



Yorkshire & Humber  
Care Record

# Joined Up

## Yorkshire & Humber

Explaining Population  
Health Management

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# 1. Executive Summary

The Yorkshire & Humber Care Record is a digital care record which enables clinical and care staff to access real-time health and care information. It also provides intelligence that can be used to tailor care to the needs of local communities and to predict and plan future care needs. This approach – Population Health Management – has the potential to help people stay healthy and to ensure that the care provided in a community meets its current and future needs. Population Health Management and data security and privacy are difficult concepts to explain to people yet will become increasingly important in how healthcare is planned and delivered. We have worked with people in Yorkshire and the Humber to co-design and test explanations of these concepts.

There were three phases to the research. The first was based on three co-design workshops to create the explanations and identify the best examples of Population Health Management. The second was based on a series of five focus groups and four paired interviews to gain insight into people’s understanding of staying healthy, and their potential response to population health activities. The final stage was a survey of over 1000 people across Yorkshire and Humber to test the explanations, identify any concerns they raise, and their support for different population health activities and outcomes. We found that most people prefer very short, clear and simple explanations, described below.

### Data security and privacy

We use international security and privacy standards that provide the highest possible level of security. To help improve the health of people in our area we analyse data from health and care records and share data with other Public Sector organisations. The data does not include your name or anything that could identify you. All these organisations are required to abide by strict data protection law.

### What is Population Health Management?

It helps us understand people’s health and care needs and how they are likely to change in the future. We share information, resources and goals and tailor services to the needs of people in the local area. This helps us to improve health, prevent illnesses and make better use of public resources. It involves the NHS and other public services including councils, schools, housing associations and social services.

Population Health Management can be further explained using **an example**: Emily is 5 years old and has asthma. Population health data shows that there are lots of people with asthma who live in her area. To find out why, information on air quality was obtained from the Department for the Environment. Information on housing quality was obtained from the council. This showed that the traffic on the nearby road was causing poor air quality, and that homes on Emily’s estate were poorly insulated, making them cold and damp. The council agreed to insulate the homes, and also to start a “no idling” campaign to encourage motorists to turn off their engines, which will improve air quality. They hope this will mean that fewer people have asthma attacks.

Fewer than 10% of people had concerns about data security and privacy, most commonly the potential for data breaches and data hacking and the possibility of data being sold. People were also concerned that the data used may not be accurate and up to date. Participants understood that Population Health Management helps to provide the most appropriate services in an area but they struggled to understand why people who would benefit from a service are being identified from data analysis rather than by their GP. There was support for the range of potential population health outcomes, including resources being diverted from healthier areas to those areas with more ill health but many participants were uncomfortable at the idea of being “singled out” as a problem. Instead, they thought it would be better if people in a community, rather than individuals, were invited to make use of a new facility, clinic, or screening test.

As in previous research, we have found that people trust the NHS more than Public Sector services, and that younger people have more trust than older ones. This research provides additional insight that can be used when planning future Population Health Management activities and we have included a series of principles that can help guide future work.

# 2. Background

The Yorkshire & Humber Care Record 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 connected through a secure computer system and so can be accessed by different care providers regardless of the computer system they use. This has clear benefits for direct/individual care, but it also provides intelligence that can be used to tailor care to the needs of local communities and to predict and plan future care needs. This approach – Population Health Management – has the potential to help people stay healthy and to ensure that the care provided in a community meets its current and future needs.

Throughout its development, the Yorkshire & Humber Care Record has put people at the heart of everything it does, for example involving them in deciding how their data should be used, and in co-designing principles for data sharing. This earlier research has shown that while there is strong support for the Yorkshire & Humber Care Record, people want clear and simple explanations of how secure their data is, and who will have access to it and for what purposes. A recent piece of work produced by YouthWatch in Leeds shows how much jargon is used when talking about health and care records and data security, and how little of it even young people understand. A video of young people talking about what they understand by these terms, and producing a clearer version of them, is available at:  
<https://yhcr.org/resources/citizen-engagement/>



Previous research for the Yorkshire & Humber Care Record also shows that people are unaware of the role that local councils play in providing and planning care services. While they support data being used to plan services, some people recognised that this could lead to a decrease in services in some areas, alongside an increase in others. Reducing health inequalities is a core part of council and NHS plans, and so it is likely that data from the Yorkshire & Humber Care Record will be used to divert preventative health measures to the more deprived areas of the region. We don’t currently know how people will respond to this: both those who are likely to see a reduction in services and those who are likely to see an increase.

This research was therefore commissioned to develop explanations of the terms used when talking about data sharing in the Yorkshire & Humber Care Record. It also generates insight into how people are likely to react to services in their area changing as they adapt to the needs of the local population. The output of the research is a set of explanations that clearly and simply explain these fundamental concepts used in the Yorkshire & Humber Care Record, and recommendations for any elements that need to be tailored to different groups of people.

In line with the Yorkshire & Humber Care Record approach of involving people in creating services the research takes a co-design approach. Together with people in the region, there is a need to create explanations for:

- Population Health Management and how it means that local services adapt to people’s needs
- Data security: how people’s records are kept safe and how secure they are compared to other sensitive records, such as bank details and HMRC records
- Data privacy: who has access to identifiable and unidentifiable records



3. Methods

There were three parts to the research, described below.

3.1 Qualitative co-design phase

We held three co-design workshops with members of the public. They took place in three different areas of the region, as shown in Table 1, and each lasted two hours. They were audio recorded and transcribed verbatim. In advance of the workshop, the Yorkshire & Humber Care Record team developed three draft explanations of population health management, two of data security and two of privacy. During the workshops, participants were grouped into twos or threes and discussed the explanations in these small groups before sharing their views in a whole-group discussion. Participants focused on how understandable the explanations are, their perceived relevance, any questions or concerns they generate, and how to address them. Participants worked together to generate better explanations that addressed the issues that are important to them, using language that is easy to understand. They also discussed several examples of how Population Health Management might be used, shown in Box 1.

Two of the workshops were recruited using a fieldwork agency to be representative of the demographics of the local population. The third was set up by HealthWatch Sheffield, with participants who were on the Improving Accountable Care Forum.



Table 1: Participants in the co-design workshops

Area	Participants	Background
Scarborough (CDW1)	7 participants: three females, four males. Age range 27-61, median 40.	All participants were working age adults, and three had existing health conditions. All were employed or self-employed.
Castleford (CDW2)	8 participants: five females, three males. Age range 29-62, median 43.	All participants were working age adults, and four had existing health conditions. All were employed, and one worked as an information manager in a Public Sector organisation.
Sheffield (CDW3)	12 participants: five females, seven males. Age range 31-91, median 65.	Participants were all on the Health Watch Improving Accountable Care Forum and were familiar with terms such as anonymous and pseudonymous data. Most were retired and most had existing health conditions.

Box 1: Population Health Management examples

Mo is 41 years old and works in an office on a business park. He has three small children and is always too busy to exercise and he has been putting on weight over the last couple of years. Population health data shows that many people are in a similar situation: they are getting heavier and less active and we know that this can lead to diabetes and many other health conditions. Because of this the NHS is working with the local authority to set up free exercise sessions based in local business parks.	Lisa is 48 years old and has recently been diagnosed with breast cancer. Her treatment involves chemotherapy, which will increase the chances of her having osteoporosis and an early menopause. The hospital will share her details with a community care team who will give her advice about how she can change her diet and exercise to protect herself from osteoporosis and to cope better with any symptoms of menopause.	Michelle is 74 years old and is unsteady on her feet. She recently fell and broke her wrist, and a district nurse has been visiting to change her bandages. The district nurse noticed that Michelle doesn't have a fire alarm, so she contacted the Fire and Rescue Service to request one for her. The Fire and Rescue Service fitted an alarm and gave Michelle other advice about how to reduce the risk of fire in her home.
Jim is 68 years old and lives with his wife. They are both healthy and go to the local leisure centre at least four times a week. Population health data shows that adults in his area are less likely to have heart disease and, on average, live 12 years longer than people in other areas. Because of this, the number of blood pressure clinics run in the area is reduced from five a week to two a week. The money saved is used to increase the number of clinics in other areas where heart disease is more common.	Emily is 5 years old and lives with her family in a rented home on a local authority estate. Emily has asthma. Population health data shows that there are lots of people with asthma who live in her area. To find out why, information on air quality was obtained from the Department for the Environment. Information on housing quality was obtained from the local authority. This showed that the traffic on the nearby road was causing poor air quality, and that homes on the estate were poorly insulated, making them cold and damp. The local authority agreed to insulate all the homes on the estate, and also to start a "no idling" campaign to encourage motorists to turn off their engines which will improve air quality. This will mean that fewer people have asthma attacks.	Sam is 52 years old and has diabetes and depression. Population health data showed that there is a high level of diabetes complications in people living in Sam's area: more people are losing their sight and at risk of limb amputations because their diabetes is not well controlled. It also showed that people who have both depression and diabetes are more likely to have diabetes complications. The NHS set up a clinic in Sam's area that helps people with depression and diabetes to manage their conditions. The data doesn't show <i>who</i> has both diabetes and depression but it does show which GP practice they are at, and the GP practice can identify individuals. The GP practice can therefore send Sam an invite to the clinic.

3.2 Qualitative insight-gathering phase

In this phase we explored people's response to the co-designed explanations of Population Health Management and data privacy and security. We included people in more deprived areas who are likely to see services increase and also those in affluent areas who are more likely to experience a reduction in services. We held a total of five focus groups, summarised below and with details in Table 2. All participants were recruited by a fieldwork agency to meet the inclusion criteria and to be representative of the local area demographics. The focus groups were with the following.

- 1. Two groups with people who live in areas of higher deprivation, and who are therefore likely to experience more health problems and to die younger, and who may in the future have greater access to services.
- 2. Two groups with people who are already experiencing health conditions or with lifestyle behaviours or situations that could limit their life expectancy, and therefore could receive targeted interventions based on combined datasets and intelligence.
- 3. One group with people who live in affluent areas and who are currently in good health, and so may in the future have reduced access to services.



### 3. Methods cont.

Table 2: Participants in the focus groups

Location	Participants	Background
Hull (FG1)	6 participants: three females and three males. Age range 26-55, median 37.	These participants lived in areas of Hull with high levels of deprivation. Most also engaged in behaviours that could cause future health problems. Two were employed and four were not working.
Hull (FG2)	6 participants: three females and three males. Age range 31-57, median 36.	These participants all engaged in behaviours that could cause future health problems such as: drinking at least twice the recommended units of alcohol; smoking; overweight and a sedentary lifestyle; or a diet based on takeaway foods. Four were employed and two were mature students who combine childcare or employment with studying.
Leeds (FG3)	6 participants: three females, three males. Age range 27-65, median 36.	These participants lived in areas of Leeds with high levels of deprivation. There was a mix of employed, self-employed and people who are full-time carers.
Leeds (FG4)	6 participants: four females, two males. Age range 42-67, median 49.	These participants lived in an affluent area and did not have any current health conditions. There was a mix of retired and working people and stay-at-home parents.
Doncaster (FG5)	5 participants: two females, three males. Age range 31-55, median 40.	These participants all engaged in behaviours that could cause future health problems such as: drinking at least twice the recommended units of alcohol; smoking; overweight and a sedentary lifestyle; a diet based on takeaway foods. Three were employed, one not working and one was a carer.

We also conducted a series of four paired interviews (Table 3). We included people who are carers, people not originally from the UK and who do not have English as a first language, people who are busy parents, and people whose social life is based on drinking alcohol with friends. The interviews took place in people’s homes, which allows us to explore how context might affect their health-related behaviours and potential response to future population health initiatives.

Both focus groups and interviews explored participants’ understanding of and response to the explanations of Population Health Management and data security and privacy, and their potential responses to Population Health Management initiatives. We also explored the barriers they anticipate experiencing to being healthy, to engaging with the services provided and how communication around changes can be framed in such a way to encourage engagement. Each focus group and interview lasted around an hour and was audio recorded and transcribed verbatim.

Table 3: Participants in the paired interviews

Area	Participants
Bradford (I1)	Sisters (age 59 and 61) who live nearby one another, with the younger a carer for her older sister. One works and one has a disability and does not work. They have lived in Bradford all their lives.
Leeds (I2)	A couple (age 55 and 50) who have been living in Leeds for four years and who are seeking Asylum, having left their home in Palestine. Their first language is Arabic, and the female is fluent in English and at times translated for her husband. They live with their teenage son. She volunteers as a translator and English teacher because they are not allowed to take paid employment..
Doncaster (I3)	Two male friends (age 40 and 44) who live nearby one another and who socialise in the pub and in one another’s homes and drink at least twice the recommended alcohol intake. One lives alone, with children visiting alternate weekends, and one lives with his three children. Both have long-term health conditions. One is employed and one self-employed
Barnsley (I4)	A couple (age 47 and 43) who have been living in Barnsley for 10 years. They live with their two children, and both work as data specialists.

### 3.3 Quantitative phase

In this phase we tested the explanations developed in the earlier stages with a larger group of people in an online survey. We also examined the extent to which they trust the NHS and other Public Sector partners with their data, and we explored any concerns they had about using health and care records for Population Health Management purposes. We recruited participants using the Yorkshire & Humber Care Record networks, and through a panel organisation.

A total of 1,144 people completed the survey: 52% from West Yorkshire and Harrogate; 24% from South Yorkshire and Bassetlaw; and 24% from Humber, Coast and Vale. 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.

Respondents were not required to give demographic details, but of those who did, there were more females (60%). There were also more people with white ethnicity (92%) than on the 2011 census (86%). There was a good mix of ages, shown in Figure 1.

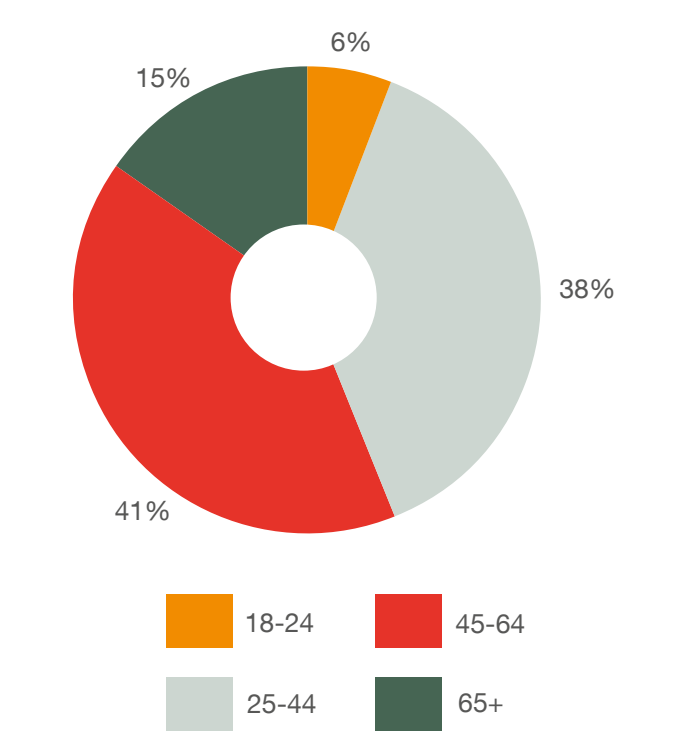
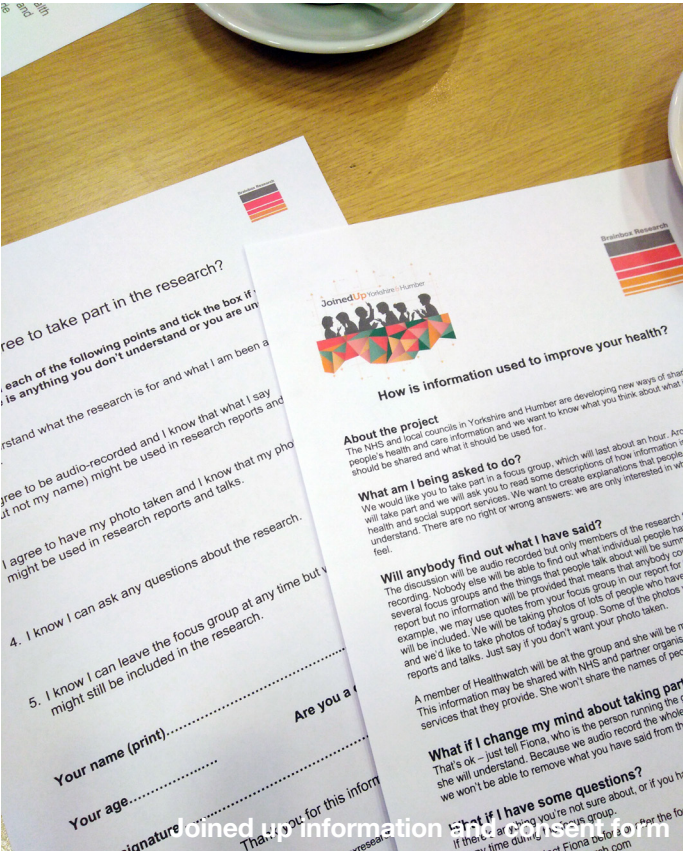


Figure 1: Age groups of survey respondents.



Respondents were asked about any health conditions or disabilities and 37% reported having at least one.

- 14% reported they have a long-standing health condition such as diabetes, cancer, HIV.
- 12% reported they have a mental health condition.
- 9% reported they have a physical disability or difficulty.
- 2% reported they have a visual difficulty and 2% a hearing difficulty.
- 1% reported that they have a learning disability or difficulty.
- 7% reported that they have another disability.

### Ethics

The research took place in accordance with the British Psychological Society Code of Conduct and Ethics. Participants in the qualitative stages were made aware of the purpose of the research, and how their information will be used. They were given the opportunity to ask questions about the research and were assured of their anonymity. They were able to contact the researchers after the research sessions should they have any queries or concerns. All gave written informed consent to take part. The online survey provided sufficient information to enable respondents to make an informed choice about taking part. Submission of their responses at the end of the survey was assumed to be consent to take part, and respondents were given contact details should they have any queries or concerns.



# 4. Results

The results are presented in three sections. The first describes the process of co-designing the explanations of Population Health Management and data security and privacy. The second explores participants’ responses to potential changes to services that Population Health Management might bring about. The third presents the findings from the survey about the explanations, about who should be able to access de-identified data and any concerns that people have.

## 4.1 How can we explain Population Health Management?

Participants discussed one of the explanations in small groups of two or three before feeding back to the rest of the group their understanding of the term, and their views on the good and bad elements of the explanation. There were three versions of the Population Health Management explanations. Two were based on text, and one on a diagram, taken with permission from the NHS England website.

**EXPLANATION 1:  
What is Population Health Management?**

Our health and care needs are changing: our lifestyles are increasing our risk of preventable disease and are affecting our wellbeing, we are living longer with more multiple long-term conditions like asthma, diabetes and heart disease and the health inequality gap is increasing.

A new approach – called Population Health Management – is helping us understand our current health and care needs and how they are likely to change in the future so we can take action in tailoring better care and support with individuals, design more joined up and sustainable health and care services, and make better use of public resources.

This involves analysing data to understand what factors make people unwell so that we can design new proactive models of care which will improve health and wellbeing today, as well as in 20 years’ time. This could be by stopping people becoming unwell in the first place, or where this isn’t possible, improving the way the system works together to support them.

Population Health Management is a partnership approach across the NHS and other public services including councils, the public, schools, fire service, voluntary sector, housing associations, social services and police. All have a role to play in in addressing the interdependent issues that affect people’s health and wellbeing. In practice, it should mean that health and care services are more proactive in helping people to manage their health and wellbeing, provide more personalised care when it’s needed and that local services are working together to offer a wider range of support closer to people’s homes.

**EXPLANATION 2:  
What is Population Health Management?**


Population Health Management is finding out who is at risk of an illness or accident and putting things into place to prevent it happening. This involves:

- Analysing different datasets, such as health records, environmental data, and local authority information.
- Enabling professionals to work together by sharing information, resources and goals.
- Encouraging and helping people to stop doing things that damage their health and start doing things that protect it.

Changing the services provided in an area based on the current and future needs of the people who live there.

Yorkshire and Humber is developing a new, region-wide information and analytics service to make use of new datasets that are available for Population Health Management.

## EXPLANATION 3: What is Population Health Management?



# A quick guide to population health management

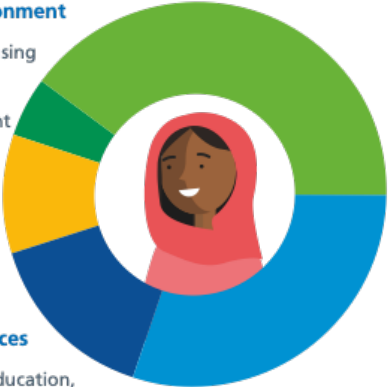
## How can it help you?

**Our health and care needs are changing: we are living longer with more multiple long-term conditions like asthma, diabetes and heart disease.**

Much of this is down to lifestyle factors and where we live rather than the health and care services treating us.

Population health management helps us understand and predict future health and care needs so that we can better target support, make better use of resources and reduce health inequalities.

**Which factors impact your health?**



**Our environment**  
**5%** housing quality and our built environment

**Healthcare**  
**10%** being able to access good quality care

**Social and economic circumstances**  
**15%** education, employment, income, family/ social support, community, safety

**Our behaviours**  
**40%** smoking, diet, alcohol use, poor sexual health

**Genetics**  
**30%** your genes can directly cause or increase your risk of developing a wide range of medical conditions



**What is population health management?**

The NHS and its public sector partners use expert analysis of data on factors like health, housing, employment and where people live as well as current medications.

They can find new insights about specific groups of people and whether they are being seen by the right professionals.

Expert medics, clinicians and public health professionals assess the data and can tailor care better to those patients.

Past public health research shows this personal care improves physical and mental health and reduces health inequalities.

**Why does it matter and who is involved?**

To solve wider issues impacting people’s health, expert insights take a more complete snapshot of a person’s needs and environment.

All our public services are involved • the NHS • the public • schools • fire service • councils • voluntary sector • housing associations • social services • police.

**Each year lifestyle and environmental factors cost the NHS**


**£11 billion**

**Impact of social and economic inequalities costs a further**

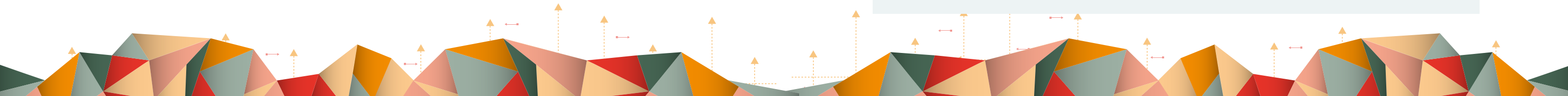
**£4.8 billion**

**A flavour of what’s been achieved so far**

- In Lancashire and South Cumbria they used data on households with assisted bin collections to find frail patients in need of more proactive personalised care to keep them living well at home.
- In Leeds analysis pinpointed 80 patients with frailty at risk of further problems - they now get better personalised care to stay well, active and independent.



Population health management is a key building block in the development of integrated care systems. To find out more visit [www.england.nhs.uk/integratedcare](http://www.england.nhs.uk/integratedcare) #futureNHS #datasaveslives



4. Results cont.

- Discussions in the groups reveal the following:
- Participants support data sharing for Population Health Management purposes and assume that data is already shared between organisations for the purpose of planning services. Nevertheless, many talked about how they had experienced situations in which the lack of data sharing has led to services being inappropriate and most talked about how there should be more, or more effective, data sharing.
  - Participants could recognise the benefits of different organisations sharing information, resources and goals.
  - Participants assumed that data is shared about individuals and few had considered how de-identified data might be shared to generate intelligence about the needs of an area.
  - Participants were aware that statistics on how many people have different conditions are collected and used in some way. They were comfortable with “being a statistic” in this way.
  - Participants liked the colours of the diagram in Explanation 3 and the statistics it includes but they did not read the text because it was too long. They found the information about what impacts your health interesting but did not understand how this related to Population Health Management. When encouraged to read the text, they did not understand how the different examples related to one another.
  - Participants preferred the shorter explanations and read all the text they contained.
  - Participants described Explanation 2 as being vague.
  - Many participants were sceptical of whether Population Health Management would lead to additional services. Many talked about how there had been valuable support services in their area but they had stopped because funding had been withdrawn.
  - There was no recall of the “National Opt Out” programme, which is a service that allows patients to opt out of their confidential patient information being used for research and planning.

**“Seriously, I’m not reading that! (Explanation 3)” (CDW2)**

**“Because there’s so many people involved at the moment and it’s so disjointed between all the services, it’s not getting shared properly. And people aren’t talking properly so we’re not getting the right services because nobody’s getting together in a big bunch and talking about what we need.” (CDW 1)**

**“We used to have lots of support, lots of prevention activity, we used to have loads of children and families, adult mental health things that are gone, cancelled. That just disappeared.” (CDW 1)**

**“Most people are aware to some extent that they’re a statistic, because statistics exist. Like we hear all these things all the time on the news like 70% of so and so’s a so and so.” (CDW1)**

**“If you had a joint venture with the NHS doing a public health campaign about healthy living and anti-drugs and the housing authority are working with local tenants and there’s schemes to tackle unemployment in the area and boost education and everyone’s working together on a joint venture, sharing that data, that’s a positive use of that data.” (CDW1)**

Participants discussed the different examples of how Population Health Management could be used and the following points were made:

- Many participants described being uncomfortable at the idea of being “singled out” as a problem. Instead, they thought it would be better if people in a community, rather than individuals, were invited to make use of a new facility, clinic, or screening test.
- Participants talked about how if an individual is identified as being at risk then their GP should contact them. They would not want a private company, e.g. a gym, to contact them to discuss their health risks.
- Participants talked about it being important that individuals are offered help to change their lifestyle, rather than being forced to make changes. They wanted a choice about whether to make any changes.
- Some participants were concerned that data on at-risk individuals might be made available to private companies, who could contact people to offer them help or to sell medicines.
- Participants were particularly wary of data about mental health being shared. They were also concerned that if somebody with depression were to be contacted because they were at risk, this might exacerbate their depression. They were also concerned that people with obesity could feel blamed and targeted.
- Participants found the Emily example of Population Health Management easiest to understand as they could see how data from different organisations had been combined to generate new knowledge. This knowledge was used to identify an area, rather than a person, as being high risk, and they felt comfortable with everybody in the area having improvements made to their home, rather than a few individuals. Participants understood that Population Health Management helps to provide the most appropriate services in an area, but in many of the examples (Box 1) they struggled to understand why people’s needs were identified from data analysis and sharing, rather than a professional referring them to relevant support services.
- Participants talked positively about allocating greater resources to areas with more health challenges but were concerned about how big each area might be. They highlighted that if the area were “South Yorkshire” or “Humberside”, then there are large differences between different parts of these areas, so that while overall people might face fewer health challenges than people in other parts of the country, those in more deprived parts of the areas might suffer as a consequence of cuts to services and facilities.
- Participants also had questions about how flexible budgets might be to address the health challenges in a particular area. They wondered whether if an area has a problem with poor quality housing, NHS money could be used to build new homes.
- Participants were concerned that the data used to make Population Health Management decisions needs to accurate and up to date. They highlighted that the demographics of an area can change quickly, for example if new houses are built, and so the decisions about what services should be provided could be wrong.





4. Results cont.

*“If you go to your doctor and you talk to your doctor about putting on weight and your doctor gives you suggestions to diet and exercise, that’s one thing. But a random company contacting you because they know you’ve been putting on weight is worrying.” (CDW1)*

*“You’ve got to consider how people would take it, as a person who suffers with that mental health issue, it might be quite upsetting to receive that letter to say, you are depressed.” (CDW1)*

*“This seems to be unnecessarily complicated. If Sam’s GP is aware of these issues, why not refer Sam to the clinic? Why does it have to be a population data thing? The purpose of this is to get Sam to the clinic. It doesn’t have to involve any population health data.” (CDW3)*

*“There’s nothing there identifiable about that individual person [in the Emily example]. It’s an area where this is happening a lot to a lot of people. There’s no specific demographic, like age demographic, or anything to do with that.” (CDW1)*

*“If the letter came through I’d feel a bit singled out, if it was directly about these two related issues [diabetes and depression] rather than just a whole thing. I think sending an invite like that, it just feels a bit singled out.” (CDW2)*

*“How does the data stay relevant? In five years the population in a small area can change drastically, e.g. a school could be built or a new old people’s homes.” (CDW3)*



Alongside the purpose of population health management, it is also important to explain how people’s data is kept secure, and about privacy. The two draft versions of the data security explanations used in the research are shown below.

**DATA SECURITY EXPLANATION 1:**  
**Data security**

Ensuring all data is secure is our number one priority. All data will be encrypted, stored securely in the UK and will not be used for any other purposes beyond Population Health Management. We control the data and will only offer access if it meets our strict instructions. The systems used are resilient and adhere to international security and privacy standards that are certified and validated by independent auditors.

**DATA SECURITY EXPLANATION 2:**  
**How do we keep your records safe?**

- We use firewalls to prevent unauthorised people from accessing your data.
- We encrypt your data using internationally approved standards so that only authorised people can read it.
- We back data up so that it can’t be lost should there be IT problems.
- We review our security methods regularly to make sure that they are kept up to date. Our methods are checked by independent experts to make sure that they provide the highest possible level of security.



Discussions in the groups reveal the following:

- Participants described Data Security Explanation 1 as being too vague and as using too much jargon. Overall, this explanation did not make them feel confident about data security. They also talked about some elements of this explanation being confusing, such as the reference to strict instructions.
- Mention of specific processes in Explanation 2 gave some participants a greater degree of confidence in how secure the data is. However, others suggested that this provides too much information and they do not want or need to know specifics. Several participants suggested that older people may not understand terms such as firewalls or encryption.
- However, participants discussed how no data system can be 100% secure and suggested that the explanations might make people over-confident in the level of security provided. They discussed whether providing more details about the steps taken to protect against hacking would be useful but most concluded that this would make the explanation too long and too difficult to understand.
- Some participants were concerned about the mention of independent auditors in Explanation 1 and assumed that if the NHS is using external experts then they must not have the necessary in-house expertise to keep data secure.

*“The first one seems almost soft, like they’re saying please believe us that we’ll keep your data safe. And it’s not convincing and this sentence saying we will only offer access if it meets our strict instructions. And I don’t know what it means by strict instructions.” (CDW1)*

*“Out comes my cynic side of me again. You just hear that many things on the TV, on the radio, you know about data goes missing. You know, all our files are backed up but why have you lost them. That doesn’t reassure me that my data is safe.” (CDW2)*

*“They don’t actually need to tell you all that waffle, really. If they just sort of said your data is safe.” (CDW2)*

*“I preferred the second one. It was a lot clearer in what the points were making. I liked the highest possible level of security, I liked that the methods were kept up to date; methods are checked. It just seemed a lot clearer for me reading it. I just felt more trusting in this one.” (CDW2)*

*“I don’t need to know any of that. I don’t need to know because there’s firewalls, I know what firewalls are, and surely a lot of people that are involved or visit the NHS are older people. Is an 89-year-old person going to know what a firewall is? And an encryption of the data and to back up all. I just need to know it’s safe. It’s all you need to tell me. I don’t need to know how it’s safe. (CDW2)*



4. Results cont.

The two draft versions of the privacy explanations are shown below.

**PRIVACY EXPLANATION 1**

All organisations that work with personal data abide by strict rules and law set out by GDPR. In compliance with applicable regulations, the data collected and used will remain in the hands of the NHS and local councils.

**PRIVACY EXPLANATION 2**

To help improve the health of people in our area we analyse data from your health and care records and share it with others who provide services. Only authorised organisations are given this data and they all abide by GDPR. We protect your privacy by only releasing small parts of your records, such as how many visits to A&E you have made and what health conditions you have. We never release your name and we make sure that you can't be identified. This means that you won't be contacted by organisations trying to sell you products.

*"I just think it's really quite lengthy and if you were given that to read then I think there's a lot of information for some people to digest and take it in." (CDW2)*

*"I prefer the first one – it's a lot more concise, and it has that information there as to who is going to be using the data." (CDW2)*

*"I wouldn't expect to go to my doctor and then someone try and flog me something in the post. It would not even enter my head that that'd happen. So, can they?" (CDW2)*

*"All organisations that deal with personal data \*should\* abide, but there is nothing to say that they do. The description should say that "they are required to" not that they do." (CDW3)*

- Discussions in the groups reveal the following:
- Most participants recognised that the data privacy explanations relate to other GDPR notices that they have encountered. They highlighted that they don't normally bother reading the "small print" on GDPR notices, so it was unusual task to think about what should be included in a privacy notice.
  - Participants liked the explanations to be clear and simple.
  - There was a preference in two of the three workshops for very brief explanations. Participants in the third one (CDW3) preferred a greater level of detail.
  - Several participants noted that nobody can guarantee that all organisations "abide by GPDR" and so this part of the explanation should be changed to say that they are "required to abide by GDPR".
  - Participants discussed whether or not the explanation should specifically state that you will not be contacted by organisations. A few were reassured by this but the majority talked about how they had not considered being contacted as a possibility, so they would be alarmed rather than reassured by this part of the explanation.
  - Participants suggested combining the data security and the privacy explanations into a single explanation as the two areas they covered are, to most people, the same issue.

At the end of this phase of the research, we had two co-designed explanations that we could test during subsequent stages.

**WHAT IS POPULATION HEALTH MANAGEMENT?**

It helps us understand people's health and care needs and how they are likely to change in the future. We share information, resources and goals and tailor services to the needs of people in the local area. This helps us to improve health, prevent illnesses and make better use of public resources. It involves the NHS and other public services including councils, schools, housing associations and social services.

**DATA SECURITY AND PRIVACY**

We use international security and privacy standards that provide the highest possible level of security. To help improve the health of people in our area we analyse data from health and care records and share data with other Public Sector organisations. The data does not include your name or anything that could identify you. All these organisations are required to abide by strict data protection law.

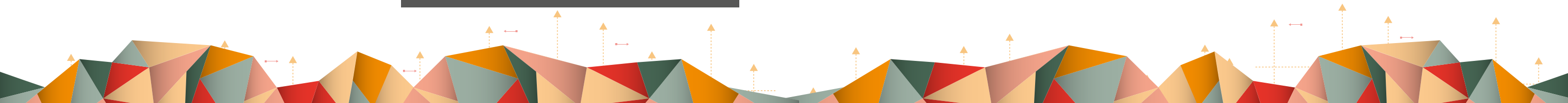


During the next stage of focus groups and interviews, participants talked about these explanations and all described them as clear and easy to understand. Very few of the participants raised any concerns about how their data would be used, or about security or privacy. One talked about which organisations might share the data, but they were reassured that they were all Public Sector. A few talked about how it is important to ensure that the data used is accurate and kept up to date, and some were sceptical that this would happen, giving examples of their own records that are inaccurate.

One of the focus groups was with people who are healthy and who live in affluent areas. They talked about how their initial reaction might be to resist any service cuts in their area, but on greater reflection, it makes sense to target areas with higher rates of ill health. They talked about how this is likely to save money in the long term, as it is cheaper to prevent conditions than to treat them.

*"No worries, no. Especially if there's no names used and I mean, it's for everybody's benefit, isn't it? In the long-term. Right from small children to old age pensioners. It's like planning for the future of everyone's health." (I1)*

*"I have no worries. If information is shared without mentioning a name, it will be helpful for someone, for her search, for making the decision. It is nothing to worry about." (I2)*





## 4. Results cont.

### 4.2 How might people respond to Population Health Management activities?

In this section of the report we describe the results from focus groups about what people associate with being healthy and how they might respond to the potential changes that population health activities could bring.

#### Healthy people and places

Participants were asked what springs to mind when they think about being healthy.

- Overwhelmingly, people talked about diet and exercise as being central to health. A good diet is one with lots of fruit and vegetables with not too many takeaways. Exercise was often going to the gym, but could also be keeping active more generally, such as going for walks.
- Many also talked about the importance of mental health.
- Other common aspects of health were getting enough sleep, not drinking too much alcohol, and having a good social group rather than being socially isolated.
- A few mentioned drinking enough water.

*“Keeping sociable and out there. Not just being stuck in the house. And also, alcohol as well. When anyone says healthy you think of alcohol and drink and stuff like that.” (FG4)*

They were also asked about whether the place they live is healthy, and why. They discussed how healthy places:

- Have places to exercise, such as gyms, leisure centres, parks and footpaths.
- Have local shops where you can buy fresh fruit and vegetables.
- Have local shops and businesses with a focus on taking care of yourself or looking good.
- Don’t have too many fast-food takeaways and restaurants.
- Have clean air and clean streets.
- Feel safe.
- Have a community of people that know and support one another.

In one of the focus groups, in a more deprived area, participants also talked about how healthy places:

- Don’t have too many vape shops.
- Don’t have people trying to sell drugs to children and young people.

*“We’re very lucky where we are because it’s so near to the park. Tennis courts. Just the park is great because you can just run around there. The kids can go on their bikes there, it’s great.” (FG4)*

*“Even though it’s a bit of a built-up area, it doesn’t matter where you walk, does it? You don’t need green fields.” (I3)*

*“Do you know I don’t think there’s one shop selling vegetables near me.” (FG2)*

*“I love to walk but I’m afraid to death of walking out on my own. You have to be so careful where you go.” (FG1)*

*“If you see somebody running around here, they’re getting chased by somebody.” (FG5)*

Participants were asked what organisations help them to stay healthy. They talked mainly about gyms and leisure centres, and exercise groups. A couple who had been put in touch with community organisations when they arrived in Leeds talked about various groups that provided leisure activities and help with mental health. A few talked about council-run swimming classes for children, but most did not specifically mention the council without being prompted. With prompting, a few talked about fitness classes in council facilities, and the Leeds Breeze scheme for children and young people. Similarly, people needed prompting to identify other Public Sector organisations such as social services and schools, as having a role in helping people stay healthy. They talked about the help being very limited, mainly based on providing information leaflets, or by schools introducing restrictions on what children can have in packed lunches. Several of the parents talked about how such school restrictions cause difficulties as their children don’t want to eat healthy food.

*“They do stuff, but they don’t do anything to help. So they’ll weigh your child or they’ll make sure they’ve grown the right size but if your child is overweight they just say here’s some vouchers, or here’s some leaflets you can use. Make sure they eat right.” (FG3)*

*“Sometimes you have to realise your kids probably might not eat the healthy option and you might provide it, but they’ll just come back home without eating it. And then you’re throwing it in the bin and your kid’s not been eating anything all day and you feel really bad.” (FG3)*

*“My kid will go to the shop before he gets to school. So, he goes to the corner shop to get Aeros, puts it in his bag and then takes it in.” (FG2)*

Similarly, very few participants talked about the NHS having a role in helping people stay healthy. One talked about how a friend had been given free gym membership by the NHS to try to tackle his weight problem, and another about how his GP had given him medication to help lose weight. One talked about the NHS providing vaccinations. However, most participants, when prompted with the NHS, talked about its role being to treat illness rather than prevent it.

*“The Health Service is for illness, operations and death.” (I1)*



Participants were asked what information non-NHS organisations might hold about them and what they might do with that information. Most assumed that the information is quite basic, such as the number of people who live in their home, and about any special health needs. One participant talked about how she thinks information has been shared with partner organisations who might be able to support her in her caring role. None of the participants were concerned about their information being shared in this way. Many participants, however, talked about how GDPR has meant that organisations are not supposed to share your details without your permission.

*“I think they do share it. I used to be carer for my late mum. Once you’re registered you find you do get a lot of calls saying we’ve had your information passed on from us, how are you feeling as a carer? Would you like to join our group and we go out walking to help ease the burden?” (FG4)*

*“I didn’t think that with this new GDPR regulation that’s come out that you were allowed to share information. I’m not saying I’m bothered, but I thought that you had to have authority and permission to pass information around.” (FG4)*



## 4. Results cont.

### Barriers to improving health

Participants talked about the things that make it more difficult to maintain and improve their health, and the challenges of improving the health of people in their communities. There were five types of barriers: motivation, confidence, time, money, austerity cuts and engaging the community.

### Motivation

Many of the participants talked about how it is difficult to find the motivation to make lifestyle changes to protect or improve your health. This is particularly the case if you are currently healthy and conditions such as heart disease or lifestyle diabetes seem like a remote possibility that may not happen for many years. Several talked about how this often involves breaking habits, which is difficult to do, especially when those habits are part of the local culture or how you were raised. This could be involve eating healthily, exercising or choosing a non-alcoholic drink in a bar. In one group participants talked about how people don't want to exercise because exercise wasn't part of their life when they were growing up, so it's not something they would consider doing. In another group, some of the participants talked about how it's even more difficult to make positive lifestyle changes if you are struggling with some other aspect of your life, e.g. financially or with mental health problems. Some participants talked about how people who lack ambition or hope for their lives also lack motivation to make healthy lifestyle changes, and often people drink and smoke because they feel they don't have anything else to do. Several participants talked about how it is easier to form new habits than to break old ones, and so it would be useful to encourage people to start new activities, rather than to tell them what they should stop doing. One participant talked about how having children motivated her to learn how to cook healthy meals and to start getting fit, as she wanted to give her children a better start in life than she had had.

A few participants talked about how a particular insurance policy helps to motivate people to become more activity by providing rewards for meeting activity targets. They wondered if a similar scheme could be set up by rewarding people with vouchers or memberships for meeting health targets.

***“Having willpower and putting things off [are barriers] because it’s easy to put things off.” (FG4)***

***“What’s the point in keeping healthy at my age?” (I1)***

***“Everybody has such busy lives and because it’s not an issue as such - it’s just something that might happen - you put it way down on the list.” (FG4)***

***“Cultural background is a big thing as well when it comes to healthy eating. I’m just stuck in Caribbean ways, so I do everything Caribbean pretty much.” (FG3)***

***“It starts from being young doesn’t it. If you’re not taking the children out to parks because of fear of their safety or whatever else then they’re not going to grow up to take their children to parks. And when they get a bit older they’re not going to be interested in exercise.” (FG5)***

***“I got brought up on a really bad diet. I got brought up with no education and no exercise and that’s why I got myself into learning about fitness because I didn’t want my children going through that. I grew up on frozen food. Fishfingers, waffles and all that sort of stuff. It was cheap and easy. She was a single parent. That’s what I am.” (FG3)***

***“Why are you talking to me about stopping smoking when I’m struggling to pay the rent? Like, no. That’s not my priority, I’m sorry it’s not.” (FG5)***

***“[They can say] Stop drinking, stop smoking. But I’m not going to do it basically. I drink more now than what I ever did in my life. Because I’m bored. I’ve got nowhere to go. Do you know what I mean?” (FG5)***

### Confidence

This barrier is about lacking confidence in your ability to change (i.e. low self-efficacy). Several of the participants talked about how many people, sometimes themselves included, don't know how to make healthy changes. Not knowing how to cook from scratch was raised as a problem by several participants. Others talked about not having safe places to exercise in their area, or not knowing what facilities or exercise groups are available. Similarly some participants talked about how they are not fit enough to start exercising, or they would be too embarrassed to go to a gym because of their body shape.

***“I had to teach my daughter-in-law to cook basic meals. She didn’t know how to do mashed potatoes, she didn’t how to cook a joint of meat and Yorkshire puddings, just simple things.” (FG1)***

***“I don’t want to embarrass myself running around, coughing my lungs up.” (FG5)***

***“Where are you taking them to learn to ride their bike? Are you going to let them go in the park and they fall on a drug needle. No you’re not. Where are you taking them?” (FG5)***

***“There’s glass all over the place and kids and teenagers in the street you can hear at night going past. But I shut my blinds, shut my curtains. Done. So it’s not scary but you’ve got to have your wits about you.” (I4)***

### Time

Many of the participants talked about how their busy lives mean that it is difficult to find the time to exercise, or to cook healthy food. Many talked about eating cheap takeaway food because it is quick and easy, despite knowing that this is not a healthy option. They talked about how they do not want to spend time cooking after a long day at work, and having children pestering for food makes it even more difficult. A few, however, talked about how there is an increasing number of vegetarian and vegan takeaway restaurants in nearby areas and how this might offer a healthier option for the future should they open nearby. Parents talked about how it can be difficult to find the time to exercise. Sometimes this is because they can't leave their children alone at home, so would need to pay for a childminder, or it can be because they spend so much time looking after their children and taking them to after-school activities they don't have time for themselves.

***“There’s too many cheap takeaways isn’t there, that’s the thing.” (FG3)***

***“You know when you’ve had a long day at work and you can’t be bothered to cook and you go through the interchange in Doncaster and as you’re coming through you think I could just eat a taco. Taco Bell, chicken wrap, chips and a drink.” (I4)***

***“Prepping for a healthy meal, especially if it’s only cooking for yourself, you just can’t be arsed.” (FG1)***

***“Time constraints, I think, is the problem. I can’t leave my daughter at home on her own to suddenly go off for a five mile walk to make myself feel better. I can’t do that. I then have to put in place childcare to be able to get out, which I then have to pay for.” (FG4)***

***“There’s a takeaway over in Hessle, it specialises in healthy meals. So, they do like salmon with vegetables and it’s sponsored by some sports people from the area and it’s supposed to be like a healthy takeaway option. I’ve not tried it.” (FG2)***



4. Results cont.

Money

Discussions about healthy being expensive arose in all of the focus groups. Participants talked about how unhealthy food is cheap and healthy food is expensive. For example, many people talked about fruit and vegetables being expensive and takeaways being cheaper than home-cooked foods. Some participants talked about healthy food being organic and therefore expensive. One talked about how ordinary salt is unhealthy and so she would like to buy Himalayan salt, which she assumed is healthy, albeit much more expensive. Exercising was also described as being expensive, as gym membership can cost a lot. Several participants talked about how going for a walk or a run is free, but some highlighted that it needs to be in a place that feels safe. A few talked about how there are syringes in their local park and so it's not a safe place to take children. Participants in two groups talked about outdoor exercise equipment in parks, although in one group participants highlighted that it had been vandalised. Participants on benefits talked about how cost is a major barrier.



***“If you’ve got less money, you can’t afford the better lifestyle. You’re buying the cheaper food. People want to go organic or healthy, but they can’t afford it.” (FG3)***

***‘It’s cheaper to buy a cake than a cabbage. You’ve got to feed your kids.’ (FG5)***

***“I find it difficult, being on benefits, not being able to afford to eat healthy or join exercise programmes.” (I1)***

***“I think one of the big problems is, because not everyone is super wealthy, it’s easy to eat crap food. Especially if you’re feeding the family, it’s easy to get rubbish food. I certainly can’t afford to go out and eat the healthiest free-range chickens every night and all that sort of stuff.” (FG1)***

***“Sometimes it’s easier to go to the takeaway down the street, spend £15 on a meal, feed all six of us and then that’s it. A couple bags of chips and a few sausages.” (I4)***

***“There are a lot of problems with the younger generation nowadays who think that they can just go around shouting abuse or mugging people. They don’t care who’s around, they don’t care who’s watching them. Even when the police are there, they’ll do stuff. And I think that makes people a lot more scared to go out and do more.” (FG1)***

***“I think they need to clean the area up. You go down to your local park, it’s full of drug needles and cans. You can’t invite kids to something like that.” (FG5)***

Austerity cuts

Most of the groups discussed challenges from austerity and the cuts to services it brings. When talking about the explanation of population health, and how it involves sharing goals and resources with partners, many became frustrated about how services to help people stay healthy have previously been introduced and subsequently cut. Two of the participants had previously worked for such programmes, and both had lost their jobs as the programmes had been discontinued. A common view was that there is nothing new about population health management: services have been introduced, people helped, and then services cut again. They were not optimistic that any facilities tailored to the needs of the local community would continue to be supported should there be a new set of priorities or targets introduced.

***“I used to be a community warden. I used to work with the older people, elderly people and vulnerable people. And we used to set up lunch clubs and take the people out to lunch clubs across the city. And we used to work with the junior wardens as well. And we used to do a lot of exercise classes and we used to take them to sessions about fire safety and stuff like that. We did a walking group as well, we were working with kids, working with older and vulnerable people. We had health wardens that used to set up quit smoking groups and these walking groups. We were partly funded by the council, the city council, yes. But obviously with the cuts coming in, the funding disappeared.” (FG1)***

***“This is another merry-go-round. At my age now, I’ve been through and I’ve heard and seen this. They do cutbacks - Breeze got cut back because that was the council responsibility through the youth service and now they’ve tried to bring it back again.” (FG3)***

***“They can come up with ideas and the ideas might be perfect on paper but unless you’ve got the funding to go with it you’re not going to get action.” (FG5)***

Engaging with the community

Several of the participants highlighted that when authorities try to make changes in an area they seldom involve the community and build on its strengths and insights. This can lead to inappropriate resources being provided, and external people being brought in when that input could have been provided by local people. Instead they suggested it will be important to work with a community to help them identify the problems and solutions, and to support the community to change. They believed that this would be more effective than singling out high-risk individuals and supporting them to make changes. They also suggested that taking a community-focused approach would be more effective in letting people know what is going on in the area, so that people are aware of groups they can join and feel more able to do so.

***“The problem with these sort of things, and I’m being a bit sceptical here, it’s okay for somebody that’s sitting behind a desk and has come up with the data and looked at the data as a set of numbers to say, yes that’s what you should be doing. I think if you just get more people talking about it in the community like you said, town hall sessions and that. Rather than sending individual letters and all this stuff. Get a whole group of people to work on it.” (FG3)***

***“You need ambassadors in each area don’t you really? You need people like spokespeople, like somebody who lives next door to you or whoever are involved in it. You can’t just have a load of council people turn up and build something.” (FG3)***



4. Results cont.

4.3 Testing the explanations and identifying concerns

In this section we present the findings from the survey with people in Yorkshire and Humber to test the co-designed explanations, and to seek their views about using their records for Population Health Management purposes.

Respondents were given the co-designed explanation of Population Health Management and asked how easy to understand it is. Most reported that it is very easy (33%) or fairly easy (53%) to understand. Only 3% reported that it is difficult to understand. There were no differences based on age group ( $F(3,1041) = 0.02, p = 0.99$ ), gender ( $F(2,1044) = 2.78, p = 0.06$ ), ethnic group ( $t(1050) = 0.01, p = 0.92$ ) or disability ( $t(1050) = 1.02, p = 0.30$ ).

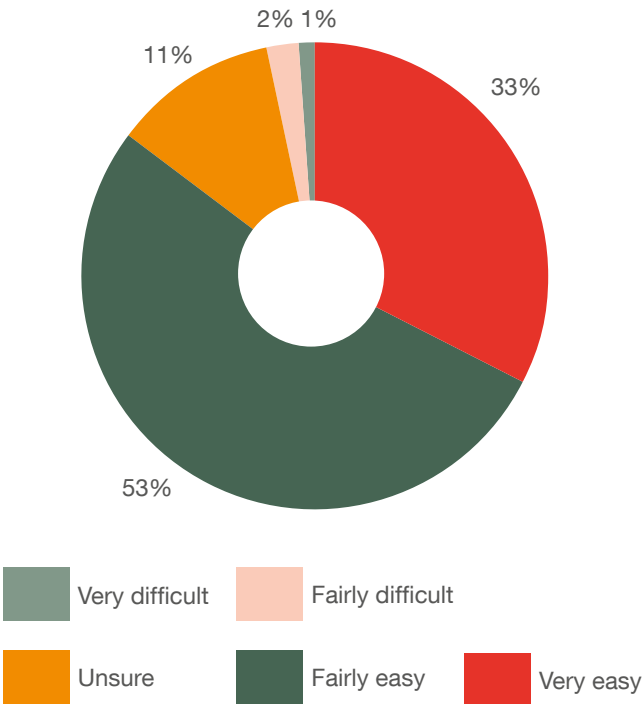


Figure 3: How easy respondents find the explanation of Population Health Management.

Respondents were asked how much they trust the NHS, and other Public Sector services, to use their health and care records for Population Health Management. They could choose from trusting them a great deal, to not trusting them at all. The percentage of respondents who gave each answer is shown in Figure 4. Respondents trust the NHS more than Public Sector services to use their data for Population Health Management ( $t = 15.56.0, p, <.001$ ).

There were no age differences in trust that the NHS using their data for Population Health Management purposes but the youngest age group had greater trust in Public Sector services using the data in this way ( $F(3,140) = 9.9, p < 0.001$ ).

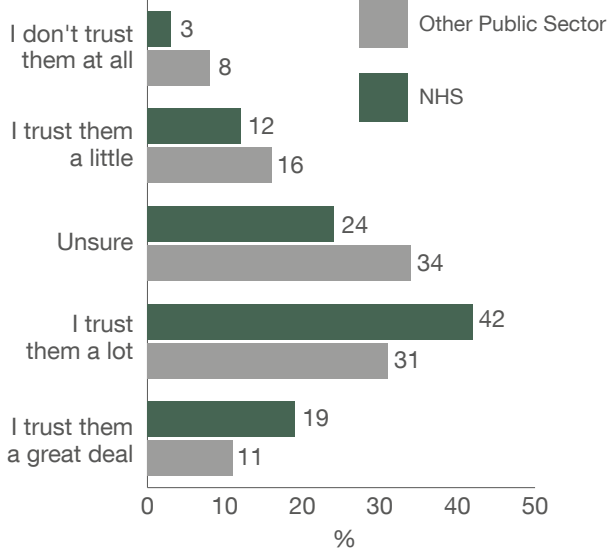


Figure 4: How much the NHS and Public Sector services are trusted to use health and care records for Population Health Management.

Respondents were asked if they had any questions or concerns about Population Health Management. A total of 109 respondents (9%) noted concerns, which are summarised below. In addition, several respondents expressed support for this use of data.

- I don't know why this is necessary
- What information is shared and with who?
- The data might not be secure
- Will the data be sold?
- Some people will have a reduction in services
- Some hospitals and clinics could close
- Is it possible to opt out?
- The Public Sector will not be able to run this effectively
- Will the data be used for other decisions not related to health and care services?
- Will this be funded sufficiently?
- Why use a complicated name like Population Health Management?

Respondents were presented with the co-designed explanation of data security and privacy and were asked how easy to understand it is. 92% reported that it is very easy (47%) or easy (45%) to understand. There were no differences based on age group ( $F(3,1041) = 2.5, p = 0.06$ ), gender ( $F(2,1044) = 2.78, p = 0.06$ ), ethnic group ( $t(1050) = 0.01, p = 0.92$ ) or disability ( $t(1050) = 0.88, p = 0.38$ ).



**“How can the needs of all people in the region be catered for - especially those with mental and physical disabilities - without detracting from health and care services for others?”**

**“I am not clear why it is necessary. Admittedly, urban areas will have more air pollution and hence greater requirement for respiratory specialists but this should already be self-evident.”**

**“I generally don’t trust public services to run efficiently and without problems.”**

**“I don’t like the idea of other public services knowing my health records, is this compulsory?”**

**“I worry a little about if sensitive information about me or my family could be used without consent especially by groups other than the NHS.”**

**“I worry that something like this could cause some hospitals to close departments. We need our hospitals.”**

**“I’d be concerned they were using the details for other things as well as coordinating the needs of the health care system.”**

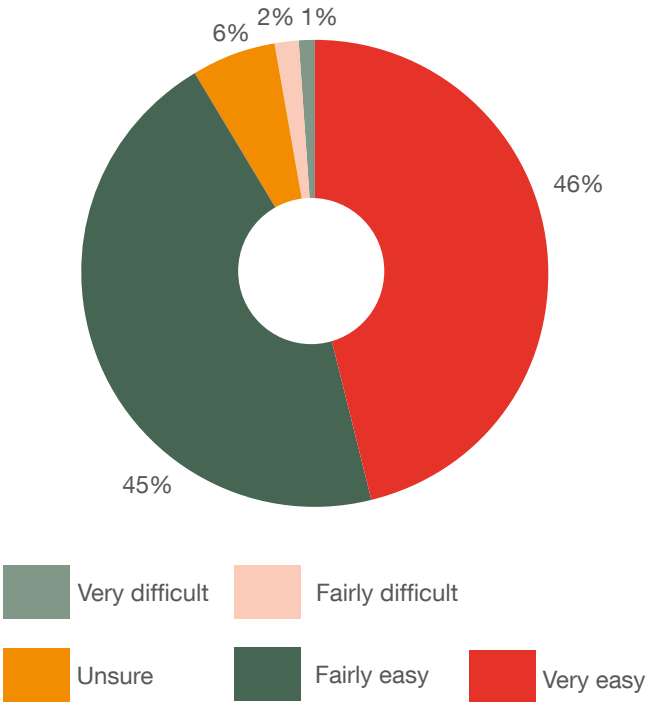


Figure 5: How easy respondents find the explanation of data security and privacy.

Respondents were asked how much they trust the NHS, and other Public Sector services to keep their records safe. They could choose from trusting them a great deal, to not trusting them at all. The percentage of respondents who gave each answer is shown in Figure 6. Respondents trust the NHS more than Public Sector services with their data security and privacy ( $t = 16.6, p < 0.001$ ). There were no age differences in trust for the NHS, but the youngest age group had greater trust in Public Sector services for data security and privacy ( $F(3,140) = 6.5, p < 0.001$ ).



4. Results cont.

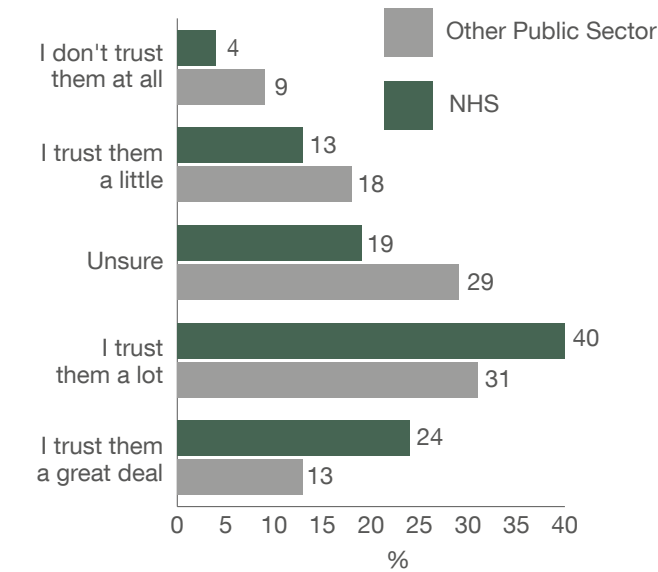


Figure 6: How much the NHS and Public Sector services are trusted to keep health and care records safe.

Respondents were asked if they had any questions or concerns about data security and privacy. A total of 76 responses (7%) noted concerns, which are summarised below. Several responses were about supporting the move, provided that individuals and families cannot be identified.

- The data could be at risk of being hacked.
- I feel generally uneasy about my data being shared.
- Many organisations have made mistakes and lost data, so will this venture be any different?
- While the data will be secure centrally, could the settings on an individual's computer compromise security?
- Who has overall responsibility for data security?
- Will the data be sold?
- Will the data be available to other countries?
- If enough data fields are released then the data could be de-anonymised.
- How accurate is the information?
- It's vague about security standards.
- It is possible to opt out?

Respondents were presented with a list of potential outcomes of using a Population Health Management approach and asked how much they agree or disagree with them. The percentage of respondents who agree or strongly agree with each outcome is shown in Figure 7. The results show that there is strong support for most of these data uses, particularly to provide extra support, and GP practices talking to people about services that they might benefit from. There was less support for spending less money in healthier areas, with 42% agreeing or strongly agreeing, 29% unsure, and 36% disagreeing. The qualitative research showed that this outcome of Population Health Management can initially seem unfair and that people support it more strongly once they have had the opportunity to reflect on what the long-term benefits might be.

***“Unless you know who wrote this, you don’t know if you can trust it. Who has confirmed that they have the highest standards of security? Anyone can put that on any website. Also it does not say if the data is shared nationally or internationally. If it is shared with China for example, how good is their security? How good is the security of the people they share the data with?”***

***“I would not say I had high levels of trust that they will get it right, but I am not worried about the sharing of my data between statutory agencies. I have greater concerns about statutory bodies hiding behind confidentiality and GDPR, when they should be sharing information for safeguarding purposes.”***

***“There is always a concern around privacy and data security, regardless of the reassurances!”***

***“Who loads the correct information?”***

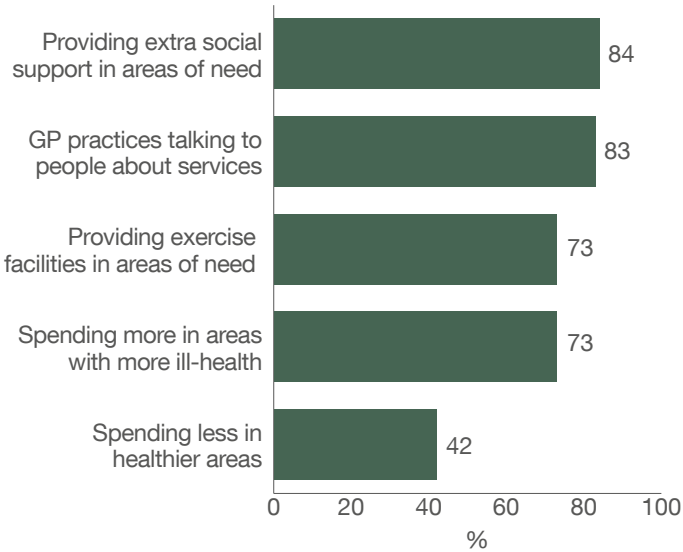


Figure 7: Support for different population health outcomes.

Respondents were told about the “Emily” example of Population Health Management. This example was chosen because the qualitative research showed that it was the easiest one to understand.

“Emily is 5 years old and has asthma. Population health data shows that there are lots of people with asthma who live in her area. To find out why, information on air quality was obtained from the Department for the Environment. Information on housing quality was obtained from the council. This showed that the traffic on the nearby road was causing poor air quality, and that homes on Emily’s estate were poorly insulated, making them cold and damp. The council agreed to insulate the homes, and also to start a “no idling” campaign to encourage motorists to turn off their engines, which will improve air quality. They hope this will mean that fewer people have asthma attacks.”

They were asked three questions, about whether this is a good use of information, about whether Emily’s GP should be given this information, and about whether Emily’s GP should tell her family about the poor air quality. They were asked to use a scale from strongly disagree (1) to strongly agree (5). The percentage that agree or strongly agree to each question is shown in Figure 8. There is strong support for all of the three elements of the example, including for direct contact with Emily’s family.



4. Results cont.

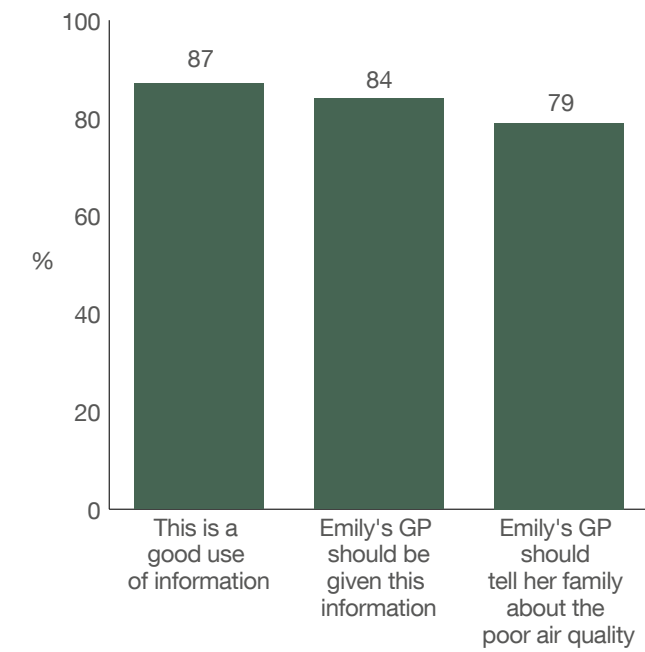


Figure 8: Percentage of respondents who agree with each example.

Participants were told that Population Health Management involves analysing information from lots of different sources and that this information shows the number of people with a condition or who access a services but it doesn't show who they are. They were asked which of a series of organisations should be able to access this information. The number of respondents agreeing that each organisation should be able to access the information is shown in Figure 9. More people support the NHS and GP practices being able to access the range of information sources. Specific council departments - public health, environmental health and social services - were more strongly supported than the local council more broadly. Less than half of respondents supported schools being able to access this information. Comments left on the survey indicate that this is because people don't think it is appropriate for schools to access the records of adults.

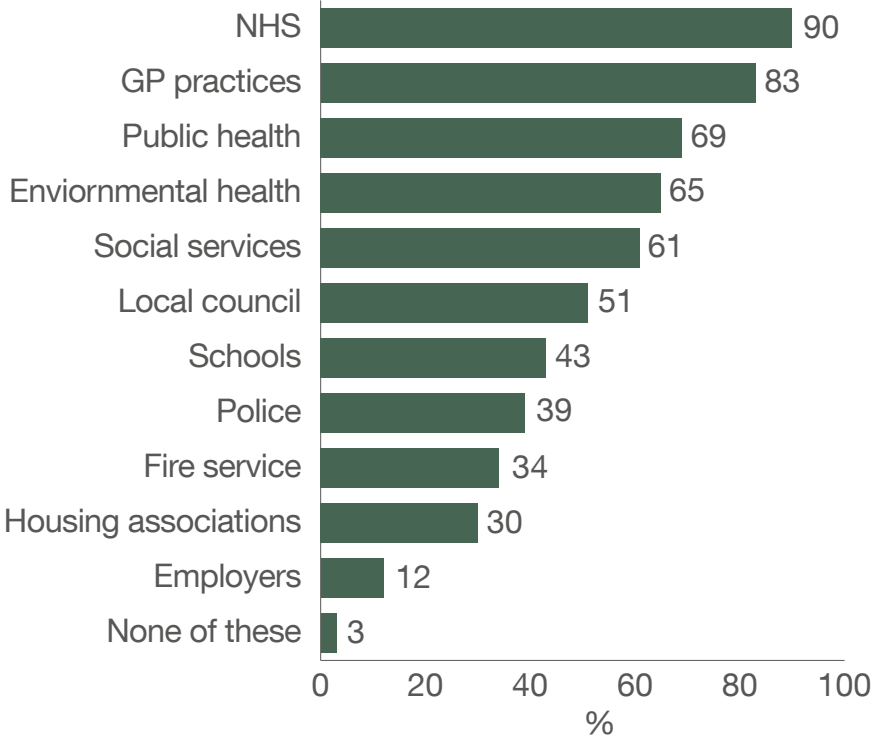


Figure 9: The percentage of respondents agreeing that each organisation should be able to access de-identified records.



# 5. Summary

Population Health Management and data security and privacy are difficult concepts to explain to people yet will become increasingly important in how healthcare is planned and delivered. The Yorkshire & Humber Care Record wants to work with people to help them understand how their data is used. This research involved people in Yorkshire and the Humber to co-design explanations of these concepts. We tested these explanations and most people find them easy to understand, and they do not raise queries or concerns. The most common concern about data security was the potential for data breaches and data hacking. However, people were also concerned that the data used should be accurate and up-to-date. As in previous research, we have found that people trust the NHS more than Public Sector services, and that younger people have more trust than older ones. This research provides additional insight that can be used when planning future Population Health Management activities.

## Future Population Health Management activities should make use of these key research findings

- 1

Keep explanations short and simple. Some people will always want more detailed explanations, but most do not read them and are not interested in details.
- 2

While people’s initial response to a potential cut in services is often negative, on greater reflection they can understand why re-targeting resources to areas of greater need will benefit everybody.
- 3

It’s useful to use an example when explaining Population Health Management.

a.

Don’t use examples involving depression or obesity, as some people are concerned that these are sensitive issues and people might feel singled out or blamed if they are targeted for support.

b.

Don’t use examples in which an individual could have been referred for additional support by their GP or other care worker as people assume that the data analysis that identified their support need is wasted.

c.

Our example of different organisations sharing data to identify and tackle asthma in a small area was easy to understand and widely supported. This does not raise concerns about individuals being identified.
- 4

If Population Health Management activities will target a specific area or demographic, people prefer the first contact to come from their GP practice.
- 5

People associate a good diet and exercise with staying healthy, and think of the NHS as an organisation that treats disease rather than keeps them healthy. They are aware of things that they can do to protect and improve their health and of how the environment can influence how easy it is to stay healthy.
- 6

People will experience many barriers to changing their behaviour, including a lack of motivation, a lack of confidence in their ability to change, a lack of time and money, and scepticism that any support they receive will be available long-term.
- 7

Future Population Health Management activities should work with the community to gain insight into the problems it faces and how they can be addressed, and to build on the strengths that community possesses.







# Yorkshire & Humber Care Record

Brainbox Research

