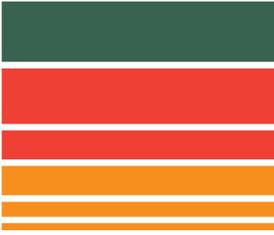


Brainbox Research



Explaining data flow in the Yorkshire and Humber Care Record

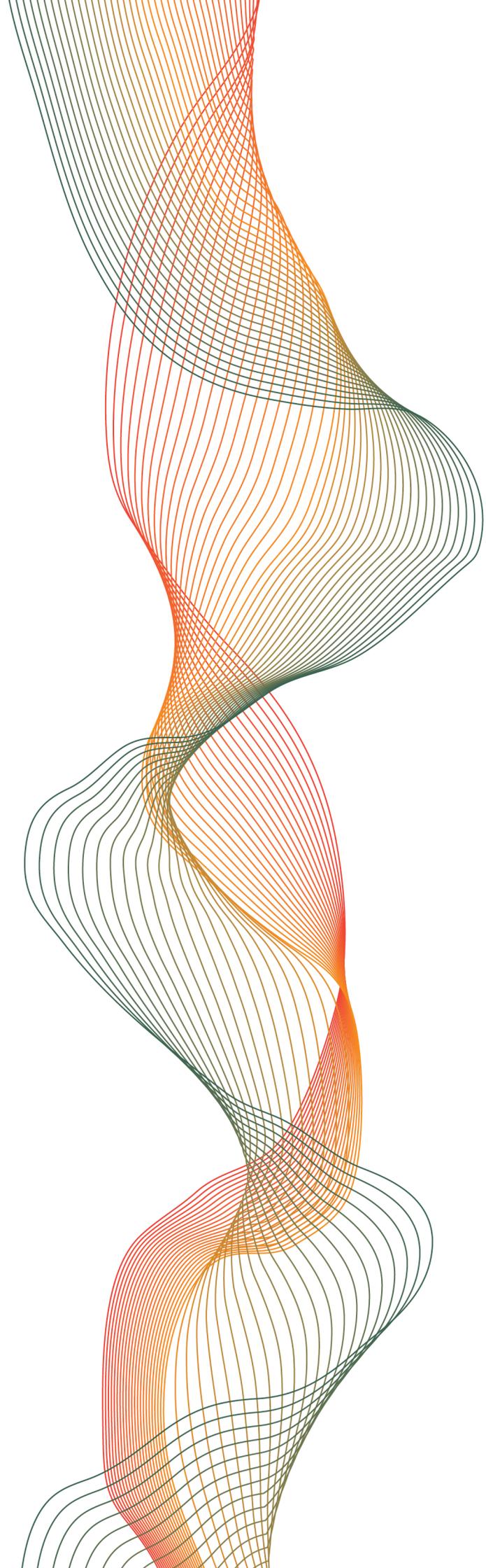
Final report for Rebecca Nichells
Yorkshire and Humber Care Record

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Insight and understanding



Summary

This report describes research with the public to explore acceptability and to co-design explanations of how data flows in the Yorkshire and Humber Care Record (YHCR) and Population Health Management (PHM) platform. The research took place to ensure that the public accept that their data must flow from NHS systems in order for the PHM platform to operate, and that the public understand at what point their data is de-identified, how they can be re-identified, and how they can opt out.

We conducted four co-design workshops in which we brought together 23 members of the public and 3 experts involved in developing and explaining the YHCR and PHM platform. The public were given explanations of how data flows and their right to opt out. They discussed their questions, concerns, the level of detail they wanted with the experts, and how best to explain data flow.

The results show that people are not concerned about their data flowing from NHS systems to the YHCR and PHM platform and indeed expect that it is necessary. They welcomed data sharing in the YHCR for direct care purposes and many had not previously been aware that they did not already have a single combined NHS record.

When it came to the PHM platform participants had more questions. Some found it difficult to understand how their individual records could be used without them being identified. Several had concerns about data security, whether identifiable data would be released to non-NHS organisations and whether commercial healthcare organisations could profit from the platform. They also wanted reassurance that if the PHM platform analysis identified them as being at risk, any contact would be made by their GP practice. After discussions

with the experts, all of the participants were happy that their data could be searched by the PHM platform; even one participant who had previously opted out of the national NHS programme.

Participants discussed different ways of opting out of the PHM platform and most supported the current method of telephoning. While they thought it would be quicker and easier to opt out online, they also anticipated that some people would opt out without full understanding or sufficient consideration. Participants thought that opting out by telephone makes it more likely that people will make an informed choice.

Participants and experts co-designed an explanation of how data flows through the YHCR and PHM platform, how they can opt out and the consequences of opting out. This was then tested in a survey of over 500 residents of Yorkshire and Humber.

Most survey respondents (83%) were happy that their data is searched by the PHM platform, while 10% were unsure and 7% did not want their data to be searched, mainly because they don't trust the system or don't know enough about it. A significant minority said they would opt out of the Yorkshire and Humber platform (12%) or the National NHS Digital opt-out programme (11%). This is higher than the number who have actually opted out (1.8%), which suggests that more people would opt out of the national system if they were aware of it and if it were easy to do. The reasons they would opt out are that they don't understand the platform, they don't understand some of the language (e.g. de-identified) or that they don't want to be included in statistics. Black and minority ethnic respondents are statistically significantly more likely to opt out.

Text on the implications of opting out did not alarm people. While most respondents felt positive

about the PHM platform, 19% felt worried. To reassure people it will be important to provide a simple example of how de-identified data is used to improve the health of people in the region. Branding the platform will have implications for its acceptability, and a title that includes NHS will engender greater support.

1. Background

The Yorkshire and Humber Care Record has been developed to address the problem of data sharing between different health and care systems. 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 can be accessed by different care providers regardless of the computer system they use. It can also be used for purposes beyond direct care as it provides intelligence that can be used for planning services and to inform population health management. This is termed the Population Health Management platform

Consulting with the public has been an integral part of the development process. Previous consultations have demonstrated public support for sharing anonymised data, and have co-designed explanations of data sharing that people understand and do not raise unnecessary concerns. However, it has recently emerged that while organisations accessing population health data *receive* anonymised data, the de-identification process takes place during, and not before, transfer. This means that there is a short period of time during which identifiable information

flows across NHS systems. It is important, therefore, to consult the public on this point, and to co-design an explanation of the data sharing protocol that people can understand and does not raise unnecessary alarm. It's also important that people are able to make an informed choice about opting out of data sharing, so this research also co-designed wording about the option and consequences of opting out.

2. Methods

To gain insight into people's information needs on a complex topic such as data flow it is important to use a qualitative approach. Data collection made use of online co-design workshops, in which we brought together members of the public and experts involved in developing and communicating about the YHCR and PHM platform, and an online survey in which we tested the explanations developed in the co-design groups.

Four workshops took place, each with 5 or 6 members of the public (total of 23) and 2 or 3 experts (total of 3). None of the public were data experts and none worked in the NHS.

Participants were given the following information about how the YHCR shares information for direct care.

Sharing records

The Yorkshire & Humber Care Record provides clinical and care staff directly involved in your care access to the most up-to-date information about you. It does this by sharing appropriate information from your health and care records between health and social care services in Yorkshire & Humber. It enables clinical and care staff to view real-time health and care information across care providers and between different systems. All health records are strictly confidential and can only be accessed by clinical and care staff who are directly involved in

your care.

Examples of what's included in my Yorkshire & Humber Care Record:

- Diagnosed conditions
- Medications
- Allergies and adverse reactions
- Test results
- Referrals, clinical letters and discharge information
- Care plans
- Contact details

They were told that the PHM platform allows staff to use people's de-identified records to plan services, and that de-identified means that it doesn't contain information that could identify you, like your name and address. They were also told that the PHM platform can find people who may have a particular combination of conditions or treatments. They were given real examples of how the PHM platform has been used to plan services and how it could be used to find people at risk.

Planning services

Some GPs in Leeds have noticed a rise in the number of young people with diabetes. They want to do some research to see if this is happening across the city. They use the Population Health Management (PHM) platform to find out how many young people with diabetes there are and in which part of the city they live. The PHM platform retrieves patient records and before it lets the GPs see them, it removes all the data that could identify a specific person e.g. name, address, postcode, data of birth. The research allows the GPs to set up some new self-help clinics in the areas of the city that are most affected.

Finding people at risk

A new treatment has been discovered that is very effective for patients with a specific combination of health conditions who are taking a particular medication. It's difficult to find these patients, though, as they receive care from lots of different places, e.g. the hospital, the GP, and community clinics. Unless we find them, they can't be offered the new

treatment.

We use the Population Health Management platform to search for patients with these conditions and medications. Because their records are stored in lots of different computer systems, we use their NHS number to combine their records. To protect their confidentiality, we swap their NHS number for a unique encrypted code. Only authorised staff hold the electronic key to unlock their NHS number.

The search finds 50 patients. The authorised staff member uses their electronic key to re-identify these 50 people and write to them to offer a meeting with their GP to discuss whether they would like to have the new treatment.

Participants were then provided with information about how they can opt out of both the PHM platform and the National NHS Digital opt-out programme:

Opting out

If you live in Yorkshire and Humber and you wish to opt out of your de-identified data being searched by the Yorkshire & Humber Care Record, please call 0113 20 64102 during normal working hours. You can discuss with the team your right to Opt Out and they can stop your de-identified data from flowing to the Yorkshire & Humber Care Record Population Health Management platform.

Please note that if you'd like to opt out of your confidential patient information being used for research and planning in other areas please contact the National NHS Digital opt-out programme.

- Online: <https://www.nhs.uk/your-nhs-data-matters/>
- By phone: Speak to the NHS Digital Contact Centre on 0300 303 5678 (Monday to Friday, 9am to 5pm, excluding bank holidays)

Following discussions of opting out, participants were shown text about the potential impact of them opting out. They then discussed their response to this information.

Potential impact of opting out

If you opt out of either the Yorkshire and Humber Care Record or the National Opt Out service, people doing research and planning may not know you exist. This may mean that your needs won't be taken into account, or if there is a new treatment or service you could benefit from you may not be told about them.

Participants were then given two separate explanations of how data flows, with more and less detail. They discussed each version, including whether the explanations addressed the questions that they have, the level of detail they want, any concerns that the explanations generate, and how to make the explanations clear and relevant.

Data Flow 1

Yorkshire and Humber Care Record Population Health Management is a digital platform developed by the NHS and local authorities to help its staff to plan and develop services to meet the needs of the populations.

The technology doesn't collect data automatically - it only allows qualified and authorised staff to search for data so they can analyse it. The data they have searched is sent electronically to the platform. Before the person can view it, all information that identifies you is removed, e.g.

- Your name and address is removed
- All free text, e.g. notes made by doctors, is removed
- Your date of birth is deleted and replaced with your year of birth
- Your NHS number is encrypted so you can not be identified.

This is done by the National De-identification system.

Data Flow 2

To ensure that your confidentiality is maintained we shall be securely providing an extract of our data to Humber Teaching NHS Foundation Trust who are acting as Data processors on our behalf.

Your NHS Number is then securely provided to NHS Digital's National De-Identify / Re-Identify service for the purpose of pseudonymising the data.

Your de-identified data will return back to the secure Yorkshire & Humber Population Health Management Data Analytics Store which is only accessed by authorised individuals.

Access to the platform is securely controlled and the list of people who have access is checked regularly.

The security controls built into the PHM platform ensures we can detect and respond to any incidents that may occur on the platform.

Participants were shown two different versions of diagrams to explain data flow, which are shown in Appendix 1.

The workshops comprised several activities:

- Discussing how data is shared for direct care.
- Discussing explanations of how data flows in the YHCR and PHM platform.
- Exploring ways to explain opting out and the consequence of doing so.
- Discussing how diagrams might help people to explain data flow.

Workshops lasted an hour, were recorded and transcribed.

The findings were used in an online survey for people living in Yorkshire and Humber. Respondents were recruited via a fieldwork panel, and NHS partners promoted the survey via Twitter. The target number of responses was 500, and 529 completed surveys were received. Of these:

- 46% live in West Yorkshire and Harrogate
- 26% live in South Yorkshire and Bassetlaw
- 24% live in Humber Coast and Vale
- 7% reported they live elsewhere in Yorkshire and Humber

This geographical distribution is in line with the population of the three different areas.

There was a good range of ages:

- 4% age 18-24
- 32% age 25-44
- 43% age 45-64
- 21% age 65+

And genders:

- 41% male
- 58% female
- 1% preferred to be identified as gender fluid or non binary

A third reported they have a disability:

- 11% have a long-standing illness
- 8% have a mental health condition
- 7% have a physical disability
- 3% have a hearing impairment
- 1% have a visual impairment
- 1% have a learning disability or difficulty

Most (82%) reported they are White British, with the remaining 8% a range of ethnicities, most commonly Pakistani, Indian, Asian, Chinese, Black Caribbean, Black African, and mixed. This represents the population in the region.

Ethics

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. All participants gave informed consent to participate.

3. Results

We report the results in three sections. The first two sections report on discussions in the co-design

workshops and are about the information that people want about data flow, and the information they want about opting out. The third section reports on the survey findings.

3.1 What information do people want about data flow?

None of our participants had previously thought much about the details of how data flows between NHS systems and the information we provided was new to them. Some discussed how they would not be particularly interested in knowing how data flows, as they trust the NHS. Others, however, talked about how the NHS may share their information with external organisations, which they do not trust as much. As in previous Joined Up research, some people don't mind who sees all their records, and others prefer to restrict who sees what, for example because they don't want others to know what medication they are taking.

"I don't need to know. I just feel like I trust the NHS."

"I think it would be good to know because it might be the NHS but they might have an external organisation holding your data." W1

Unless they had experienced problems with lack of data sharing between clinical settings they assumed that they have one single healthcare record that is accessed by all NHS organisations.

"I was a bit naive, thinking that I just had an NHS record and that was just in one place, one accessible place. I hadn't appreciated that there were so many different systems." W1

They immediately saw the benefits of data sharing for direct care and had no concerns about it. There were discussions on the ability to opt out and about the “break glass” process of accessing records in an emergency. Participants fully supported this. A few talked about how they would like to be able to keep some aspects of their records private. However, the benefits of data sharing for direct care outweighed any concerns about privacy.

When it came to using the YHCR for PHM, participants had more questions. Some found it difficult to understand how their individual records could be used in a way that meant they could not be identified. All the participants were happy that their data is searched but some talked about having friends or family who might object.

“My grandmother’s well into her 80s and there’s absolutely no way she’d consent to information being shared. Whereas I’m a lot happier for information to be used. I work for a large organisation that handles a lot of data so I know about all the GDPR and all the regulations we have to follow.” W2

Some participants talked about important benefits that could arise from analysing datasets. This included being contacted if they were identified as being at risk or as somebody who might benefit from a new treatment. However, others wanted to know who would contact them: they did not want to be contacted “*out of the blue*” by somebody they did not know. They were reassured by discussions with the experts that the contact would usually come from their GP practice.

“I would be very happy if somebody contacted me and said a new treatment has come available for people who have been suffering from migraines. I would be very grateful.” W3

Participants had questions about whether commercial organisations could get access to information, and whether they might profit financially from it. Participants were happy for the NHS to search their records, but several participants talked about how if their anonymous data were shared with commercial companies they would like to know who it is being shared with and for what purpose. Others said that they would *never* be happy if their data were shared with or sold to private companies. They described two concerns. The first is that private companies would make a profit from their data. The second is that they might be identified and contacted.

“We trust the NHS a lot and we respect them. So why wouldn’t you? But if we were somebody we didn’t trust that much we’d be less responsive to sharing the information.” W2

“The NHS has got a very good reputation so I don’t think it’s going to cause any major ripples in the papers.” W3

Participants were reassured by discussions with the experts that the PHM platform does not share anonymised data with external private organisations. Indeed, once they talked through the two examples

of how the PHM platform data could be used, they were very supportive of it.

“I don’t have a problem with my data being found like that.” W2

The first explanation of data flow, which gave clear examples of how information is removed from their records, was reassuring. Participants praised how clear it is and how they like how it states exactly how they will be de-identified.

“It seems like a really good way of using that data. And I think it looks like a secure way of doing it as well. I like that it’s all outlined how it’s been encrypted, how it’s going to be used, who can access it. It looks like a really good thing.” W2

In contrast, the additional information about how their data flows was not valued. Participants found it confusing and they did not understand terms such as pseudonomising. They were not aware of NHS Digital’s National De-Identify / Re-Identify service and were not interested in finding out about it. They did not care that Humber Teaching NHS Foundation Trust is the Data Processor and they did not find this explanation reassuring. It raised questions about who the authorised people are and how often their authorisation is reviewed. Some participants did not like the text about responding to incidents and thought it might worry people about data breaches. They suggested having this level of detail on a separate clickable link for those who want to know more without “spooking people” who might not want to know.

“I think it’s too long. If I saw that I wouldn’t read it because it looks boring and long and I think a lot of people are like that.” W1

“I don’t understand what a lot of that stuff is. I don’t know what a Population Health Management platform is or what a deidentify reidentify service is.” W1

One of the participants expressed concerns that people who no longer work for the NHS could retain their access to records. Other participants discussed whether current NHS staff could look at records of people who they are not caring for. Participants were reassured by the discussion with experts about how access is restricted and also regularly audited.

During discussions we explored participants’ responses to their identifiable data flowing from NHS systems before opt-outs are applied and people are de-identified. The diagrams in Appendix 1 were useful to explain this point, with participants preferring the simplicity of Diagram 1. Most participants thought that the “lego men” people in the diagrams helped them to understand when their records are individual, and when they are grouped. However, participants in one group suggested removing the figures to further simplify the diagram.

“It’s saying that your information’s hidden. When it’s inputted by the healthcare people, they can see it, but then it’s all hidden and you become anonymous: a big group of people.” W1

“I think that’s clear in terms of how it all works. The lego man’s a nice touch because it shows when you’re identifiable, when you’re not identifiable, and when you’re grouped.” W2

None of the participants had any concerns that their data must flow in order for them to be de-identified. They did not want their de-identified data to flow to commercial organisations but they were happy that it flows to the YHCR.

3.2 What information do people want about opting out?

Participants were shown information on opting out of the YHCR. They discussed whether they would read the information and most thought they would not, as they trust the NHS and want to help. They discussed that some people might be predisposed to opt out and they would want to read information on how to do so. A few of the participants worked in schools or colleges and talked about how lots of parents opt out of data sharing because they are in a habit of declining all requests about information sharing, rather than making an informed choice, don’t understand what they are being asked, and don’t understand the impact of opting out.

“I think you’d probably only look at that if you already had it in your head that you wanted to opt out of everything.” W1

They thought that some people might choose to opt out because of concerns about their data being hacked and used fraudulently. They talked about seeing information about HMRC data being used for identify theft and thought that people who want to opt out might be concerned that NHS data could also be used in this way. Most of the participants, however, could see strong advantages in their data being used to help others in their community.

“I think it’s also about helping others in your community with any health inequalities that might be present but you don’t know about.” W1

Only one participant had chosen to opt out using the National NHS Digital opt-out programme. He had done so on the basis of security concerns. During discussions with experts, he explained that he is confident in the security that the YHCR and PHM platform has in place and would not opt out.

Participants thought the text about the potential impact of opting out was clear and that it is important to tell people as it helps them understand the consequences of opting out.

“It certainly focuses your mind a lot more, that you might not get treatment for something that could save your life because you have opted out. It’s certain to make you think twice. And members of your family, it might make them think twice too.” W1

Participants discussed the consequences of opting out locally versus nationally. They held different views, with some believing that they would be less inclined to opt out of the PHM platform as it is more likely to bring local benefits. Others thought that they would be *more* inclined to opt out of the PHM platform as it might not have as much security resources as a national system. One of the participants discussed how he would feel more anonymous in a national system as he is “*a much smaller data point in a much bigger pool.*” and so less likely to be identified.

“I think people maybe trust things that are more local to them a bit more than the national system. The more removed you are from things the less you trust them.”

“I agree with that. You’re more likely to see tangible benefits more quickly locally than on a national system.” W1

Participants were unsure as to why there are two different ways of opting out: the PHM platform requires people to telephone, whereas the National NHS Digital opt-out programme can be done online. They discussed how most people would want to opt out online as it is quick and easy. They thought it is a good thing to provide a telephone opt out service for people who are less confident using the internet, e.g. older people. They assumed that people need to

phone up in order to give NHS staff the opportunity to dissuade them from opting out. However, they discussed how this is not necessarily a bad thing, as people may opt out without sufficient thought about the consequences of doing so, or because of misperceptions of how their data is used.

“I think it is acceptable to ask people to phone. Yeah, I think maybe we need to explain it a little bit because that makes sense that you’re having a rational conversation about what the benefits are or are not. I guess from your perspective you might be able to convert some of the opt outs to opt ins.”

Participants thought that the language used is fairly easy to understand, although they had not come across some terms before, such as de-identified, and they wondered if the general public would know what this means.

“I just wonder about the language, like before today I wouldn’t have a clue about what my de-identified data is.” W1.”

3.3 How do people respond to the Yorkshire and Humber Population Health Management platform?

Survey respondents were shown the explanation of the PHM platform, which was adapted following the co-design groups.

There is a digital platform developed by the NHS and local authorities to help its staff to plan and develop services to meet the needs of the populations.

The technology doesn't collect data automatically - it only allows qualified and authorised staff to search for data so they can analyse it. The data they have searched is sent electronically to the platform. Before the person can view it, all information that identifies you is removed, e.g.

- Your name and address is removed
- All free text, e.g. notes made by doctors, is removed
- Your date of birth is deleted and replaced with your year of birth
- Your NHS number is encrypted so you can not be identified.

This is done by the National De-identification system. Your de-identified data will return back to the secure platform which is only accessed by authorised individuals. Access to the platform is securely controlled and the list of people who have access is checked regularly. The security controls built into the platform ensure we can detect and respond to any incidents that may occur.

They were asked if they are happy to let their de-identified data to be searched.

- 83% said yes
- 7% said no
- 10% said they weren't sure.

If they said no or were unsure they were asked why. Their reasons are shown in Table 1. The number of people who gave this reason is shown in brackets.

Table 1: Reasons why people would not want their information to be searched.

I have security concerns (17)	I don't want my personal details to be released (11)
I don't trust the de-identification process (11)	I don't want any data about me released (9)
I don't trust it (6)	I don't know enough about it (4)
I'm not sure or I don't trust who the information will be shared with (4)	I don't understand how the information is useful (4)
I don't want my data to be used (2)	I don't understand it (2)

I don't understand why Local Authorities are included (2)	I don't want companies profiting from publicly held data
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We ran a chi squared test to find out if ethnicity, age, or having a disability might affect willingness to have your data searched. There is a statistically significant association between willingness and ethnicity (chi squared = 6.8, p = 0.01) so that people from ethnic minorities are less likely to be happy for their data to be searched. There is also a difference based on disability, so that if people have a disability they are more likely to be happy to have their data searched (chi squared = 5.8, p = 0.02). There are no age- or gender-related differences.

Respondents were shown information on how to opt out and asked if they would opt out of the PHM platform. This was the same text used during the co-design groups.

- 70% said they'd stay in
- 12% said they'd opt out
- 18% said they weren't sure.

If they said no or were unsure they were asked why. They gave similar reasons to those in Table 1. Some of their quotes are shown below.

"Don't understand this, need someone to explain it better to me."

"The wording isn't 100% clear - de unidentified is a bit of a unusual way to word it."

"I don't want anyone to know about me or use my data for statistics."

"I have no wish for my information to be used anywhere by anyone!"

"I think it would be better to protect my data and privacy to keep it from being misused."

"I would need to know more about it and what its intended use would be and how secure it actually was to ensure it doesn't get leaked into the wrong hands."

"It only takes one person to be tempted by a commercial offer and information could be widely distributed."

"I am not really sure, however, anything digital today can be worrying. I would be unsure as to whether something I had on my file could be misinterpreted."

If, however, this helped people in the long term and this could not happen, then I would be more likely to agree to this."

We analysed any demographic differences in intention to opt out. There is a statistically significant association between intention to opt out and ethnicity (chi squared = 13.5, $p = 0.001$): 11% of White British people would opt out versus 27% of people from an ethnic minority. There are no differences based on disability or age.

Respondents were also asked if they would opt out of the National NHS Digital opt-out programme programme.

- 71% said they'd stay in
- 11% said they'd opt out
- 18% said they weren't sure.

If they said no or were unsure they were asked why. Their reasons were similar to those behind opting out of the PHM platform.

There is a statistically significant association between intention to opt out and ethnicity (chi squared = 12.0, $p = 0.001$): 10% of White British people would opt out versus 25% of people who are not White British.

There is a difference based on age, with people in the 18-24 (13%) and 25-44 (18%) groups being slightly more likely to opt out than those in the 46-64 (10%) and the 65+ (7%) groups. There are no differences based on disability or gender.

However, a binary logistic regression combined age, ethnicity, disability and gender into a single analysis and showed that ethnicity (Exp $\beta = 0.44$, $p = 0.025$) is the only independent predictor of opting out of the national system, with the effects of age no longer significant (Exp $\beta = 0.7$, $p = 0.08$) when controlled for by ethnicity.

Respondents were then shown the text on the impact of opting out. This was the same text used during the

co-design groups. They were asked if this made any difference to their views on opting out.

- 69% said it's even more important to stay in
- 5% said it's even more important to opt out
- 26% said it hadn't made a difference.

They were asked if it made any difference to how they feel about the platform. They could choose from feeling more positive or negative about it, more concerned or more reassured about it, and that it hadn't change how they feel about it. They could select more than one answer.

- 42% said they feel more positive about it
- 4% said they feel more negative about it
- 15% said they feel more reassured about it
- 9% said they feel more reassured about it
- 36% said they haven't change how they feel about it.

They were asked to select words that describe how they feel about the platform and could select more than one word.

- 44% feel protected
- 27% feel happy
- 27% feel enthusiastic
- 19% feel worried
- 8% feel proud
- 5% feel threatened
- 5% feel annoyed
- 2% feel sad.

Respondents were told that platform is a safe digital space that allows the NHS and local authorities to analyse the health and care needs of people who live in the region without seeing anybody's identifiable details. They were asked what the platform should be called. They could choose from a list of suggestions and could also suggest their own.

- 42% chose NHS Data Safe
- 35% chose NHS Health & Care Improvement Platform
- 4% chose Secure Information Platform
- 4% chose Safe Harbour

- 3% chose Safe Information System
- 2% chose Information Harbour
- 2% chose Data Haven
- 1% chose Intelligence Harbour

29% made an alternative suggestion. A few of these demonstrated suspicion about the platform, e.g. Big Brother Snooper Platform, Spyware, and Gross Intrusion. Others were more serious, and most involved the term NHS, e.g.

- NHS Care Improvement Platform
- NHS Data Platform
- NHS Health and Care Improvement System
- NHS Harbour
- NHS Systems
- NHS Secure Insight Portal
- NHS Regional Data
- Safe Patient Database
- Secure Information System
- Yorkshire and Humber Health Analytics

4. Conclusions

Our research has explored how people would respond to the Yorkshire and Humber Care Record being used for direct care and for research and planning.

- People have few concerns about data sharing for direct care.
- Most of the concerns around using data for research and planning are because people don't understand how or why their de-identified data could be used. Explanations of the population health management platform therefore need to be accompanied by a simple example of how de-identified data can be useful.
- Some people want to know more about data security before they are willing to trust the platform, so should be able to access details.

This should be on a supplementary page/document to prevent overloading the majority who do not want this level of detail.

- The higher percentage of people from ethnic minorities who would opt out of both Yorkshire and Humber and National programmes is concerning and could lead to greater health inequalities. While all the co-design groups contained people from ethnic minorities, more research exploring their concerns and how to overcome them would be valuable.
- People do not object to information about potential negative impacts of opting out, and indeed, they believe it is important for people to know this so that they can make an informed choice about opting out.
- A higher proportion of our respondents stated that they would opt out of the national programme than have actually done so. This might be because they don't know there is a national programme or how to opt out of it, or because not everybody who intends to opt out actually does so. There is a danger that raising their awareness of opting out will lead to increased numbers who do so, especially if opting out is as simple as clicking a box.
- Participants in our co-design groups preferred to be able to opt out digitally but thought that providing this option would risk people opting out without understanding their decision. Overall, they saw the benefits of speaking to a person about their concerns so that there is the opportunity to address any misperceptions.

Appendix 1: Diagrams used to explain data flow

Diagram 1

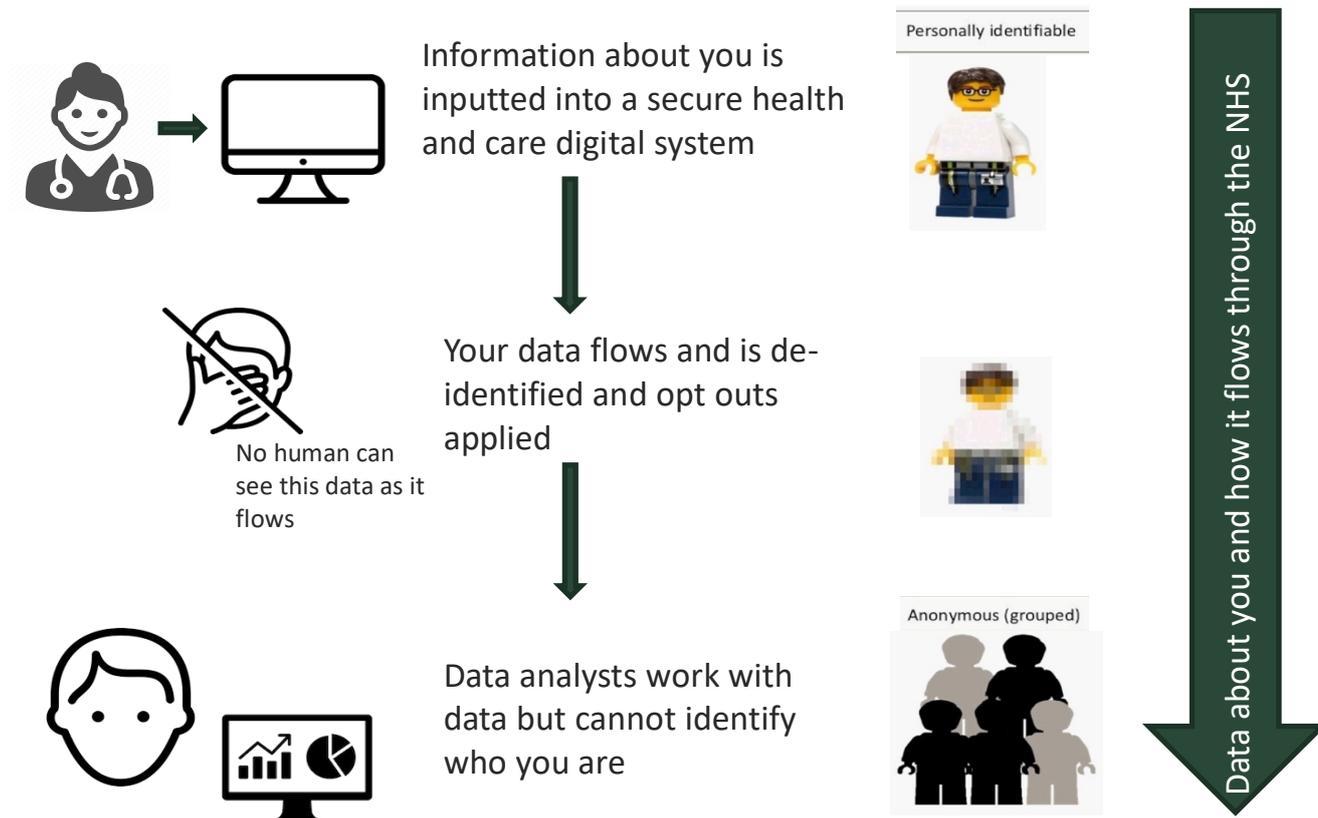
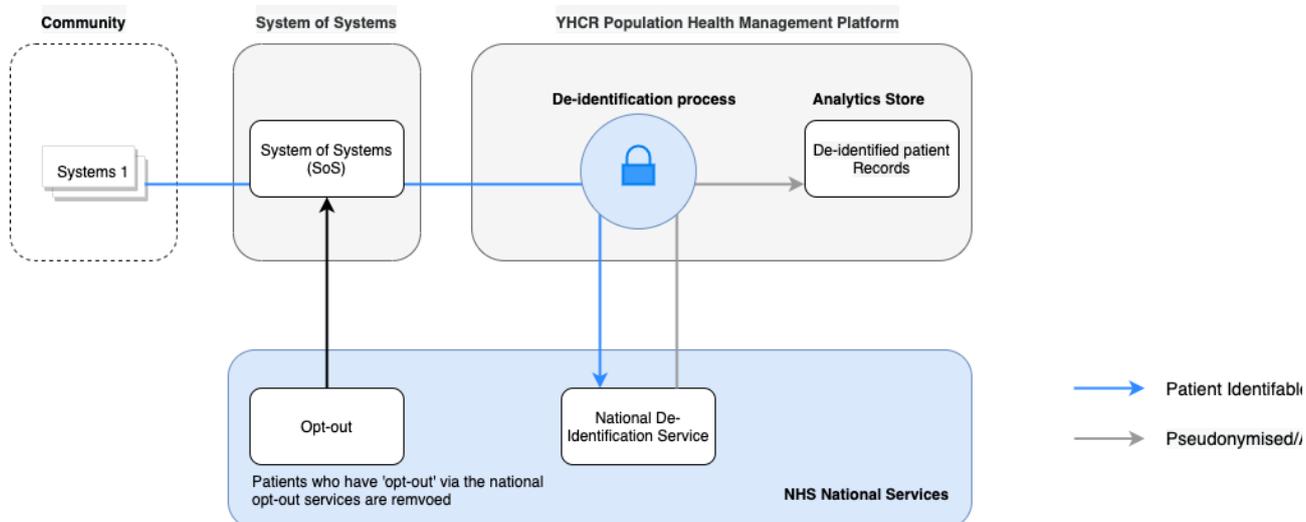
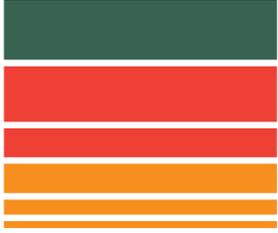


Diagram 2



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