now need to seek permission to keep personal data and they were aware that they have a certain degree of control over who keeps information about them and what it is used for. Many talked about how they would expect to give consent for their identifiable data were to be used for research purposes.

“If a 13-year-old kid can hack into the Pentagon, nobody’s data is safe.” (Male HC & V)



3. Results cont.

The third reason is that some people were concerned that information in their health and care records may be used against them. This could be the NHS itself, for example by rationing care on the basis of information in their record such as lifestyle choices that people have made. A few talked about how care is already restricted on the basis of age and wondered if the situation could be more extreme in the future, even leading to eugenics, for example limiting care to people who carry a genetic condition.

“They might say all these people over 75 we don’t need them anymore they are taking too much time and energy out of the National Health Service and that is that, like they did with Jewish people. It’s extreme but that could happen or if you are a carrier of some disease and it is going to go through your family they might want to do away with that so can be quite sinister as well.” (Female WY & H)

They also talked about how they could be adversely affected if other organisations find out about their health condition. Several talked about being faced with raised insurance costs or difficulties obtaining a mortgage if organisations were aware of their medical conditions or risks of developing a future condition.

A few talked about how the NHS and local councils may either choose or be forced to share information with other organisations that might not be so benevolent. For example, the NHS might share information from the records of people who are refugees or asylum seekers with government bodies, and these bodies might use this information to locate, detain or deport individuals.

“At this present time I think the information would only be used for good but you can’t guarantee this will always be the case.” (Female, WY & H)

Rules that would allay concerns

During the workshops, participants discussed what rules should be put in place for four different types of organisations that might access their data. The results are summarised below.

Private hospitals and clinics providing direct care or commercial practices such as dentists, opticians and physiotherapists

- Data obtained from the NHS and local councils should only be used for the purposes of direct care and should not be used to help the organisation become more profitable and it should not be shared with third parties.
- Processes for sharing NHS and local council health and care information should be governed effectively.
- The highest possible data security standards should be applied.

Organisations that develop new equipment and treatments

- Data can be used for research for the public good.
- Research using anonymised data does not require consent but individuals should give consent for research that uses their identifiable records.
- There should be clarity on which aspects of an individual’s records is and isn’t shared.
- All research projects should go through an ethics review process.

Organisations that help people stay healthy or live independently

- Data can be used if it provides a positive outcome for people.
- People should be provided with the ability to opt in or opt out.
- Only current and relevant information should be shared and people should be able to check which aspects of their records have been shared.

Companies that help the NHS function, e.g. providing IT systems, mail services, accounts software or staff training

- Where possible, data should be anonymised.
- Data should be kept confidential and there should be a governance process that detects and deals with any breaches.
- There should be an explanation of why this organisation has accessed your record.



3.6 Are there different data personas?

In this section we describe five different fictitious personas that summarise the different clusters of beliefs that people have about how their health and care information is used. These may be of value when communicating with the public about how health and care information is used. Personas were developed by coding focus group discussions about health and care information being shared and noting which codes occur together within individual participants. This formed five different typical responses patterns that described people's clusters of beliefs and experiences. They varied on:

- Previous experience of the NHS;
- Trust in NHS data security;
- Willingness for anonymous and identifiable data to be used;
- Concern about identifiable data;
- Willingness to be contacted if identified as at risk.

Participants in the review workshops discussed these personas and all personas were identified by at least one participant as being most like them. However, most participants wanted to be informed, especially if the disease is preventable, and so this element of the personas was removed. Data from the review workshops were used to refine the personas, which are described below. Two of the personas were combined, and in addition to the remaining four (which arose directly from the data collected during the study), we recommend including a fifth group. While we have no direct evidence from the research for this group, we believe it is important to consider this potentially missing voice. These five personas may help guide future communication about information sharing.

Chris

I am proud of the NHS and social care services and I trust them with my information. I am happy for my information to be shared with people who care for me as well as with people who plan services and undertake research. I haven't thought much about data security in the past and I don't think it's a problem if I could be identified from my health and care records.

Jordan

I have had relatively little contact with the NHS and social care and I assume that my records are available to anybody involved in my care. I often share my personal information on social media sites. I know that personal data is valuable but I'm not worried about what might happen to my health and care information.

Ali

I have experienced previous problems with poor communication or connectivity in the NHS and local authority so I know that my health and care records aren't easily accessed by people who are involved in my care. I am keen for this to change and I know it will require more data sharing. I am happy for my information to be used for planning services and for research, although I want to be able to opt out.

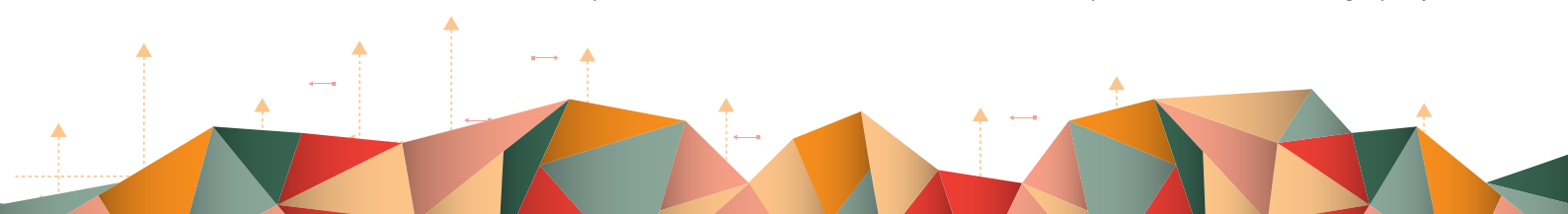
Alex

I am happy for my information to be shared with people involved in my care but I am wary of who might see what. I want access beyond staff treating me to be restricted and I want to be able to track who has accessed my records. I don't want my health and care information to be used by commercial organisations without my consent. I am sceptical that the healthcare system can keep my data secure.

Sam³

I have complicated health or social needs which make me vulnerable and I face many barriers to accessing healthcare. I am not too concerned about who can access my health and care records because I have more pressing needs. I may have problems that make it more difficult to access or use technology that others take for granted.

3. This persona was not observed in the research but we believe it important to consider that such a group may exist.



4. Conclusions



The results show that people welcome greater sharing of health and care records, particularly by clinical staff for their direct care. They also recognise the benefits of the NHS and local councils analysing their anonymous health and care records to plan services and to better understand and treat diseases. There is clear support for the Yorkshire and Humber Care Record for:

- direct care;
- planning services;
- research for the public good;
- engaging people in their health management.

There have been changes since the previous Joined Up Leeds research, with:

- more people aware of the value of personal data;
- more aware of the control they have over their data;
- and more concerns over the potential for security breaches.



People's concerns present several technical, practical and communication challenges for the Yorkshire and Humber Care Record team. The key challenges are:

1 People differ in how much of their information they want to be able to share for their direct care, particularly with social care and third sector professionals. But who decides which information is current and relevant? How can people be reassured that non-clinical staff understand what they access? Will access be time-limited to the duration of their referral?

2 People are cautious about their identifiable data being shared for purposes other than direct care. They want to know:

- Who accesses it;
- Why they want it
- What they will do with it.

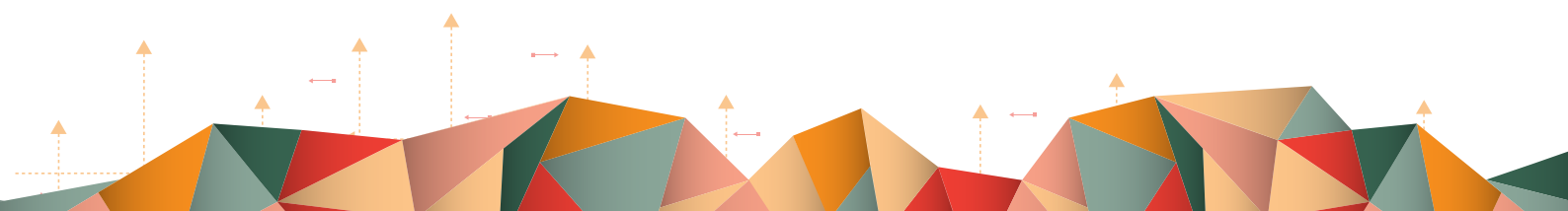
How can individuals maintain control over their records? Will they be able to track who has accessed their record? It will be important to explain why it matters that their information is shared, i.e. the benefits that sharing their data brings to themselves or others.

3 People are willing for their information to be used for research for the public good but will the health and care system have the capacity to implement the findings, such as new screening or treatment programmes? How can people be reassured that data sharing with commercial organisations is for the public good? What governance is in place to ensure these organisations do not misuse information?

4 If people were flagged as being at higher risk of a disease, most want their GP to tell them. Will GP practices have the capacity to take on this role? If not, who should contact people to tell them of their raised risk? If lifestyle factors put people at risk will resources be available to support them to change their behaviour? How will the NHS ensure that individuals retain choice over whether or not to change their behaviour?

5 In the future the NHS and local councils may work more closely with commercial organisations, e.g. for social prescribing or supporting individuals to change their behaviour or to remain living independently. What governance is in place to ensure that commercial organisations don't contact individuals to upsell additional services or share data with third parties who might contact them

6 People are concerned about the security of their information. How is people's data protected from cyber security and other threats? Do staff have the skills and training to keep data secure? How does the "system of systems" approach limit security risk? How can this approach be described to people in a simple way? How secure are people's health and care records compared with, for example, their online banking records?



Appendix 1: Case study cards

JoinedUp Yorkshire & Humber

The NHS and your local council want to start making smarter use of information but they want people to help decide how their information is used. Who should be able to see information about us? What should it be used for? How will our privacy be protected?

Read the story on this card then answer a few quick questions by making a tear in the card through your answer.

1. Is this a good use of information? Yes No

2. Would you be happy for your information to be used in this way? Yes No

3. Which age group are you in?

<input type="checkbox"/> <18	<input type="checkbox"/> 18-24	<input type="checkbox"/> 25-45	<input type="checkbox"/> 46-64	<input type="checkbox"/> 65-84	<input type="checkbox"/> 85+
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Saffi's story

NHS researchers looked at information from everybody's medical records to find out what makes it more likely that somebody will develop cancer. They searched the records to find people who are more at risk and shared this information with local health clinics. Saffi's records showed that she is at higher risk so her local health clinic wrote to her to invite her for screening.

"I was surprised to get a letter from the clinic. At the appointment they explained why I am more likely to get cancer and they gave me lifestyle advice and offered me a screening test"

Saffi can have a screening test every year. By using information from everybody's medical records, the NHS aims to detect cancer sooner and treat it more successfully.



Mohammed's story

Mohammed is 42 years old and has recently been diagnosed with diabetes. During a review of people's health records, the NHS found that there were a lot of people with diabetes in Mohammed's area. They set up a local diabetes group to support people with diabetes. It provides information about diabetes, advice about exercise and healthy eating, blood tests and medical treatments.

"I probably wouldn't go to the diabetes group if it were in the hospital but because it's local I go every week"

The NHS used information from the healthcare records of everybody in the region to find out where new healthcare services are needed.



Neil's story

Neil is 58 and lives alone. He has recently had surgery for lung cancer. Neil needed a lot of support when he left hospital. His health and care team assessed his needs and shared this, along with his medical records, with his GP and the community care team.

"The community worker visited me in hospital and he talked to my GP and arranged for the nurses, the physiotherapist and the social worker to visit me when I came home"

Because Neil's health and care records were shared with different professionals, they were able to work together to provide the support that Neil needs.



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, Ali fell over while playing football. He hit his head and his arm was cut and bleeding so Ali's Dad took him to A&E.

The A&E doctors wanted to give Ali antibiotics. 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, which showed he was allergic to the antibiotic they were going to give him. Instead they gave him a different one. The hospital doctor was worried about Ali's bruises and checked Ali's council records to check whether social services had logged any concerns about violence at home. 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 health is good but she is unsteady. Sheila received a visit from a charity worker, who explained that the local health and care record system had flagged her up as being frail and at risk of falling.

"I was surprised they knew I was worried about falling. The grab rails help me get up and down the stairs and in and out of the shower. I feel much more confident now"

The charity worker arranged for grab rails to be fitted in Sheila's home to reduce her risk of falling, and for physiotherapy appointments to strengthen her muscles. These changes should help Sheila to stay living independently in her home.



Sarah's story

Sarah is 21 years old and has suffered from alcohol abuse and mental health issues for some time. Her psychiatrist prescribed Lithium to help. At her most recent appointment her psychiatrist checked her local health and care record, which allows doctors from different hospitals and GP practices to see a patient's medical records. This showed that Sarah had gone to A&E and her blood tests showed her Lithium levels were too high. He prescribed a different medication for her.

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

Without the local health and care record her psychiatrist wouldn't have been able to see the A&E test results and wouldn't have changed her medication.





Yorkshire & Humber
Care Record

Brainbox Research

