healthwatch
Norfolk

Patient Data Project

Using Patient Data without prior consent to improve the health of the population

June 2025

Supported by:

healthwatch
Cambridgeshire

healthwatch
Peterborough

Contents

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Please contact Healthwatch Norfolk if you require an easy read; large print or a translated copy of this report.

Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.
The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.
Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.
We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Supported in this project by our colleagues from:

healthwatch Cambridgeshire healthwatch Peterborough

Summary

Why we looked at this

Cambridgeshire and Peterborough Integrated Care Board (ICB) and Norfolk and Waveney Integrated Care Board (ICB) were both wishing to obtain patient and public feedback, in support of previous current and planned applications to the Confidentiality Advisory Group. (CAG) These applications are to allow the ICBs to bring together confidential patient level data from a variety of NHS (and other) data sources and to analyse it *without obtaining prior consent from individuals.*

Analysed data would then be used for a variety of purposes including service planning and evaluation, and to offer preventive care and targeted interventions, all intended to lead to better health outcomes. Healthwatch Norfolk led on this project, with support from Healthwatch Cambridgeshire and Peterborough.

Aims and Objectives

The first purpose of the project was therefore to enable the ICBs to satisfy the CAG that they have involved patients and the public in respect of past and future applications. The outputs from this project will be used as evidence by the ICBs.

The second, linked purpose, was to support them in achieving planned benefits for patients, by making recommendations for action by the ICBs, that will enable them to improve the way that they carry out this work, and in particular continue to involve patients and the public in doing this.

How we did this

Both commissioners wanted us to complete this project as quickly as possible, so that it could provide them with evidence of appropriate patient and public involvement that they could use in their interactions with the Confidentiality Advisory Group. They wished the work to support both previous applications, and to be used in future ones.

Given the purpose of the project, the scope of its work, and its agreed timetable, it was decided that this would be conducted through a survey together with a minimum of five focus groups. We received a total of 469 survey responses that could be analysed and held six focus groups with a total of 50 participants.

What we found out and what this means?

This project took place in a context in which both ICBs are already carrying out projects (e.g.: for risk stratification) that involve the analysis and use of patient data without obtaining prior consent from individuals. These projects are supported by existing Section 251 approvals and operate within current legal frameworks, including the use of pseudonymised data.

The clear national strategy is to support and encourage the greater use of the 'Population Health Management' approach and the use of 'risk stratification'.
The ICBs should therefore be encouraged that the survey and focus group respondents, whether looking at the wider question, or specific schemes, were generally supportive of it happening.

In both the survey responses, and in the discussion about a specific example in the focus groups, there was a clear consensus that respondents were happy with the aim of sharing data (using the pseudonymisation method) in order to assist the evaluation of services and benefiting future service planning.

When it came to schemes that 're-identified' people following this analysis in order for them to be contacted and offered access to a service intended to benefit them, the views expressed were more mixed. Participants in the focus groups had the opportunity to discuss two schemes where this was the case in some depth.

The survey responses indicated a high level of support for using patient data in these two examples to achieve benefits for individuals. The focus groups discussion went further to examine how these benefits could be achieved. There was a strong feeling expressed in the focus groups that the ICBs and other bodies would benefit from finding ways to 'involve' interested members of the public and patient groups in contributing to all stages of the development and implementation of these schemes. It was recognised that there were a variety of ways in which this could happen.

- Discussing the initial ideas being thought of, and how they would achieve a positive outcome for patients.

- Looking at the different potential methods of contacting and notifying people to get the best outcome whilst avoiding an adverse reaction from some individuals.
- Evaluating scheme to learn lessons for the future.

Both survey respondents and focus group participants saw the benefit of the wider public being informed about what the ICBs were doing, and planning to do. Such information could provide greater re-assurance that everything was being done in a way that minimised the risks with data safety and security.

By disseminating information that included evidence of positive outcomes and patient benefits this could also reinforce confidence.

Being 'open and transparent' with the public was seen as a very positive thing. A number of suggestions were made as to how this could be done.

The key findings were used to inform the recommendations below.

Recommendations

This report recognises that the two ICBs are at different stages in their development of work in this area. They are both also in the middle of substantial organisational change, which will impact on the functions that they carry out, and the resources available to do this.

The recommendations are based on the key findings from our survey and focus group work. They are therefore grounded in the views and experiences of local people. We believe that they are therefore relevant to the future work of whichever NHS organisations are responsible for this.

1) Informing People

Ensure that the public are fully informed about the local use of data without prior consent by:

- Providing a clear explanatory briefing outlining the approach and activities of the ICB, and including assurances on data safety and security, and opting out (see below)
- Continuing to provide information on existing schemes through NHS body websites, screens in waiting areas, newsletters, on-line sites and media outlets as appropriate.

2) Involving people

Seek to involve interested members of the public / patient groups in all schemes where data is to be used without prior consent including:

- Discussing initial ideas
- Identifying the desired outcomes and benefits to people / patients
- Considering any potential adverse impacts and how to reduce / eliminate these.
- Evaluation of completed schemes

3) Notifying people who have been identified to be offered access to a service.

Review the different methods and types of material used in contacting people (letters, texts, e mails, phone calls etc) who have been identified to be offered access to a service following the data analysis, using the learning from previous experience within the ICBs together with the comments and views expressed in the focus groups.

4) Opting Out

Clarify the arrangements for individuals being able to opt out of sharing their data and then ensure that this information is included in any relevant explanatory briefing (see above)

5) Future Work

ICBs to meet with local Healthwatch organisations for their area to discuss the recommendations in this report, the actions they propose to take as a result, and how they will continue to include the patient and public voice and views in their future work. (timescale to be agreed but we suggest within 3 to 6 months)

Why we looked at this

1) Commissioning by two Integrated Care Boards (ICBs)

Cambridgeshire and Peterborough ICB and Norfolk and Waveney ICB were both wishing to obtain patient and public feedback, in support of previous current and planned applications to the Confidentiality Advisory Group. These applications are to allow the ICBs to bring together confidential patient level data from a variety of NHS (and potentially other) data sources and to analyse it *without obtaining prior consent from individuals.* Analysed data would then be used for a variety of purposes including service planning and evaluation, and to offer preventive care and targeted interventions, all intended to lead to better health outcomes. After discussions they decided to commission Healthwatch Norfolk to lead on this project, with support from Healthwatch Cambridgeshire and Peterborough.

2) Background – the rise of the Population Health Management approach

The NHS collects a large amount of data about every individual patient it comes into contact with. This data will include everything from name and address to a record of assessments and diagnoses, prescriptions, and care and treatment provided by potentially a whole number of different NHS bodies. For individual patients it is assumed that this data can be shared across these organisations who are all responsible for providing health care unless the person has chosen specifically to 'opt out' of allowing this to happen. The NHS, for example, routinely operates on the basis of the actual or implied consent of patients to their data being shared, to provide them with the best possible care and treatment.

Increasingly health service bodies have recognised the potential value of bringing this data together at a 'population' level. It can then be used to identify individual patients, or groups of people, who can be offered additional 'preventive' support, on a proactive or targeted basis. This emphasis on 'prevention' is designed to provide people with the best possible health outcome by supporting them before they get to a point where they might need a greater level of intervention from the NHS. This approach is often called 'Population Health Management' and is intended to lead to better outcomes for individuals; tackle health inequalities; and be better value for money.

3) Bringing data together

To undertake such work, the NHS must bring together data for large numbers of people and then analyse it to identify those ‘at risk.’ In these circumstances it would be impossible to obtain individual consent in advance. Typically, a considerable proportion, and possibly the majority of patients, would not reply to a such request. This might even worsen health inequalities if patients in more deprived areas or within greater health needs are less likely to respond. The NHS therefore has to seek ‘permission’ to do this analysis without prior consent. They do so by putting in requests to the Confidentiality Advisory Group who then advise the Secretary of State on whether a specific proposal can be supported.

4) What the ICBs have done, and are planning to do

Both ICBs have previously submitted CAG applications associated with ‘Risk Stratification.’ Cambridgeshire and Peterborough ICB have recently submitted a further application for ‘Population Health Management’. Norfolk and Waveney ICB intend submitting a new application, focused on expanding the scope of their current work and the linking of data from other public bodies.

5) Aims and Objectives

The Project was designed to gather evidence that the two ICBs can produce to satisfy the CAG that they have undertaken appropriate ‘public involvement.’ The CAG helpfully provide advice on what they expect:

‘CAG expects to see evidence of public involvement that specifically tests the public acceptability of using confidential patient information without consent for the purpose of your application.’

The first purpose of the project was therefore to enable the ICBs to satisfy the CAG that they have involved the public in respect of past and future applications. The outputs from this project will be used as evidence by the ICBs.

The second, linked purpose, was to support them in achieving planned benefits for patients, by making recommendations for action by the ICBs, that will enable them to improve the way that they carry out this work, and in particular continue to involve patients and the public in doing this.

How we did this

Both commissioners wanted us to undertake this project so that it could provide them with evidence of appropriate patient and public involvement work that they could use in their interactions with the Confidentiality Advisory Group. They wished this to support both previous applications, and to be used in future ones. It was agreed that the project would therefore take place over a four-month period, between February 2025 and May 2025.

Given the purpose of the project, the scope of its work, and its agreed timetable, it was decided that this would be conducted through a survey together with a number of focus groups.

It was agreed with the Commissioners that the project would cover the whole of the area of the two Integrated Care Boards. It was assumed that the responses and results from the project would be equally applicable to the work of both ICBs. We did not expect there to be any differences in feedback attributable to the two ICB areas. It did mean that we could get a sufficient response through the survey (469 responses in total) together with six focus groups (50 participants) that enabled us to bring together across them a good range of people.

Healthwatch Norfolk led the project and prepared most of the material used, including the survey questions and the focus group material. Healthwatch Cambridgeshire and Peterborough supported the project, through the dissemination of communications material, and conducting one of the focus groups.

A Communications plan was developed. The survey was promoted via the two Healthwatch websites, their newsletters and social media. A variety of stakeholder organisations were provided with a project summary and disseminated this. A media release was issued, and this achieved some press and radio coverage.

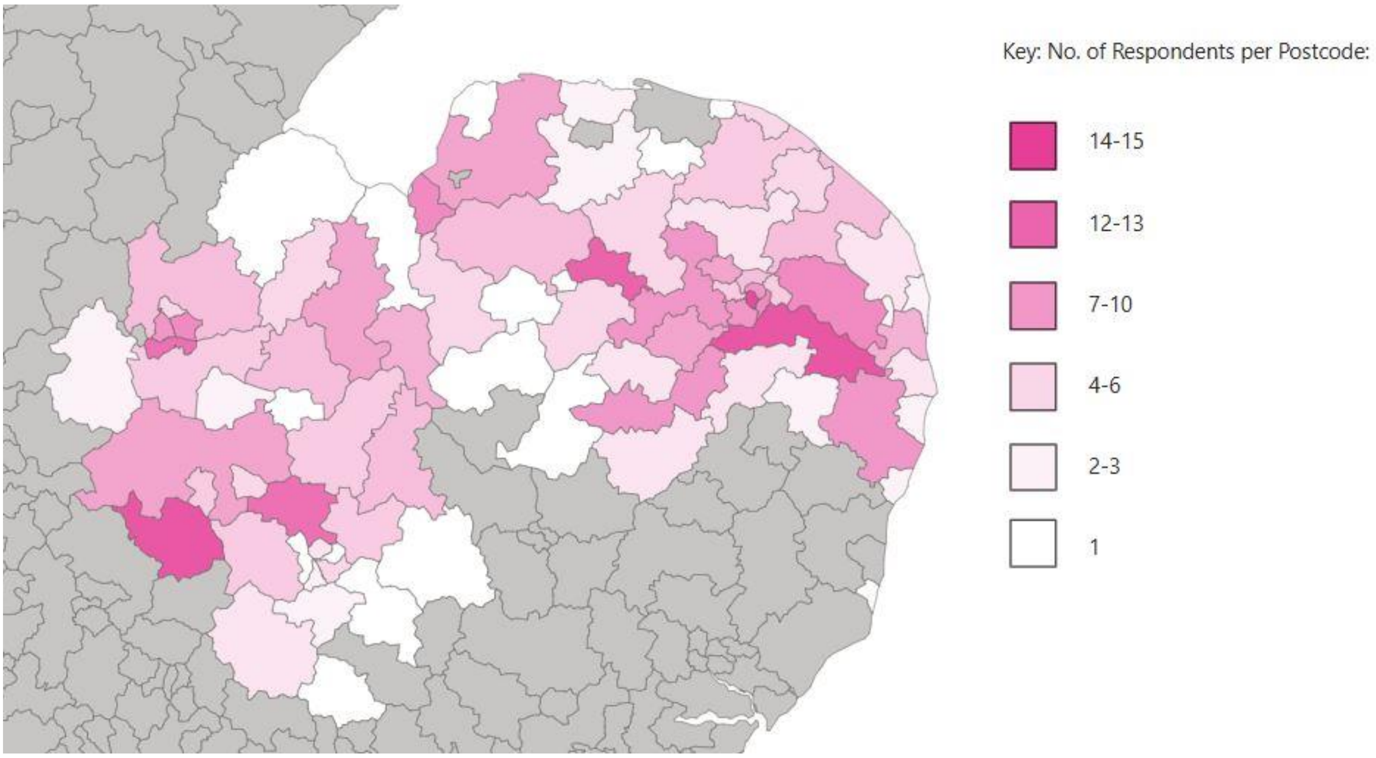
Given the tight timescale for the project both the survey questions and focus group material were developed primarily through reference to previous national and regional work in this associated area, together with discussion with the Commissioners about the areas that they wish to be examined.

Survey

The survey consisted of a range of questions. This included a mixture of closed multiple choice questions, together with some open-ended questions. The on-line version of the survey was run through Smart Survey. A paper copy was made available. Almost all of the responses we received were through the on-line method. A copy of the survey questions can be found in the Appendices.

The survey was completed by a total of 469 people. We made every effort to gain a good response from all geographical areas. The distribution of responses can be seen in the 'heat map' below. Further demographic information is included in the Appendices.

Map showing distribution of survey respondents by postcode area



Focus Groups

The focus groups were seen as a very important part of the project. Whilst examples were given within the survey, it was felt that there would be greater opportunity in the focus groups to use these to explore the issues in more depth. This proved to be the case.

The six focus groups were held in Peterborough, King's Lynn (2 groups), Dereham, Wymondham, and Norwich, with a total of 50 participants. The locations of the focus groups together with further demographic details of the participants can be seen in the Appendices.

We were pleased with the range of participants we were able to gather, from volunteers at the Norfolk and Norwich Hospital, to a mixed group in Peterborough, together with a group of college students from West Norfolk.

Limitations and Coverage

There were clear limitations to this project. The scope of the work covered by the two ICBs means that in theory any member of the public / patient could be included in one of the many specific projects that they have undertaken, or plan to do in future. The resources required to carry out a survey based on a fully representative sample would be well beyond the means of the ICBs.

Equally the focus group participants were also self-selected. It would not have been possible, in the time available, to attempt to achieve a representative sample of the population by ‘sifting’ those who volunteered to participate. However, every effort was made to ensure that the focus groups in total had a diversity of participants, in terms of age, geography, and other factors to mitigate this.

We conducted this project during a period when the NHS was subject to the application of ‘pre-election’ rules and guidance as a result of local elections. As a consequence, some stakeholder organisations were unsure whether they could disseminate survey material at such a time. We extended the survey period by a couple of weeks in order to offset any impact from this.

Despite these limitations, we are confident that the combined feedback from the survey and the six focus groups is more than sufficient for the ICBs to be able to demonstrate that they have listened to public voices from across their communities. The feedback obtained is therefore of value in shaping and supporting their future work.

What we found out

Introduction

The survey covered some specific questions where a choice of answers was available and also included opportunities to provide a brief text response. Two illustrative examples were given as a way of testing out the respondents' views on these uses of patient data.

The focus groups then explored some of these questions in more depth, including the same two examples with an additional one.

The results from the survey and focus group have been brought together by 'theme' and are shown below.

Using technical terms – 'Pseudonymisation' and 'Re-identification'

One of the challenges that we faced was that the process used by the NHS and other bodies to share and analyse data, is described using an unfamiliar term to many of 'pseudonymisation'. Rather than use this word in the survey and focus group we included a non-technical explanation of the way in which personal details were not available.

> *'Data is shared and analysed in a way that protects privacy. Personal details are removed or replaced with a code so individuals cannot be identified.*
>
> *(from introduction to the survey and in a focus group slide)*

Where some survey respondents and focus group participants referred to this as making the process 'anonymous' we are confident that they did this in the knowledge of the specific 'pseudonymous' way in which this would be done.

We were also keen to ensure that survey respondents and focus group participants understood what was involved when 're-identification' was used to produce a list of individuals who might then be offered access to a service.

We did this by including the same introductory text in both the survey and a slide for the focus groups.

'In cases where re-identification is necessary—such as for direct patient care—strict legal and ethical safeguards apply. Identifiable data is never shared unless there is, or will be, a direct relationship between the service provider and the patient.'

(from introduction to the survey and in a focus group slide)

We then reinforced this by using specific examples which we were able to discuss in more detail within the focus groups.

Awareness of the NHS sharing data

We were clear in both the introduction to the survey and to the focus groups what uses of patient data we were asking questions about and discussing.

'The NHS securely collects and stores patient information to provide care. This includes details like medical history, test results, and treatments received from GPs, hospitals, and community health services.
Beyond direct care, this data helps the NHS and its partners—such as local councils and charities—improve healthcare and public services. By linking health data with other sources, we can:

- *Identify people who may need extra support before their health worsens.*
- *Assess how well services meet community needs.*
- *Design better care for the future.'*

(from introduction to the survey and in a focus group slide)

We started our survey by asking people whether they were aware, or not, that the NHS uses patient data for 'more than just direct patient care'.

Table 1

Are you aware that the NHS uses patient data for more than just direct patient care e.g.: planning services, improving public health, and identifying people most at risk of getting an illness that can be helped? (survey question 1)

Answer	Number of Responses	Percentage
Yes	344	75%
No	76	16%
Not Sure	41	9%
TOTAL	461 *	100%

(* please note that each survey question received a different number of responses)

75% of respondents (344) indicated that they were aware, with a further 9% (41) 'not sure'. This shows a substantial majority of people who were aware of the NHS using patient data without prior consent in this way.

Other responses in the survey and the focus groups would suggest that people were broadly aware that their data could be shared, along with the knowledge that they could opt out of this happening, without necessarily distinguishing between the different purposes for which it could be shared.

The respondents to the survey and indeed participants in the focus groups were all self-selected. As a result, they may be more interested in this subject and more knowledgeable than other members of the public.

Views on the sharing of data (without prior consent)

The project explored through the survey and the focus groups two different **uses** of patient data.

- for the purposes of planning and potential allocation of resources etc – where the patient data is analysed in a way that means individuals cannot be identified, and where the results are presented in the same way.
- For the purposes of identifying a group of individuals who are then 'offered' something of potential benefit to them

We also looked at two different sets of **users** of patient data.

- just using NHS patient data from one or more sources
- combining NHS patient data with data from other public services – such as councils, the police etc

The responses to two survey questions (shown below) indicated that a substantial proportion were either 'very' or 'somewhat' comfortable with both 'uses' and both types of 'users'.

Table 2
How comfortable are you with the NHS using patient data for more than just direct care e.g.: planning services, improving public health, and identifying those most at risk?
(survey question 2)

Answer	Number of Responses	Percentage
Very comfortable	205	45%
Somewhat comfortable	132	29%
Neutral	48	10%
Somewhat uncomfortable	39	8%
Very uncomfortable	35	8%
TOTAL Responses	459	100%

Table 3
How comfortable are you with the NHS linking its patient data, in a way that means individuals cannot be identified, with information from other public services (e.g.: councils, charities, police) to improve healthcare and public services?
(survey question 3)

Answer	Number of Responses	Percentage
Very comfortable	212	46%
Somewhat comfortable	124	27%
Neutral	47	10%
Somewhat uncomfortable	38	8%
Very uncomfortable	39	9%
TOTAL Responses	460	100%

As can be seen from the answers to these survey questions there was a substantial 'positive' response (Very or Somewhat comfortable) to both questions about using patient data, both within the NHS and between the NHS and other public bodies. There was a much smaller number of all responses that were either 'neutral' or 'negative' (Very or Somewhat uncomfortable). - 26% for Question 2 and 27% for Question 3.

Demographic variation?

We were able to use the demographic data available from survey responses to assess the responses to these two questions by age.

Table 4
How comfortable are you with the NHS using patient data for more than just direct care e.g.: planning services, improving public health, and identifying those most at risk? (survey question 2 – split by age group)

Answers by Age Group	Number of Responses (and percentage)				
	16-35	36-55	56-75	76+	TOTAL
Very comfortable	13 (57%)	52 (48%)	85 (44%)	33(47%)	183(46%)
Somewhat comfortable	7 (30%)	36 (33%)	57 (29%)	20 (28%)	120(30%)
Neutral	2 (9%)	8(7%)	22(11%)	8 (11%)	40(10%)
Somewhat uncomfortable	1 (4%)	5(5%)	16(8%)	7(10%)	29(7%)
Very uncomfortable	0 (0%)	8 (7%)	15(8%)	3(4%)	26(7%)
TOTAL Responses	23(100%)	109(100%)	195(100%)	71(100%)	398(100%)

Table 5

How comfortable are you with the NHS linking its patient data, in a way that means individuals cannot be identified, with information from other public services (e.g.: councils, charities, police) to improve healthcare and public services?
(survey question 3 – split by age group)

Answers by Age Group	Number of Responses (and percentage)				
	16-35	36-55	56-75	76+	TOTAL
Very comfortable	15 (66%)	59 (54%)	79 (41%)	39(54%)	192(48%)
Somewhat comfortable	6 (26%)	29 (26%)	62 (32%)	14 (19%)	111(28%)
Neutral	1(4%)	8(7%)	18(9%)	10 (14%)	37(9%)
Somewhat uncomfortable	1 (4%)	5(5%)	14(7%)	5(7%)	25(6%)
Very uncomfortable	0 (0%)	9 (8%)	21(11%)	4(6%)	34(9%)
TOTAL Responses	23(100%)	110(100%)	194(100%)	72(100%)	399(100%)

There was a more 'positive' response to both questions (Very and Somewhat comfortable) from 16–55-year-olds, than the older age groups.

The answers to survey question 4 *'What thoughts, if any, do you have about the NHS and other public services using linked data in this way'* provided some clear reasons behind the different earlier responses.

Those who were generally positive stressed the benefits to patients.

> *'Anything the NHS can do to use non identifiable data to help improve patient outcomes is something I'd support.'*
>
> *Providing data is stored safely and is used anonymously I strongly support it being used to improve healthcare and public services.'*

The other strong message was that many people were concerned about the data being used in what they saw as the wrong way, to the benefit of 'foreign' 'commercial' organisations. Respondents who mentioned this issue were almost unanimous in not wanting this to happen. If data was to be shared, and analysed, it should only be for the specific purpose identified, and therefore there should be very clear 'rules' around this.

'I would like to be reassured that NHS data is not being given to big tech companies, through some sort of NHS or government commitment.'

'No USA companies being involved at all!'

'So long as the data is kept away from companies who can and will mine it for private services / products, I am OK with the public services holding our data and using it for research and non-direct care purposes.'

Opting Out

We asked some specific questions in the survey about this. We wanted to establish what everybody understood about this.

We first asked whether people knew how to opt out of their data being shared. Table 4 below shows the response to this question.

Table 6

Do you know that you can opt out of your NHS data being shared? (survey question 7)

Answer	Number of Responses	Percentage
Yes	317	69%
No	97	21%
Not Sure	44	10%
TOTAL	458	100%

This shows a substantial majority of respondents (69%) were aware that they could opt out but still 21% who did not know.

We then asked whether people knew how to opt out, if they wanted to do this.

Table 7
If you wanted to opt out of your NHS data being shared
do you know how to do this? (survey question 8)

Answer	Number of Responses	Percentage
Yes	144	31%
No	204	45%
Not Sure	108	24%
TOTAL	456	100%

Nearly half of the respondents indicated that they did not know how to do this.

We asked one final question about opting out – where people would go to find out information on this. Respondents were given the opportunity to select up to 3 options and on average chose two.

Table 8
Where would you go to find out information on opting out? - select up to three options – (survey question 9)

Option	Number of times option chosen	Percentage
The NHS App	222	49%
Internet Search	209	46%
My GP surgery website	192	42%
Contact my GP surgery	167	37%
Website of an NHS service that I have used	69	15%
Contact an NHS service that I have used	32	7%
All other responses	38	8%
TOTAL Responses	458	100%

Almost all those completing the survey did so on-line and so it might be reasonable to expect the answers to this question to focus on on-line sources. However. it is clear that the two main preferred 'NHS' sources were the GP Practice, and the NHS App. Equally prominent was the 'internet search'.

There was some confusion expressed in the focus groups about whether it was or was not possible to opt out of sharing your data in relation to specific projects. Whilst people understood that they could only do so as part of an overall opting out process, they were unsure whether it was possible to opt out of sharing data related to NHS that they may have used.

> *'Who are we opting out to when so many agencies have access to our data? If we opt out, will that result in access to our data being removed from all linked agencies or even parts of the NHS?'*

Data Safety and Security

One of the questions asked in the survey was 'What *would reassure you that your data is being used safely and securely'.*

Some respondents simply said, 'nothing *would reassure me'*.

This was based in some cases on previous experience.
'Previous data that were supposed to be safe and secure still managed to be hacked. Therefore, I have no confidence in sharing personal data systems.'

Others suggested that it might be impossible to guarantee that data could be held securely.

> *'In the current circumstances and in this day and age I don't believe any data can be totally secure'.*

There were a number of suggestions made as to how the risks of this happening could be mitigated in practice.

Holding any shared data anonymously was seen as positive.

'The fact that patient data is anonymous is reassuring – because sadly these days you just can't trust everyone 100 per cent'

There was a real emphasis on the NHS (and other) bodies being open and transparent about what they were doing with the data.

'Making public in simple basic English the procedures you will take to secure data'. Information for the public needs to be at the right level.'

Practical suggestions included.

'Maybe a newsletter through the GP advising about how data is used properly'. or 'a letter from the NHS advising (in layman terms) how data is used and shared safely and securely.

'staff training as some of the issues are human errors'

Some respondents wanted there to be an opportunity to see the detail of the approach taken.

'Being able to see the method used and data that is being shared to ensure that it is safely protected.'

'Openness to allow tracking of data paths at all times, but not the data itself'

There was also an emphasis from some respondents (who probably had the greatest level of knowledge in this area) of the importance of the *'use of data protection standards, secure networks, and data sharing agreements.'*

Using data for service planning and evaluation

One of the examples used in the focus groups was of bringing data together across a number of public sector agencies. This could include NHS data, Social Care data, and police data. The aim with this was to be able to evaluate a specific initiative from the Police where some people experiencing mental health issues were transferred from initial contact to NHS mental health services.

EXAMPLE – Right Place, Right Care

The Norfolk Office of Data and Analytics (NODA) is collecting data to understand how changes in emergency response are impacting health and care services. As part of this, they are monitoring the effects of 'Right Care, Right Person', a police initiative designed to ensure vulnerable people receive support from the most appropriate service, rather than defaulting to a police response. Under this approach, calls that do not involve immediate risk to life or a crime are redirected to relevant agencies, such as the NHS or social care services.

By linking and analysing data from across the system from partners such as The Police, Adult Social Care, Children's Services, and the ambulance service NODA aims to assess how this shift is affecting demand for each service and the associated impact on care and outcomes.

This was seen as a good use of shared data. Given that all analysis was done on an anonymous basis and that it was used to inform the better planning of services for the future.

> *'Practical use of an application. This is what the system should be doing.'*

It was seen as an example of using data to inform a positive outcome for individuals in the future.

> *'You need to see how it currently looks, what could be done better. So that without that data you don't know where to put the money in.'*

One focus group participant even preferred the use of data in this way because *'I'd be much more willing for it to be used without concern because I know I'm not going to get anything, you know bombarded with letters or phone calls!'*

A more general support for this kind of use of data was found in survey responses (to Question 5).

> *'There ought to be more of this, assuming that data stays anonymous. There are lots of linked issues / services e.g.: housing, health, social care etc and services need to be streamlined so they deliver the best outcomes for people.'*
>
> *Using data analysis in this way to help join up services was seen as beneficial.*
> *'Data is needed to help improve our services and overall living standards'*
>
> *'Too often in this country our public services are not joined up and this results in a poorer service to the general public'*

Using data to identify individuals for targeted support

In both the survey and the focus groups we asked questions based on two examples of data being used to identify a group of individual patients. They were then offered access to a specific service designed to benefit them.
In the 'warm homes scheme' this was offering patients with respiratory problems potentially access to a (free!) home improvement initiative that could help them better heat their homes and avoid ill health and even an acute hospital admission.

EXAMPLE – Warm Homes Scheme

To reduce hospital admissions for illnesses that affect people's breathing, councils identify people who may struggle to keep their homes warm. The councils use their own data sources, such as housing records, and share data with the NHS in a way that means that individuals cannot be identified. The NHS then analyses this data to identify individuals at higher risk of getting an illness that affects their breathing because of their housing conditions. Once the analysis is complete, the NHS shares clear, relevant data back with the councils so they can offer targeted support, such as help for people to heat their home, to those in need.

With the 'mental health' scheme patients who were identified as taking prescribed drugs for 'anxiety and depression' were contacted to be encouraged to self-refer to the well-being service as they had not already accessed it.

EXAMPLE – Mental Health Scheme

To improve mental health support for people, the NHS cross-checks GP prescriptions with mental health service records. Patients who have been prescribed antidepressants or anti-anxiety medication but have not yet accessed mental health support are contacted to inform them about available services and how to self-refer. Data is used in a way that means individuals cannot be identified when establishing those most as risk, with re-identification only occurring when outreach to the patient is required.

These examples were used in the focus groups to draw out views on the wider use of this approach.

In the survey we asked whether respondents thought that these two schemes were 'an appropriate use of patient data'. In both cases a relatively low number answered 'no'. (20% for the warm homes one and 18% for the mental health one).

Table 9

Do you think Example A (Warm Homes scheme) is an appropriate use of patient data? (survey question 10)

Answer	Number of Responses	Percentage
Yes	346	80%
No	87	20%
TOTAL	433	100%

Table 10

Do you think Example B (Mental health support scheme) is an appropriate use of patient data? (survey question 11)

Answer	Number of Responses	Percentage
Yes	267	62%
No	77	18%
Not Sure	88	20%
TOTAL	432	100%

This would suggest a majority of survey respondents were in favour of using and analysing patient data when it leads to individuals being offered something of potential benefit to them.

We were able to explore the issues with this approach in much more depth through the focus groups.

What emerged was a set of issues and concerns that people felt needed to be addressed in relation to each specific proposed scheme.

Whilst there was support for the outcomes that the NHS (and other bodies) were seeking to achieve it was questioned whether a particular scheme was the best way to achieve these.

With the warm home scheme:

> *'My neighbour has COPD, and I know that they wouldn't want anyone coming in to give them a new boiler'*

It was felt that some people might not react well to what they see as an offer of help.

> *'a lot of pensioners I worked with didn't want charity'*

With the mental health scheme:

> *'If you were likely to access the well-being service, you've already gone and approached your GP and there's going to be information in the Practice waiting area, usually about well-being…I think there's plenty of other opportunities to find out about it.'*

There was a lot of discussion about how people might be contacted, and who by. The consensus was that people needed to be contacted by letter, and that this should give you confidence that it had come from a 'trusted source' such as the General Practice.

> *'Definitely letter. I would pay more attention to a letter than a phone call because it would have my name on it. Yeah, and I guess possibly an NHS number or some reference'*
>
> *'I think sending out something that's saying you know, this is what is available, and you can self-refer. Yes, that's good. But then to follow up with a phone call, I would be very suspicious.'*
>
> *'So, if you've been, if you've been phoned up saying we've identified you because you're on a GP list etc, you might well not even answer the phone'*

The clear message from the focus groups was that the way in which any scheme was managed needed to be thought through very carefully. This would help to make it successful and to avoid unintended consequences. This included:

1. **Who was approaching individuals** – a GP Practice for example was seen as a trusted source by many participants.

'For me, it's a lot about how best it's done, and if you're going to make a phone call to someone who's been identified, it would be better, in my opinion, to come from a trusted source.

'Example about mental health is highly sensitive…. only acceptable scenario would be for the GP to contact person and offer additional support.'

'Due to the nature of mental health, contacting people out of the blue could do more harm than good.'

2. **The timing of any approach** - *'they might be managing perfectly fine. Thank you very much. And if somebody then calls or they get a letter bearing in mind we are dealing with potential mental health issues?'*

3. **How individuals were approached** – the methods to be used including written letters, e mail, texts, and phone calls.'

4. **What was being 'offered' to the individual** – and how might they react to this offer?

5. **The availability of any offer** – to ensure that there was no adverse impact because the service was not available. *'you often have long waiting lists because they are already heavily subscribed'.*

Informing patients and the public

When this was discussed in the focus groups there was strong support expressed for the public being informed of what the NHS was doing with patient data.

A number of practical suggestions for where information could be made available included:

- Information available in GP surgeries and Pharmacies
- On social media
- Through Radio and TV
- On the NHS App
- Use of screens in waiting areas

> *'I think it does matter…. the NHS has a lot of resources from doctors' surgeries to ER rooms to corridors where they could flash this kind of information as well. And a huge amount of people would see it.'*

Involving patients and the public

As well as informing people, the focus groups discussed how people might be involved.

It was recognised that whilst it was good to inform as many people as possible, it was likely that only a much smaller number of people might be interested in being more actively involved.

> *'Might there be almost two levels? There's stuff that you might want as many people as possible to have some awareness of, and there might be specifics that you want a given group of people to be able to answer more specific questions or contribute more specifically. So, it might be a combination of things.'*

Evidence of this interest in being involved actually came through this project. For example, as part of the survey we asked respondents whether they would like to be put on the relevant Healthwatch newsletter circulation. We also asked if people were interested in attending a focus group. Although time did not allow us to include the latter in the face-to-face focus groups there were a considerable number of people who both asked to be put on the newsletter circulation list and expressed an interest in contributing to future work. These could well be a source of volunteers for any such work.

What this means

The project took place in a context in which both ICBs are already carrying out projects that involve the analysis and use of patient data without obtaining prior consent from individuals. The clear national strategy is to support and encourage the greater use of the 'Population Health Management' approach and the use of 'risk stratification'.
The ICBs should therefore be encouraged that the survey and focus group respondents, whether looking at the general question, or specific schemes, were generally supportive of it happening.

Where people were less happy about this kind of data sharing being conducted, they were primarily concerned with the potential misuse of data. They lacked confidence on the ability of the NHS to keep data secure, either from external threats such as cyber-hacking, or from internal processes and behaviour.

Those who were positive about it happening still frequently mentioned the need for this to be done in a safe and secure way. The 'anonymisation' and 'pseudonymisation' of data during analysis was seen as a good way of doing this.

> *'The key is robust systems in place to ensure personal identifiable data dies not get into the wrong hands and is used inappropriately'.*

The other strong message was that some respondents were concerned about the data being used in what they saw as the wrong way, to the benefit of 'foreign' 'commercial' organisations. Those who mentioned this issue were almost unanimous in not wanting this to happen.

When data was to be shared, and analysed, it should only be for the specific purpose identified, and there should be very clear 'rules' around this. Data safety and security was therefore seen as very important.

In both the survey responses, and in the discussion about a specific example in the focus groups, there was a clear consensus that people were happy with the aim of sharing data anonymously in order to assist the evaluation of services and benefiting future service planning.

When it came to schemes that ‘re-identified’ people following this analysis in order for them to be contacted and offered something the views expressed were much more mixed. There were a number of key messages from the focus groups in particular, who had the opportunity to discuss two schemes where this was the case in some depth.

Whilst people generally supported the outcomes that the schemes were intended to achieve, they had a number of concerns. These have been converted into some questions which could be applied to any individual scheme. These included:

- Is the patient benefit / outcome that is being sought by the NHS (and other bodies) best achieved through a scheme that uses patient data?
- Is the proposed scheme the best way of doing this in a way that will maximise the intended patient benefit (whilst minimising any adverse consequences etc)?
- Has the method of contacting individuals, including who and where any information comes from, been fully considered and the most appropriate one chosen?
- Have we learnt from previous schemes and can then apply this learning to future ones?

Both survey respondents and focus group participants saw the benefit of the wider public being informed about what the ICBs were doing, and planning to do. Such information could provide greater re-assurance that everything was being done in a way that minimised the risks with data safety and security.

By disseminating information that included evidence of positive outcomes and patient benefits this could also reinforce confidence. Being ‘open and transparent’ with the public was seen as a very positive thing. A number of suggestions were made as to how this could be done.

As indicated by the feedback on the schemes that included contacting people, there was a strong feeling expressed in the focus groups that the ICBs and other bodies would benefit from finding ways to ‘involve’ interested members of the public in contributing to all stages of the development and implementation of these schemes. This particularly applied to schemes that including contacting people. It was recognised that there were a variety of ways in which this could happen.

The key findings from this feedback have been incorporated into the recommendations that follow.

Recommendations

This report recognises that the two ICBs are at different stages in their development of work in this area. They are both also in the middle of substantial organisational change, which will impact on the functions that they carry out, and the resources available to do this.

The recommendations are based on the key findings from our survey and focus group work. They are therefore grounded in the views and experiences of local people. We believe that they are therefore relevant to the future work of whichever NHS organisations are responsible for this.

1) Informing People

Ensure that the public are fully informed about the local use of data without prior consent by:

- Providing a clear explanatory briefing outlining the approach and activities of the ICB, and including assurances on data safety and security, and opting out (see below)
- Continuing to provide information on existing schemes through NHS body websites, screens in waiting areas, newsletters, on-line sites and media outlets as appropriate.

2) Involving people

Seek to involve interested members of the public / patient groups in all schemes where data is to be used without prior consent including:

- Discussing initial ideas
- Identifying the desired outcomes and benefits to people / patients
- Considering any potential adverse impacts and how to reduce / eliminate these
- Evaluation of completed schemes

3) Notifying people who have been identified to be offered a service etc

Review the different methods and types of material used in contacting people (letters, texts, e mails, phone calls etc) who have been identified to be offered something following the data analysis

- Learning from previous experience within the ICBs
- Learning from the views and comments expressed in the focus groups in this project

4) Opting Out

Clarify the arrangements for individuals being able to opt out of sharing their data and then ensure that this information is included in any relevant explanatory briefing (see above)

5) Future Work

ICBs to meet with local Healthwatch organisations for their area to discuss the recommendations in this report, the actions they propose to take as a result, and how they will continue to include the patient and public voice and views in their future work. (timescale to be agreed but we suggest within 3 to 6 months)

Response from Cambridgeshire and Peterborough and Norfolk and Waveney Integrated Care Boards

We'd like to thank Healthwatch Norfolk and Healthwatch Cambridgeshire and Peterborough for delivering such a thoughtful and impartial programme of engagement. This report gives voice to the public at a critical time, as we seek to improve how data is used across our health and care systems.

We know that the public expect their data to be used responsibly, transparently, and only where it has a clear purpose, and this report reflects those expectations well. The feedback we've received has helped us strengthen the way we explain our technical environments such as the Data Hub, tighten the safeguards we have in place, and ensure that people's preferences are recognised and respected.

Most importantly, the engagement has reinforced the value of involving patients and the public from the outset. It's clear that people support data being joined up if it leads to better care, but only if their trust is earned and maintained.

We're grateful for the honest conversations and helpful recommendations, many of which we have already acted on. This work will play a vital role in ensuring our future data initiatives are built on openness and transparency.

Pete Best, Associate Director of Insight & Analytics, NHS Norfolk and Waveney ICB
Chris Gillings, Associate Director of Business Analytics, NHS Cambridge & Peterborough ICB

Appendices

Appendix 1 – Survey Questions

Use of Patient Data – Introduction

The NHS securely collects and stores patient information to provide care. This includes details like medical history, test results, and treatments received from GPs, hospitals, and community health services. Beyond direct care, this data helps the NHS and its partners—such as local councils and charities—improve healthcare and public services. By linking health data with other sources, we can:

- Identify people who may need extra support before their health worsens.
- Assess how well services meet community needs.
- Design better care for the future.

Data is shared and analysed in a way that protects privacy. Personal details are removed or replaced with a code so individuals cannot be identified. In cases where re-identification is necessary—such as for direct patient care—strict legal and ethical safeguards apply. Identifiable data is never shared unless there is, or will be, a direct relationship between the service provider and the patient.

We want to hear your thoughts on how NHS data is used. Your feedback will help us ensure data is handled responsibly and securely while supporting better healthcare and services for you and your community.

---

1) Are you aware that the NHS uses patient data for more than just direct patient care (e.g.: planning services, improving public health, and identifying people most at risk of getting an illness so they can be helped?

Yes	
No	
Not sure	

2) How comfortable are you with the NHS using patient data for more than just direct care (e.g.: planning services, improving public health' and identifying those most at risk?

Very Comfortable	
Somewhat comfortable	
Neutral	
Somewhat uncomfortable	
Very uncomfortable	

3) How comfortable are you with the NHS linking its patient data, in a way that means individuals cannot be identified, with information from other public services (e.g.: councils, charities, police) to improve healthcare and public services?

Very Comfortable	
Somewhat comfortable	
Neutral	
Somewhat uncomfortable	
Very uncomfortable	

4) What thoughts, if any, do you have about the NHS and other public services using linked data in this way?

5) The NHS follows strict security and confidentiality rules when sharing data for non-direct care purposes. How confident are you that your data will be protected?

Very Confident	
Somewhat confident	
Neutral	
Somewhat unconfident	
Not very confident	

6) What would reassure you that your data is being used safely and securely?

7) Do you know that you can opt out of your NHS data being shared?

Yes	
No	
Not Sure	

8) If you wanted to opt out of your NHS data being shared, do you know how to do this?

Yes	
No	
Not Sure	

9) Where would you go to find information on opting out? (Select up to three options).

My GP surgery website	
Contact my GP surgery	
The NHS App	
The website of an NHS service that I have used	
Contact an NHS service that I have used	
Internet search (Google, Bing)	
Ask a friend or family member	
Other (please specify below)	

We are now going to give you two examples of NHS data use.

Example A – Warm Homes Initiative

To reduce hospital admissions for illnesses that affect people's breathing, councils identify people who may struggle to keep their homes warm. The councils use their own data sources, such as housing records, and share data with the NHS in a way that means that individuals cannot be identified. The NHS then analyses this data to identify individuals at higher risk of getting an illness that affects their breathing because of their housing conditions. Once the analysis is complete, the NHS shares clear, relevant data back with the councils so they can offer targeted support, such as help for people to heat their home, to those in need.

10) QUESTION - Do you think Example A is an appropriate use of patient data?

Yes	
No	
Not sure	

Example B – Mental Health Support

To improve mental health support for people, the NHS cross-checks GP prescriptions with mental health service records. Patients who have been prescribed antidepressants or anti-anxiety medication but have not yet accessed mental health support are contacted to inform them about available services and how to self-refer. Data is used in a way that means individuals cannot be identified when establishing those most as risk, with re-identification only occurring when outreach to the patient is required.

11) Do you think Example B is an appropriate use of patient data?

Yes	
No	
Not sure	

12) Based on these examples, do you have any additional thoughts on how NHS data should be used or what safeguards should be in place

Appendix 2 - Demographics of Survey Respondents

AGE		
	Response Percentage	**Response Total**
16-25	2%	8
26-35	4%	15
36-45	10%	41
46-55	17%	69
56-65	22%	89
66-75	27%	106
76-85	17%	68
86 plus	1%	4
TOTAL Responses	100%	400
GENDER		
Answer Choice	**Response Percentage**	**Response Total**
Male	30%	122
Female	66%	273
Non-binary	0%	0
Genderfluid	0%	0
Genderqueer	0%	0
Intersex	0%	0
Prefer not to say	3%	11
Prefer to self-describe:	1%	6
TOTAL Responses	100%	412

SEXUALITY		
Answer Choice	**Response Percent**	**Response Total**
Bisexual	4%	15
Gay or Lesbian	3%	11
Heterosexual or straight	83%	335

Pansexual	Less than 1%	2
Prefer not to say	10%	39
TOTAL Responses	100%	402

ETHNIC GROUP

Answer Choice	**Response Percent**	**Response Total**
Chinese	<1%	1
Indian	<1%	3
Caribbean	<1%	1
Asian and White	<1%	2
Black Caribbean and White	<1%	1
Any other Mixed / Multiple ethnic groups background	<1%	2
White:		
British / English / Northern Irish / Scottish / Welsh	87%	353
Irish	<1%	3
Any other White background	5%	19
Other:		
Any other Ethnic Group	1%	4
Prefer not to say	5%	18
TOTAL Responses	100%	407

Please select any of the following that apply to you:

Answer Choice		**Response Percent**	**Response Total**
1	I have a disability	21%	84
2	I have a long-term condition	43%	174
3	I am a carer	14%	55
4	None of the above	39%	156
5	I prefer not to say	5%	22
	TOTAL Responses	100%	401

Appendix 3 – Focus Group Details

Venues, Dates, and Numbers of participants

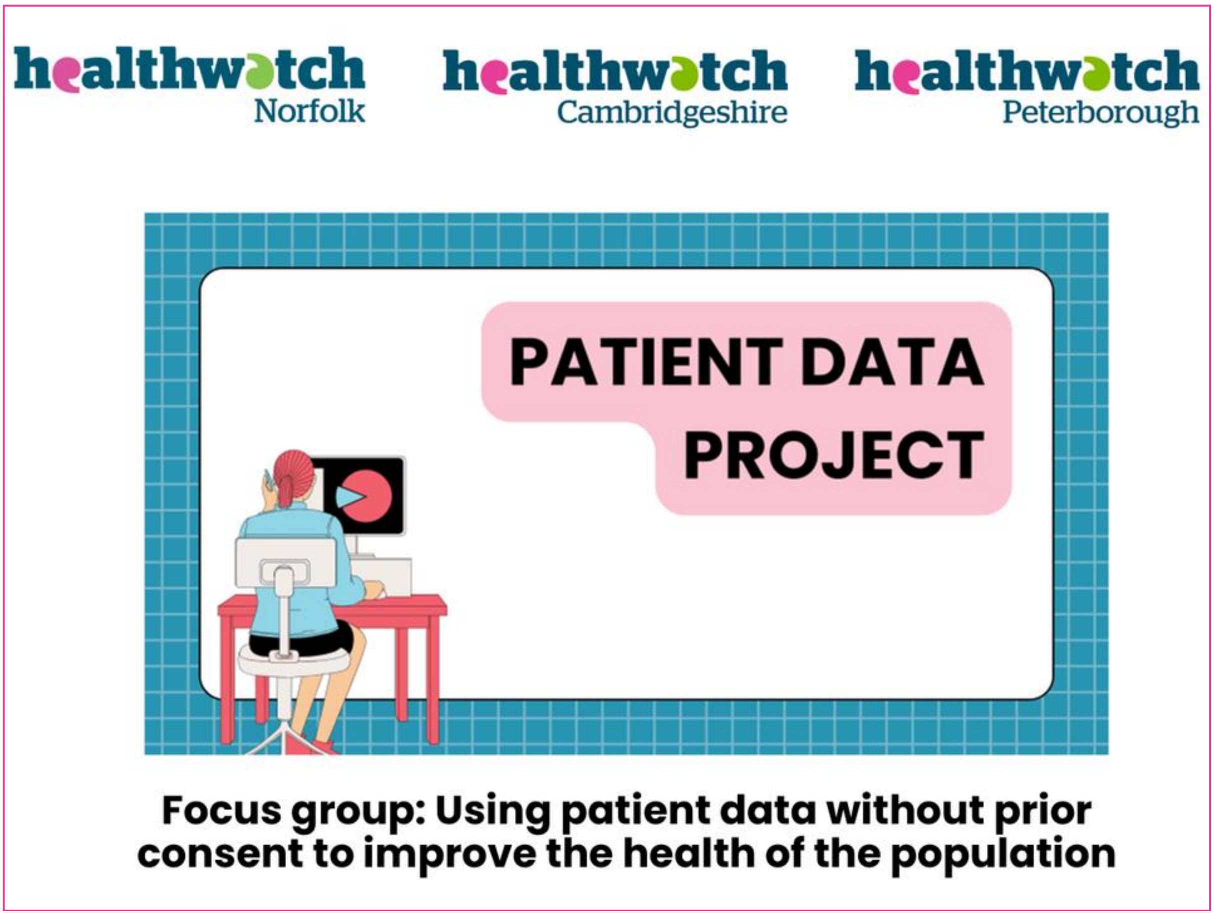
Location	**Date**	**Number of participants**
Healthwatch Norfolk Offices - Wymondham	24th March, 2025	7
The Fleet Community Centre, Fletton, Peterborough	28th April, 2025	12
West Norfolk College, King’s Lynn x 2	2nd May, 2025	12
Toftwood Social Club, Dereham	10th May, 2025	10
Bob Champion Centre, Norfolk and Norwich Hospital, Norwich	12th May, 2025	9
TOTAL	6	50

Appendix 4 – Demographics of Focus Group Participants

AGE		
	Response Percentage	**Response Total**
16-24	34%	14
25-49	17%	7
50-64	12%	5
65-79	32%	13
80 plus	5%	2
TOTAL Responses	100%	41

GENDER		
Answer Choice	**Response Percentage**	**Response Total**
Male	23%	11
Female	73%	35
Non-binary	4%	2
TOTAL Responses	100%	48

Appendix 5 - Focus Group presentation slides



healthwatch Norfolk

healthwatch Cambridgeshire

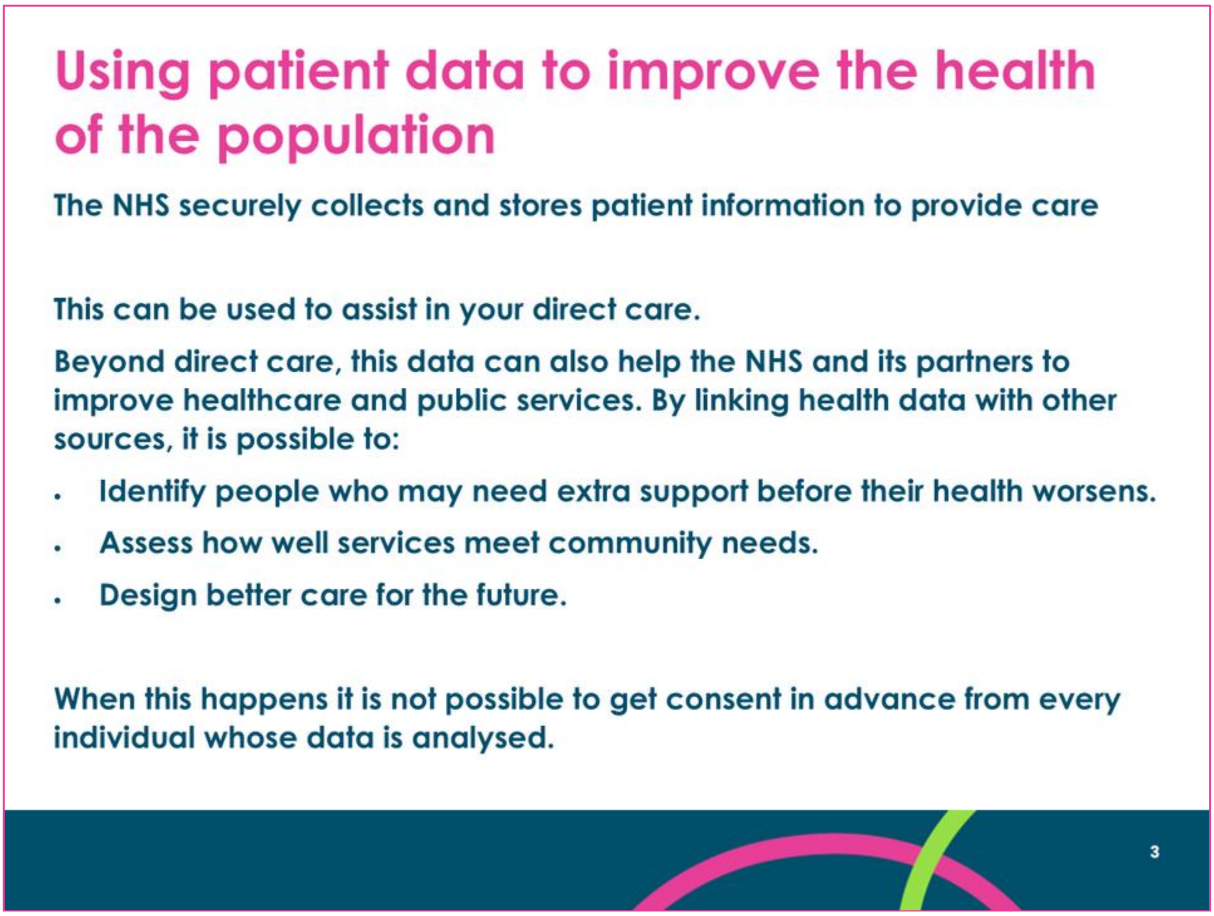
healthwatch Peterborough

PATIENT DATA PROJECT

Focus group: Using patient data without prior consent to improve the health of the population

Welcome!

- Consent and demographics forms
- Recording consent
- House keeping
- Healthwatch Norfolk



Using patient data to improve the health of the population

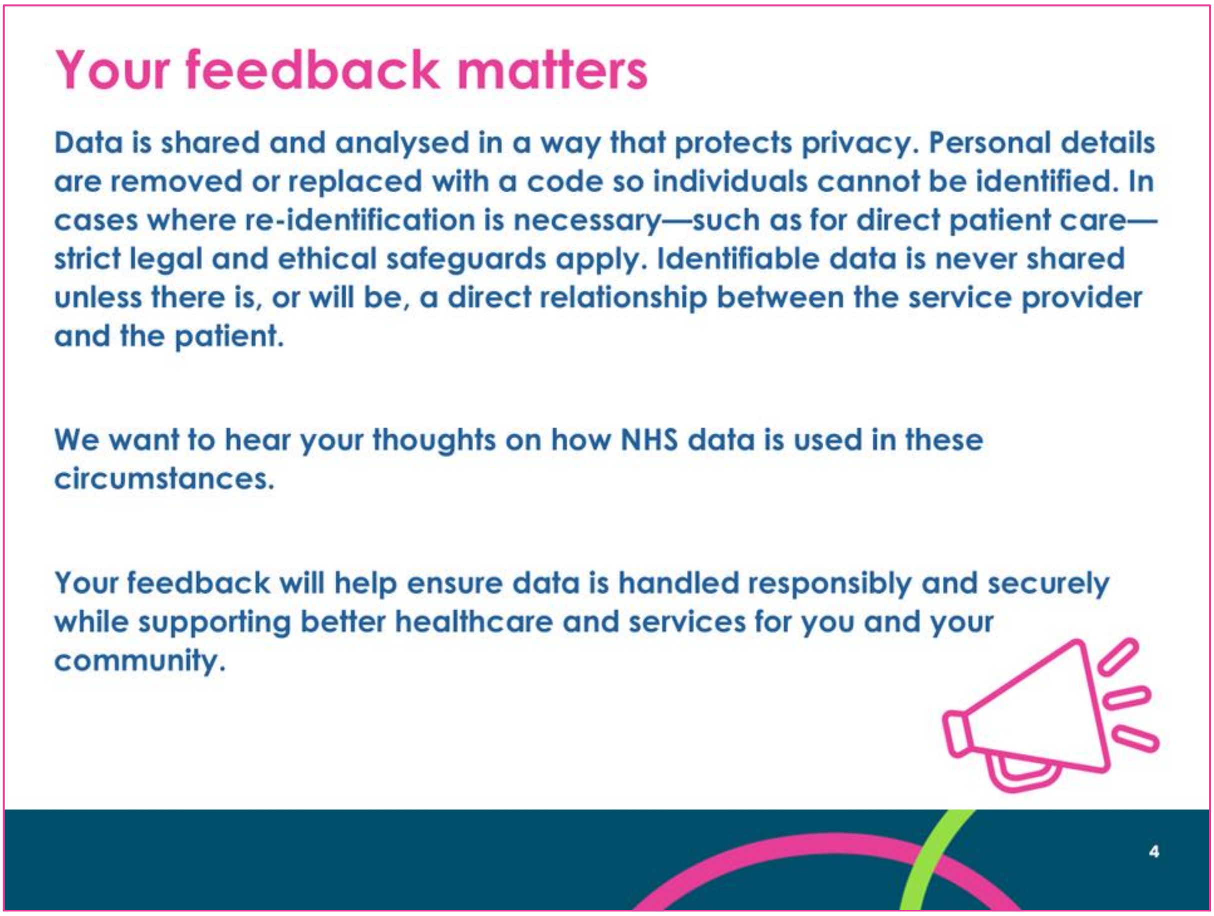
The NHS securely collects and stores patient information to provide care

This can be used to assist in your direct care.

Beyond direct care, this data can also help the NHS and its partners to improve healthcare and public services. By linking health data with other sources, it is possible to:

- Identify people who may need extra support before their health worsens.
- Assess how well services meet community needs.
- Design better care for the future.

When this happens it is not possible to get consent in advance from every individual whose data is analysed.

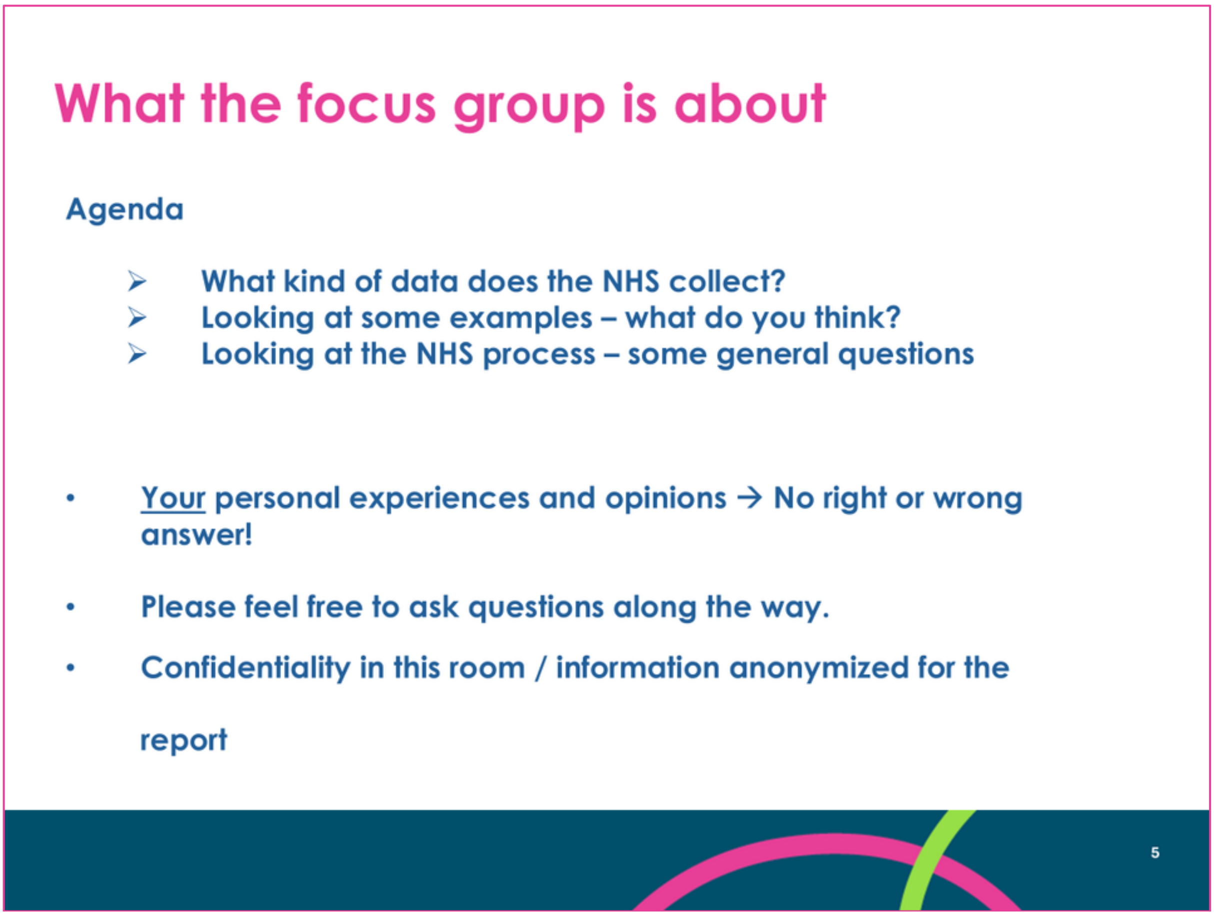


Your feedback matters

Data is shared and analysed in a way that protects privacy. Personal details are removed or replaced with a code so individuals cannot be identified. In cases where re-identification is necessary—such as for direct patient care—strict legal and ethical safeguards apply. Identifiable data is never shared unless there is, or will be, a direct relationship between the service provider and the patient.

We want to hear your thoughts on how NHS data is used in these circumstances.

Your feedback will help ensure data is handled responsibly and securely while supporting better healthcare and services for you and your community.

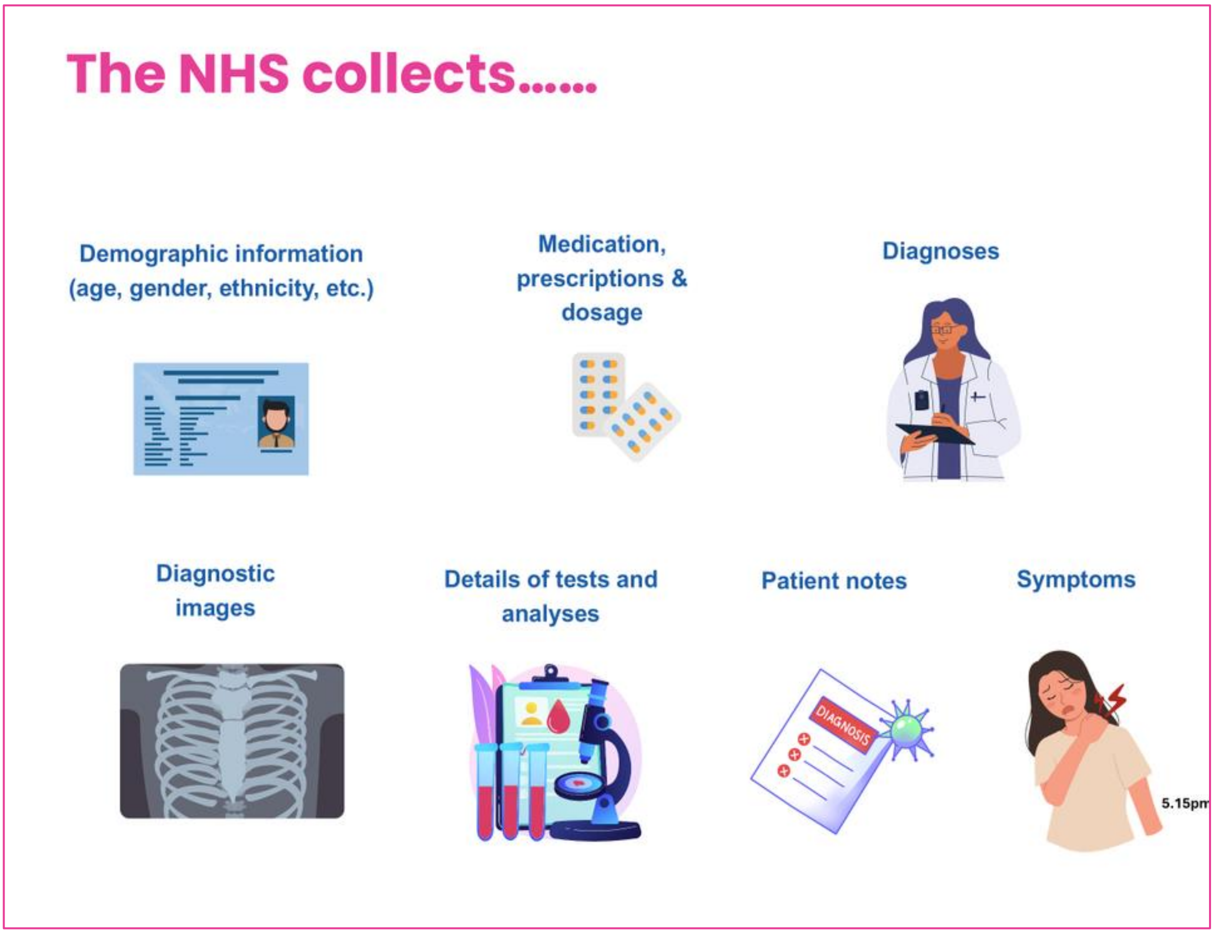


What the focus group is about

Agenda

- What kind of data does the NHS collect?
- Looking at some examples – what do you think?
- Looking at the NHS process – some general questions

- Your personal experiences and opinions → No right or wrong answer!
- Please feel free to ask questions along the way.
- Confidentiality in this room / information anonymized for the report



The NHS collects……

Demographic information (age, gender, ethnicity, etc.)

Medication, prescriptions & dosage

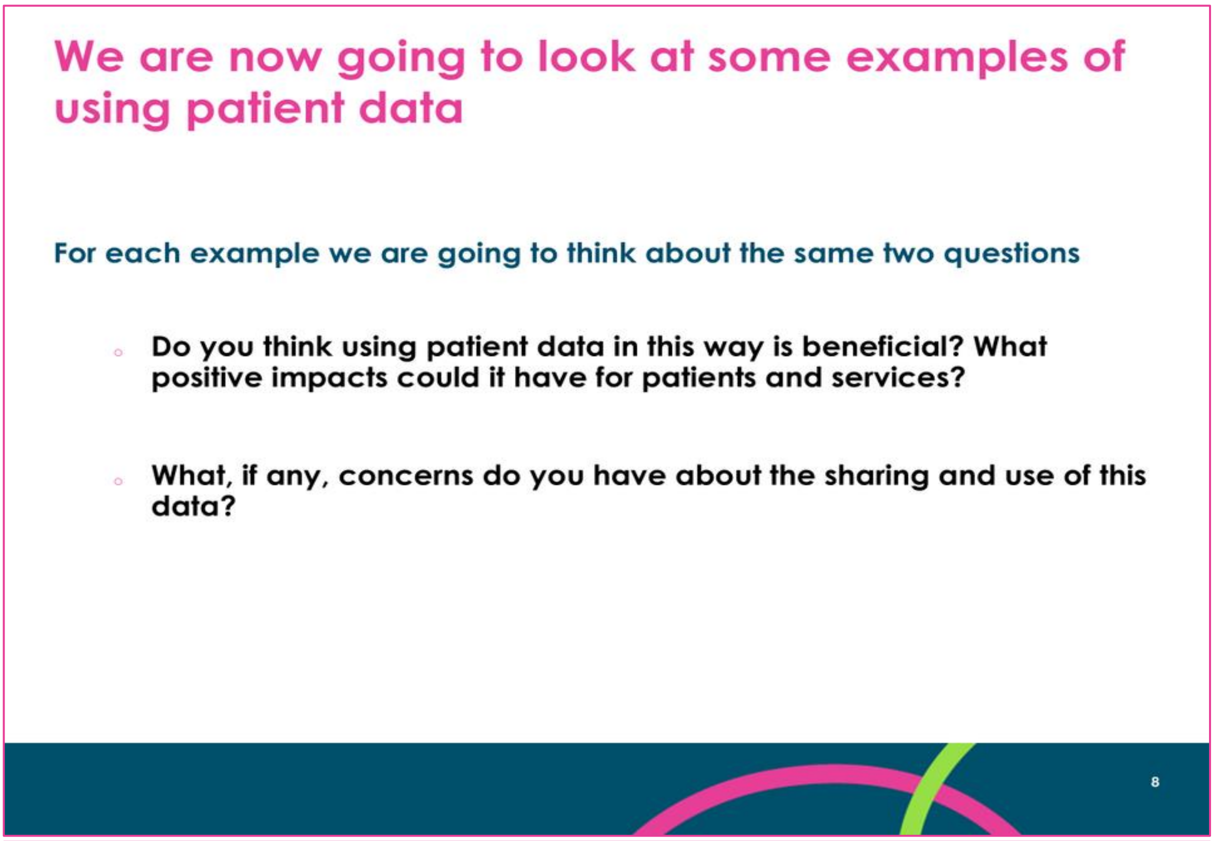
Diagnoses

Diagnostic images

Details of tests and analyses

Patient notes

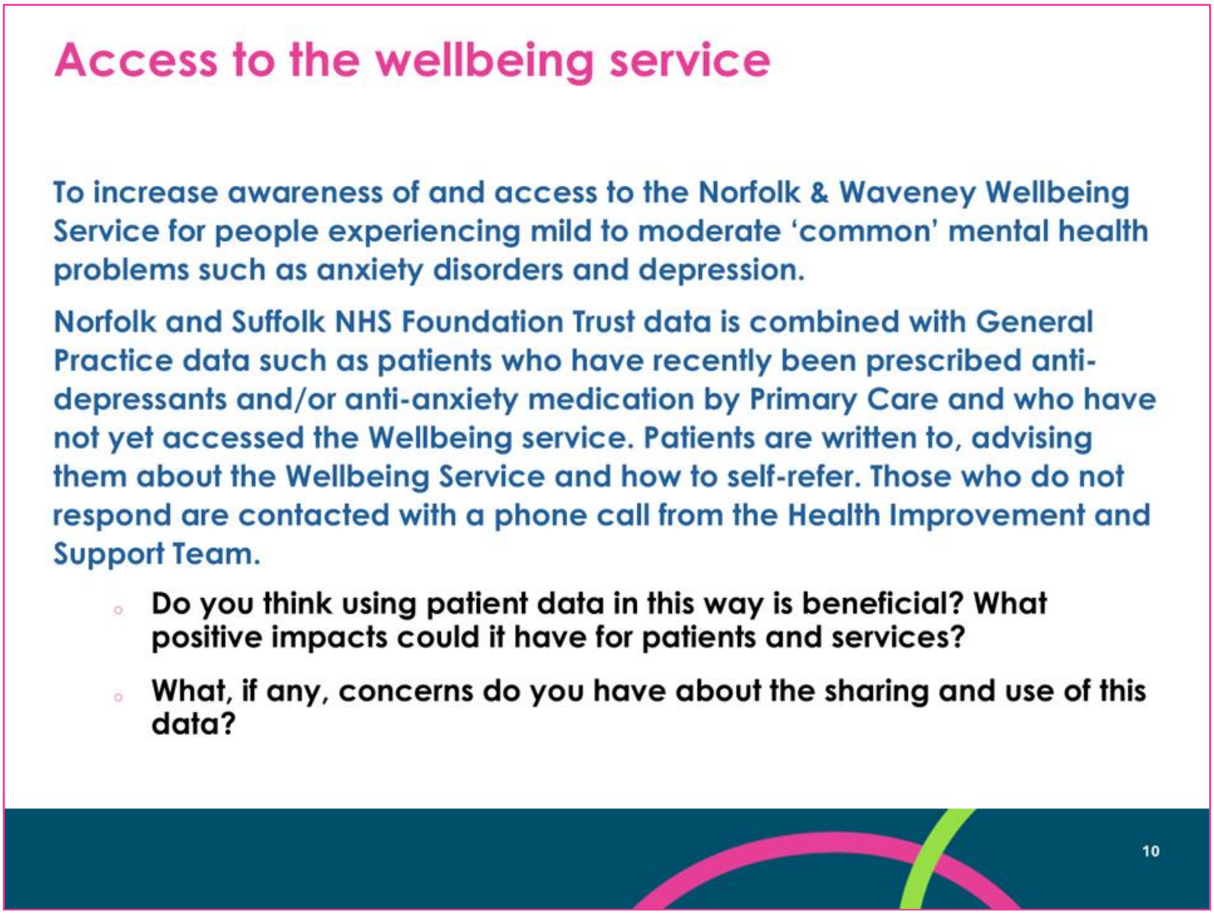
Symptoms



We are now going to look at some examples of using patient data

For each example we are going to think about the same two questions

- Do you think using patient data in this way is beneficial? What positive impacts could it have for patients and services?
- What, if any, concerns do you have about the sharing and use of this data?

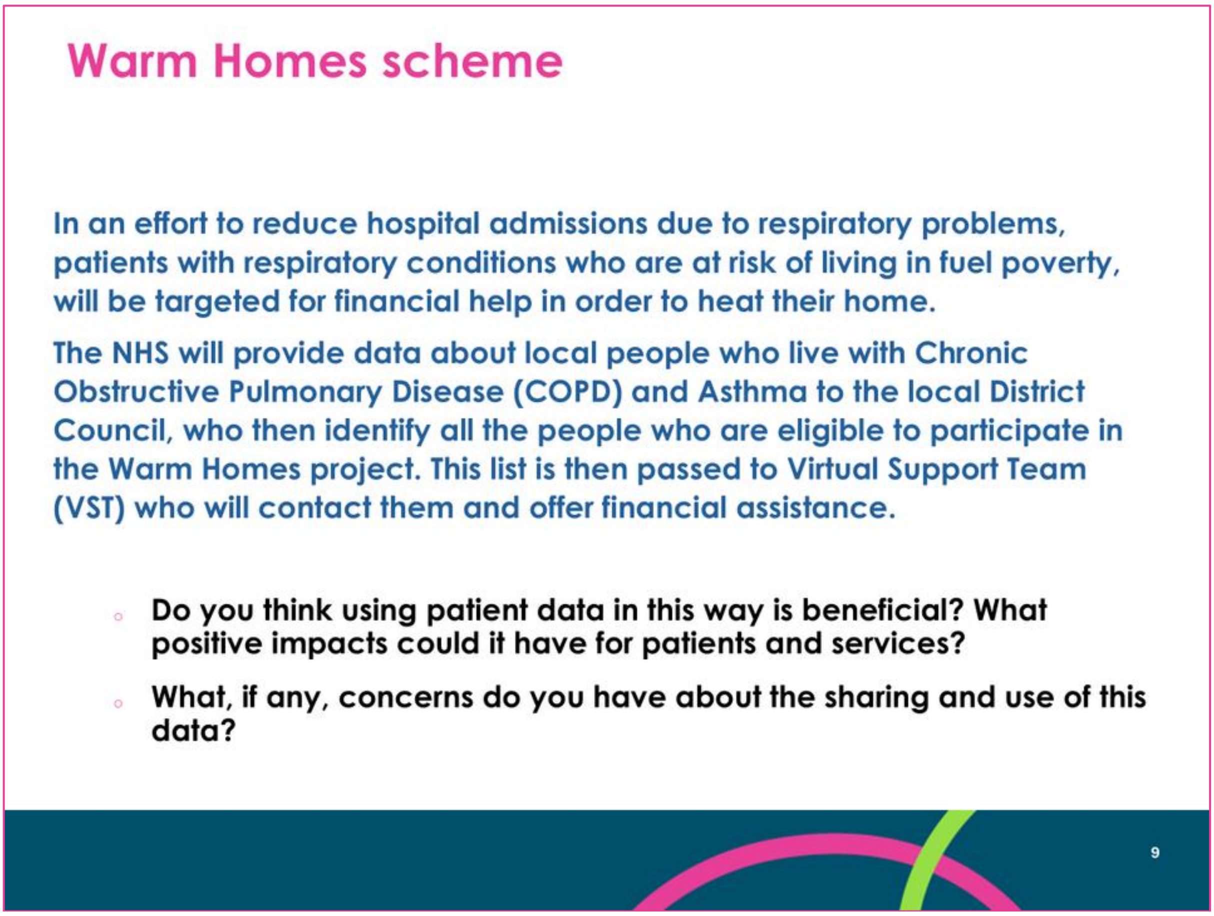


Access to the wellbeing service

To increase awareness of and access to the Norfolk & Waveney Wellbeing Service for people experiencing mild to moderate 'common' mental health problems such as anxiety disorders and depression.

Norfolk and Suffolk NHS Foundation Trust data is combined with General Practice data such as patients who have recently been prescribed anti-depressants and/or anti-anxiety medication by Primary Care and who have not yet accessed the Wellbeing service. Patients are written to, advising them about the Wellbeing Service and how to self-refer. Those who do not respond are contacted with a phone call from the Health Improvement and Support Team.

- Do you think using patient data in this way is beneficial? What positive impacts could it have for patients and services?
- What, if any, concerns do you have about the sharing and use of this data?



Warm Homes scheme

In an effort to reduce hospital admissions due to respiratory problems, patients with respiratory conditions who are at risk of living in fuel poverty, will be targeted for financial help in order to heat their home.

The NHS will provide data about local people who live with Chronic Obstructive Pulmonary Disease (COPD) and Asthma to the local District Council, who then identify all the people who are eligible to participate in the Warm Homes project. This list is then passed to Virtual Support Team (VST) who will contact them and offer financial assistance.

- **Do you think using patient data in this way is beneficial? What positive impacts could it have for patients and services?**
- **What, if any, concerns do you have about the sharing and use of this data?**

healthwatch
Norfolk

Supported by:

healthwatch
Cambridgeshire

healthwatch
Peterborough