Patient Data for Planning and Population Health – Views and Expectations

Survey Findings and Research Materials

For Understanding Patient Data

18th April 2024

MRS Evidence Matters™ Company Partner

QaResearch

Contents

1. Methodology

The research consisted of two strands:

- Quantitative survey with members of the general public
- Qualitative online workshops with members of the general public

This report contains findings from the quantitative survey only.

Sample

For this research, a nationally representative sample (n=1,000) was gathered through an online panel survey in the UK.

The sampling strategy was informed by Nomis, enabling accurate insights into the demographic composition of the general UK population.

Survey Question Development

Following the preliminary desk research which helped pinpoint knowledge gaps relating to public and patient views, a series of survey questions were formulated.

The survey covered the following sections:

- General attitudes towards the NHS and the use of data
- Awareness of patient data uses
- Levels of support for different uses of patient data
- Benefits and risks of using data for planning and population health
- Views on identifiability and choice

The survey took on average 15 minutes to complete.

Cognitive Testing

Prior to the online panel survey going live, the survey was tested with 10 members of the general public. Cognitive tests were used to ensure that survey questions were clear, easily understandable, and effectively measured what they intended to measure.

Testing the survey was particularly important as the sample from the general public had varying levels of language proficiency, education and cultural backgrounds. Consequently, the sample deliberately included participants that were more prone to encountering challenges with the online survey, for example older in age or speaking English as a second language.

The 10 cognitive tests took place from Friday 26th – Monday 29th January 2024. Participants matched the following quotas:

Figure 1

UK Profile	Final Sample
Gender	
Male	5
Female	5
Age	
Under 35	2
35-49	2
50-64	3
65+	3
Region	
North	2
South	2
Midlands	2
Scotland	2
Wales	2
Disability	
Disability	3
No disability	7
Language	
English as first language	8
English as second language	2
Total	***10***

Sample profile
A quantitative approach was adopted to ensure the sample was demographically diverse, ensuring a representative sample of the general public.

Data collection was conducted using an online panel provider Dynata. The survey remained open from February 6th to February 20th, 2024, and a total of 1,000 surveys were successfully completed through this approach.

Quotas were established during the recruitment phase of the online survey, based on gender, age, region, ethnicity, socio-economic group and disability.

The table shows the final sample which closely matches population as of the 2021 census:

Figure 2

UK Profile	Population	Final Sample	
Gender	*%*	*n*	*%*
Male	48.30%	481	48.10%
Female	51.70%	516	51.60%
Age			
18-34	27.50%	277	27.70%
35-44	16.30%	164	16.40%
45-54	16.70%	166	16.60%
55-64	16.00%	162	16.20%
65+	22.90%	231	23.10%
Nation/Region			
North East - England	4.00%	42	4.20%
North West - England	11.00%	108	10.80%
Yorkshire and Humber - England	8.20%	83	8.30%
East Midlands- England	7.30%	71	7.10%
West Midlands - England	8.80%	88	8.80%
East - England	9.40%	96	9.60%
London - England	13.00%	132	13.20%
South East - England	13.80%	136	13.60%
South West - England	8.70%	87	8.70%
Wales	4.70%	47	4.70%
Northern Ireland	2.60%	26	2.60%
Scotland	8.40%	84	8.40%
Ethnicity			
White British or Irish	78.80%	781	78.10%
Any other ethnic group	21.20%	212	21.20%
Social Grade			
ABC1	55.50%	554	55.40%
C2DE	44.50%	437	43.70%
Disability			
Disability	20.50%	204	20.40%
No disability	79.50%	780	78.00%
Total		***1,000***	

Confidence

The overall sample size provides findings which in research terms means we can be 95% confident that the data at an overall level has a variance no more than +/-5.0% accuracy. A 95% confidence level refers to the statistical likelihood (probability) that the true value of the population lies within a range (95% confidence interval) of the estimated percentage. The specific confidence intervals in this instance were +/- 3%.

However, it is important to note that there are limitations to which we can make inferences about some of the smaller populations in the sample due to sample sizes.

Validation

In order to validate responses, self-completion responses were quality checked by the Qa project manager throughout the surveying period. This was done through several logic checks, including a question asking the respondent's age at the end of the survey. This was then cross-checked to ensure it matched with the age bracket that respondents had given at the start of the survey. Any erroneous responses or responses completed too quickly were removed and replaced by the panel provider. During this process, 75 responses were removed.

A note on quantitative analysis and how the data is presented in the report

The base (i.e. the number of respondents answering the question) is shown in each table or chart. Please note that base sizes may vary throughout the report where respondents have selected 'prefer not to say'.

When interpreting results throughout this report, not all percentages will equal 100% when totalled due to two reasons. Firstly, figures are rounded to whole numbers (with any figures of 0.5 or higher being rounded up). Where the figure is shown as 0%, at least one respondent gave this answer, but the total count makes up less than 0.5% of the overall total; a blank shows no-one gave this answer. Secondly, some questions were multiple response questions, where respondents had the option of giving more than one answer.

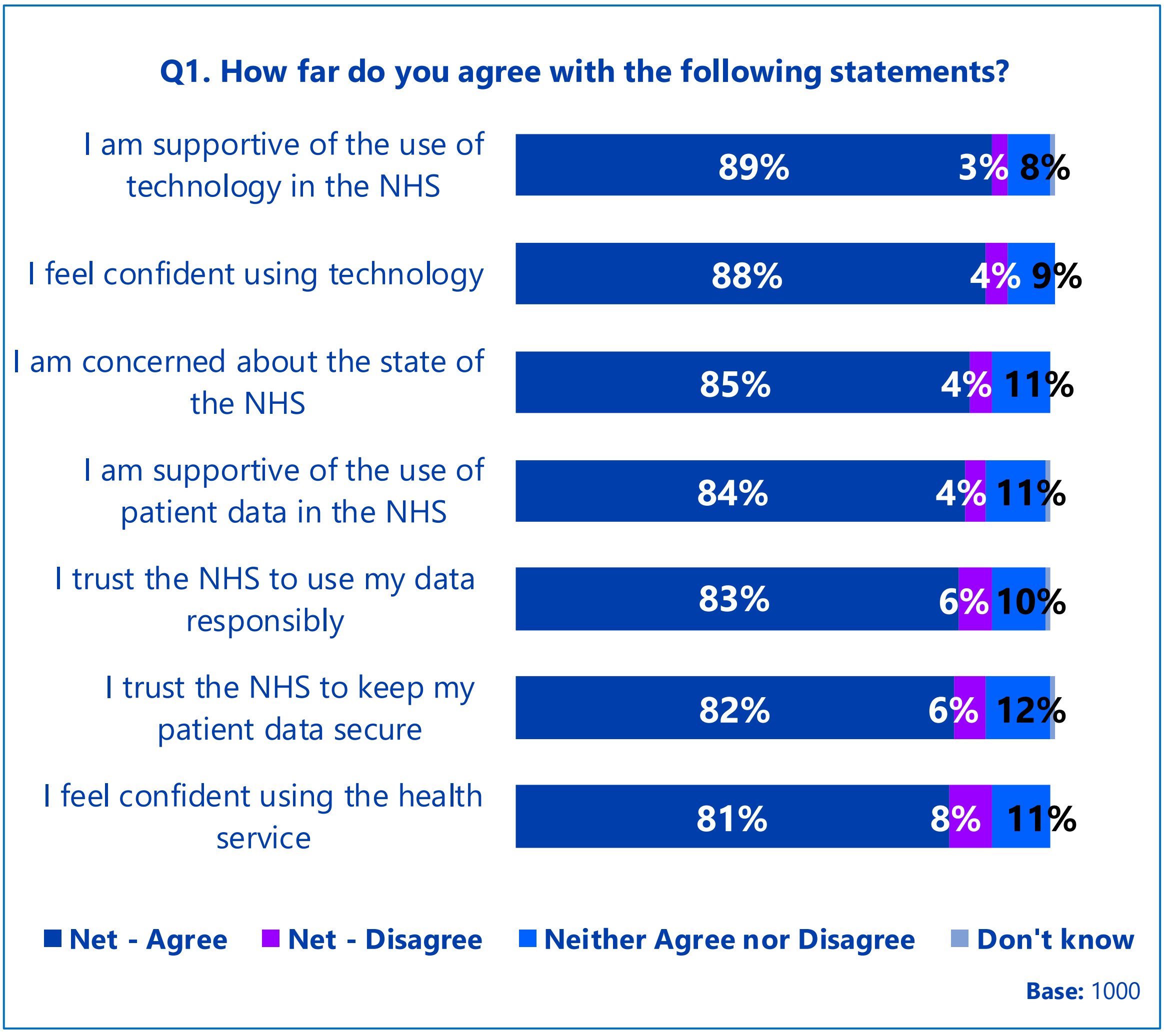
When interpreting results throughout this report, not all percentages will equal 100% due to rounding (with any figures of 0.5 or higher being rounded up). Where the figure is shown as 0%, at least one respondent gave this answer, but the total count makes up less than 0.5% of the overall total; a blank shows no-one gave this answer.

Open-ended verbatim answers were either back-coded to align with existing answers or categorised into new themes during the coding process. The analysis was run using Askia software. The questions have been cross tabulated, with relevant statistically significant differences commented upon within the report.

2. Survey Results

Section 1: General attitudes towards the NHS and the use of data

Figure 3



Support for the use of patient data in the NHS

As the table below shows, certain demographic groups were significantly more likely to support the use of patient data in the NHS than others. Any statistically significant differences are highlighted in blue.

Figure 4

Q1: I am supportive of the use of patient data in the NHS	Net - Agree	Net - Disagree	Neither Agree nor Disagree	Don't Know
Age				
18-34	80%	**6%**	13%	1%
35-54	81%	**5%**	12%	2%
55+	**90%**	2%	8%	1%
Ethnicity				
White ethnic background	**86%**	3%	10%	1%
Minority ethnic background	78%	7%	14%	1%
Social grade				
ABC1	**87%**	4%	8%	1%
C2DE	80%	4%	14%	2%
Base: 1000				

Trust around the use of patient data in the NHS

The table below shows that were differences in levels of trust between some demographic groups.

Figure 5

Q1: I trust the NHS to keep my patient data secure	Net - Agree	Net - Disagree	Neither Agree nor Disagree	Don't Know
Ethnicity				
White ethnic background	81%	**6%**	11%	1%
Minority ethnic background	83%	3%	13%	0%
Disability				
Has a disability	78%	**9%**	12%	1%
No disability	83%	4%	11%	1%
Base: 1000				

For each statement, any respondent who answered '*strongly disagree*' was asked why they gave this answer. Only a very small proportion of respondents, no more than 2%, strongly disagreed with each statement.

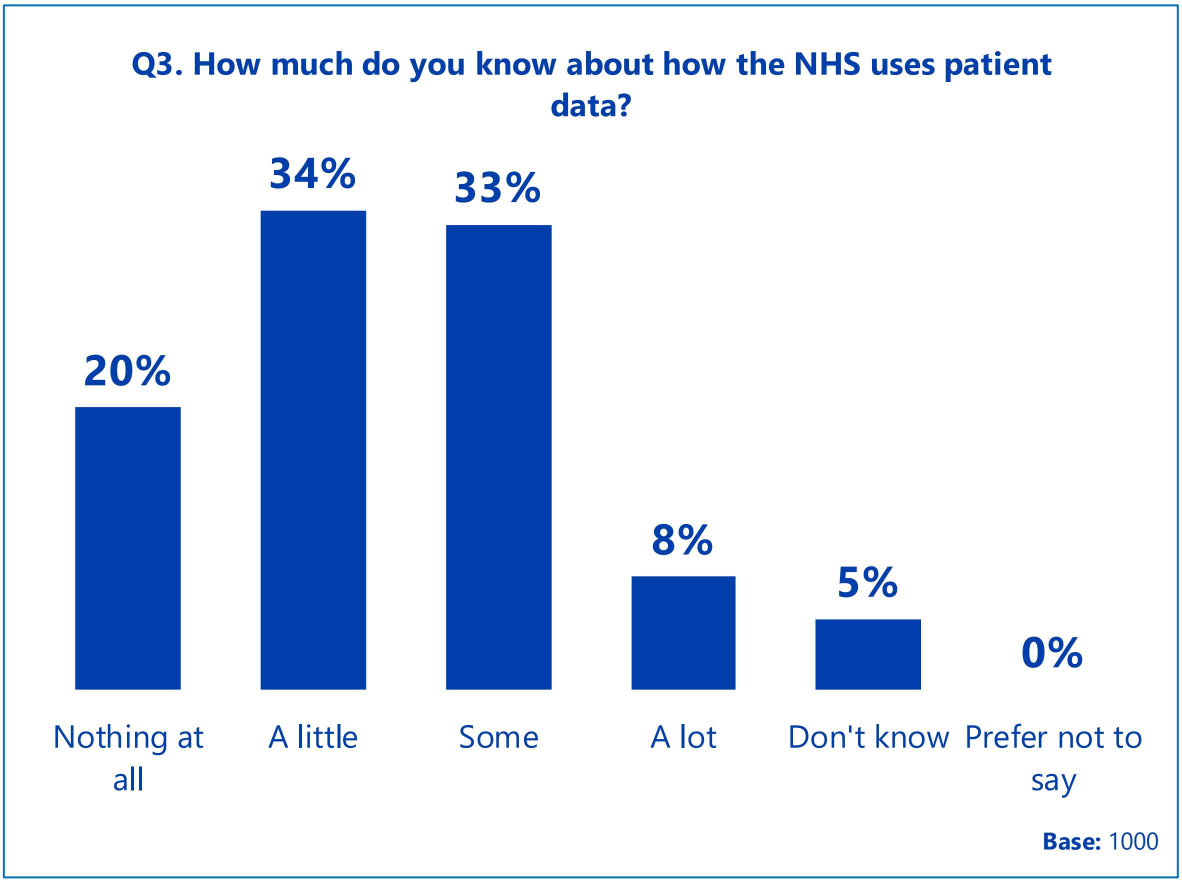
The verbatim answers covered:

- concerns about waiting times for appointments
- confusion around using the NHS
- fears around data breaches
- third party organisations accessing patient data
- apprehensions about the misuse of data by the NHS

Section 2: Awareness of patient data uses in the NHS

Awareness of patient data in general

Figure 6



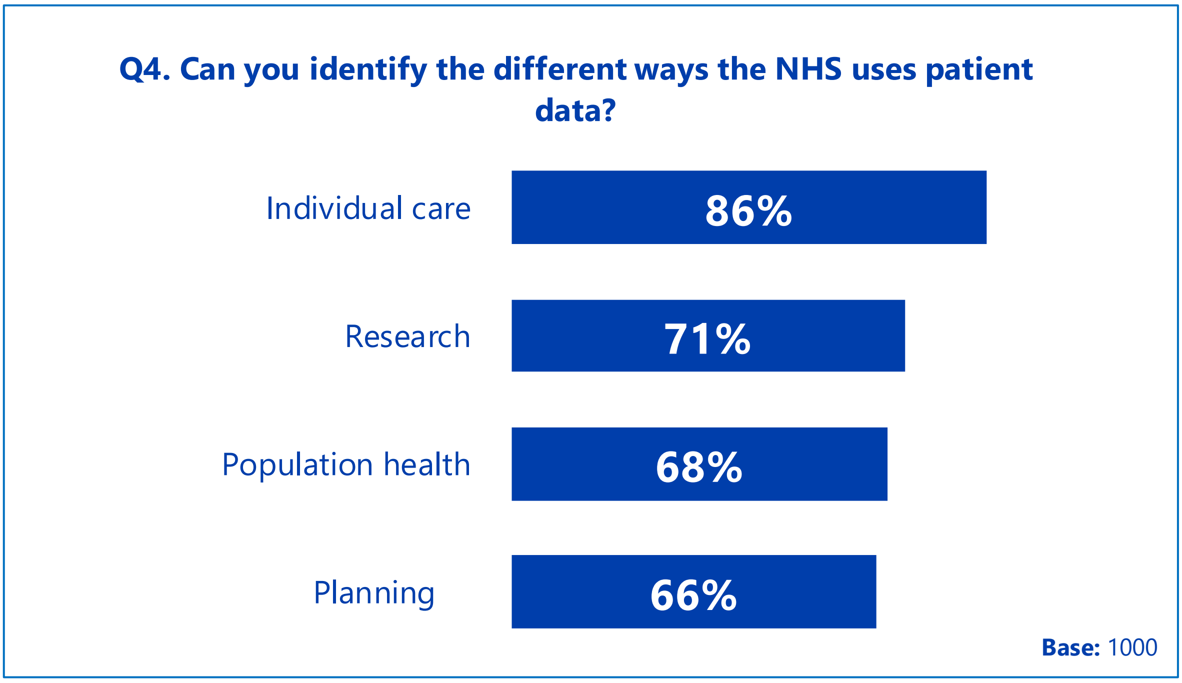
The table below shows any statistically significant differences between demographic groups. These are highlighted in blue.

Figure 7

Q3. How much do you know about how the NHS uses patient data?	Nothing at all	A little	Some	A lot	DK/PNS
Age					
18-34	12%	30%	36%	**15%**	6%
35-54	**23%**	29%	36%	**7%**	4%
55+	**24%**	**40%**	28%	4%	4%
Ethnicity					
White ethnic background	**23%**	**37%**	30%	7%	4%
Minority ethnic background	11%	24%	**46%**	**13%**	7%
Social grade					
ABC1	17%	33%	**38%**	9%	3%
C2DE	**24%**	35%	28%	7%	6%
Base: 1000					

Identifying use cases

Figure 8



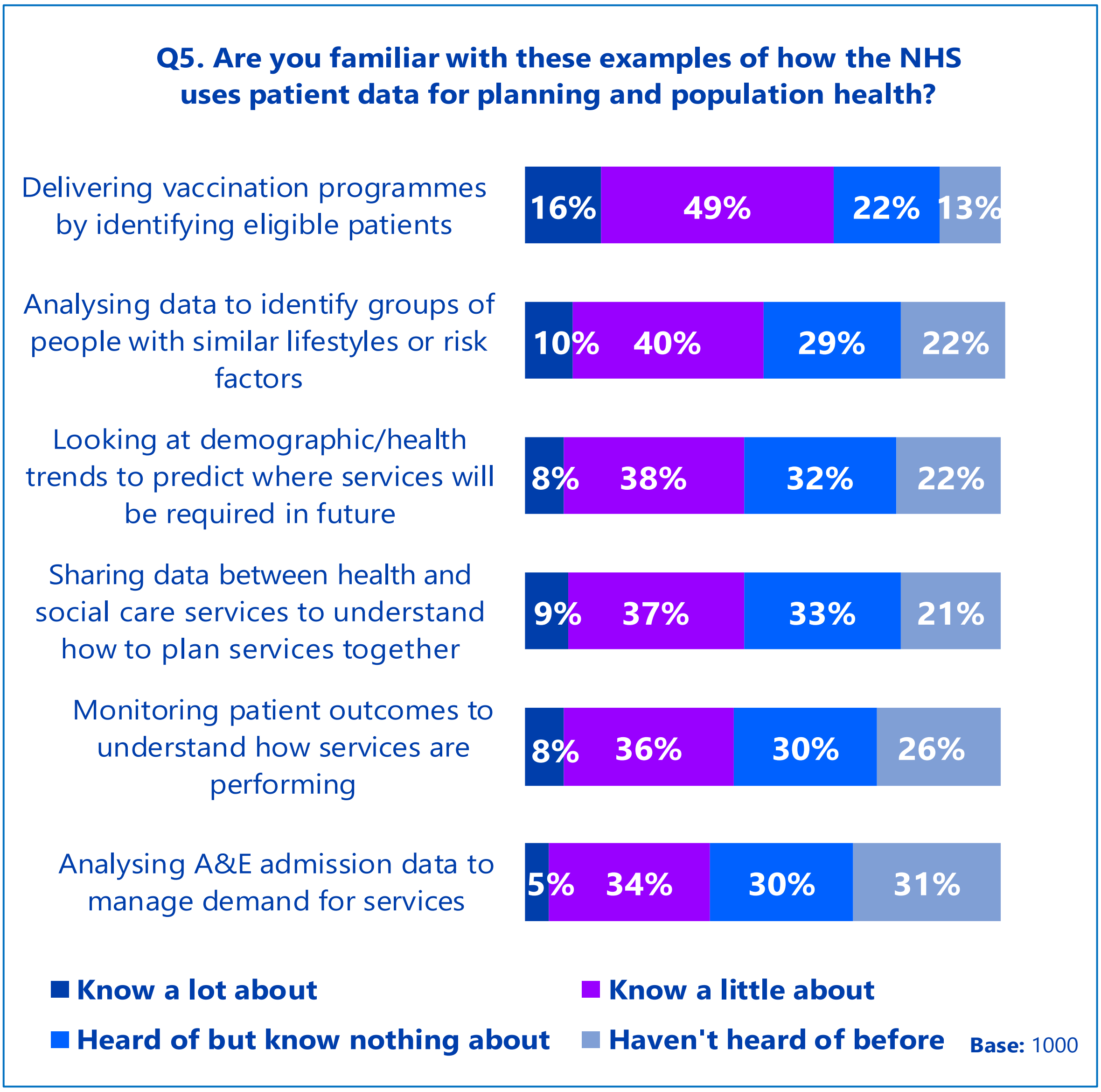
Responses varied by demographic group:

Figure 9

Q4. Can you identify the different ways the NHS uses patient data?	**Individual care**	**Research**	**Population health**	**Planning**
Age				
18-34	78%	64%	66%	61%
35-54	**85%**	70%	67%	63%
55+	**92%**	**77%**	70%	**72%**
Ethnicity				
White ethnic background	**88%**	**73%**	69%	**68%**
Minority ethnic background	77%	63%	65%	57%
Social grade				
ABC1	**89%**	**75%**	**71%**	**70%**
C2DE	82%	67%	64%	60%
Base: 1000				

Specific use case examples

Figure 10



Section 3: Support for different uses of patient data for planning and population health

Support for specific use case examples

Figure 11

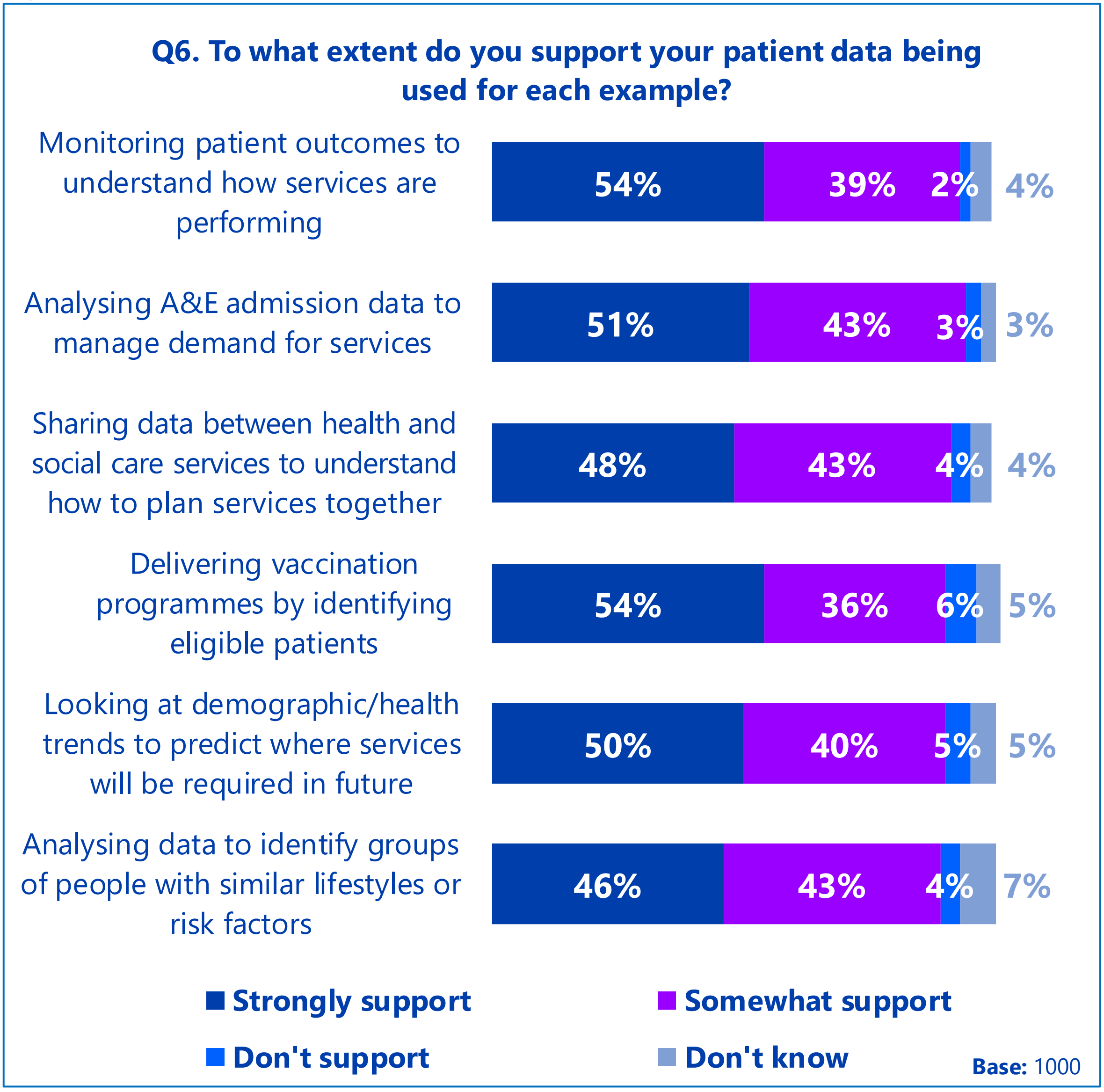
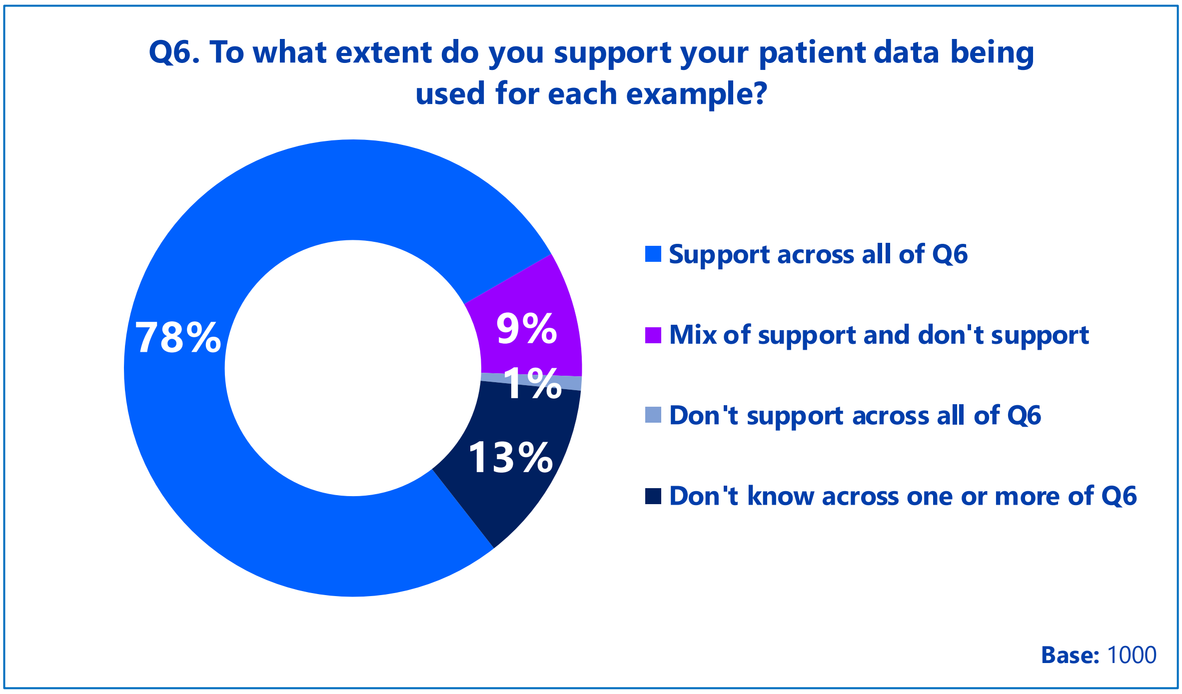


Figure 12



The table below demonstrates how levels of support varied by demographic group. Any statistically significant differences are highlighted in blue.

Figure 13

Q6. To what extent do you support your patient data being used for each example?	**Support across all of Q6**	**Mix of support and don't support**	**Don't support across all of Q6**	**Don't know across one or more of Q6**
Age				
18-34	69%	**15%**	1%	14%
35-54	75%	**9%**	0%	16%
55+	**85%**	4%	-	10%
Ethnicity				
White ethnic background	**80%**	8%	0%	12%
Minority ethnic background	69%	11%	1%	**18%**
Social grade				
ABC1	**81%**	8%	1%	10%
C2DE	73%	9%	0%	**17%**
Base: 1000				

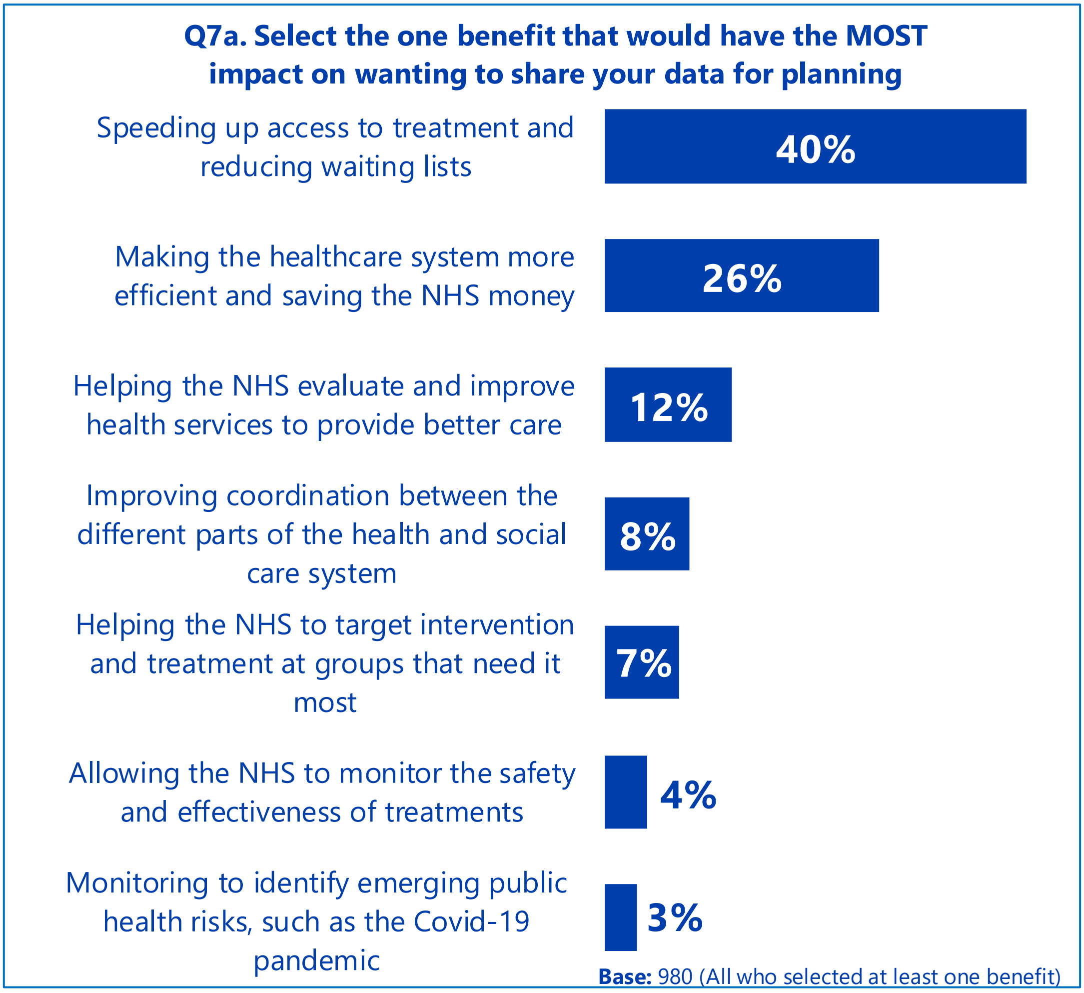
Section 4: Attitudes towards the potential benefits and risks of sharing patient data for planning and population health

Benefits of sharing patient data

Figure 14

Q7. Benefits of sharing data	%
Speeding up access to treatment and reducing waiting lists	87%
Making the healthcare system more efficient and saving the NHS money	82%
Helping the NHS evaluate and improve health services to provide better care	76%
Monitoring to identify emerging public health risks, such as the Covid-19 pandemic	74%
Allowing the NHS to monitor the safety and effectiveness of treatments	74%
Improving coordination between the different parts of the health and social care system	73%
Helping the NHS to target intervention and treatment at groups that need it most	72%
None - I wouldn't want to share my data with NHS to support planning and population health	2%
Something else	1%
Base: 1000	

Figure 15



The benefit that respondents felt most compelling varied by their level of awareness. The table below shows the proportion of respondents who selected each risk split by how much they said they knew about how the NHS uses patient data at Q3. Statistically significant differences are highlighted in blue.

Figure 16

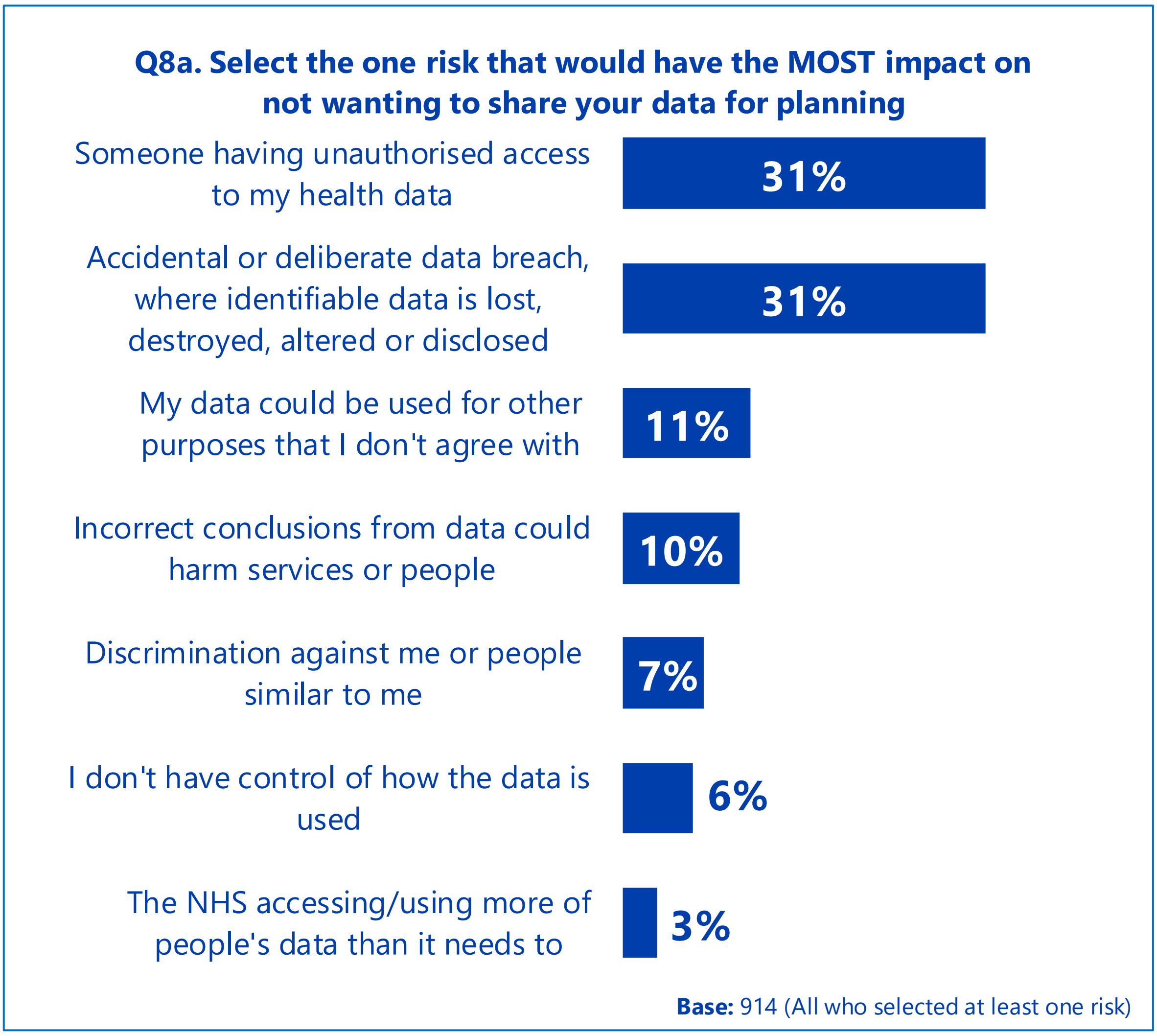
Q7a (main benefit) vs Q3 (amount known about patient data)	**Nothing**	**A little**	**Some**	**A lot**	**DK**
Speeding up access to treatment and reducing waiting lists	**45%**	**43%**	38%	24%	37%
Making the healthcare system more efficient and saving the NHS money	**33%**	23%	24%	23%	39%
Improving coordination between different parts of the health and social care system	7%	7%	9%	**18%**	2%
Helping the NHS evaluate and improve health services to provide better care	7%	13%	12%	16%	10%
Helping the NHS to target intervention and treatment at groups that need it most	5%	5%	9%	**15%**	10%
Allowing the NHS to monitor the safety and effectiveness of treatments	2%	3%	6%	3%	-
Monitoring to identify emerging public health risks, such as the Covid-19 pandemic	2%	4%	2%	1%	2%
Other	1%	0%	-	-	-
Base: 1000					

Risks of sharing patient data

Figure 17

Q8. Risks of sharing data	**%**
Someone having unauthorised access to my health data	66%
Accidental or deliberate data breach, where identifiable data is lost, destroyed, altered or disclosed	64%
My data could be used for other purposes that I don't agree with	52%
Incorrect conclusions from data could harm services or people	45%
I don't have control of how the data is used	41%
Discrimination against me or people similar to me	38%
The NHS using more of people's data than it needs to	33%
None of the above – these do not concern me	9%
Something else	<1%
Base: 1000	

Figure 18



Base: 914 (All who selected at least one risk)

Some demographic groups were more likely to identify certain potential risks as the most impactful. The table below only shows the potential risks that had significant differences between demographic groups. Any statistically significant differences are highlighted in blue.

Figure 19

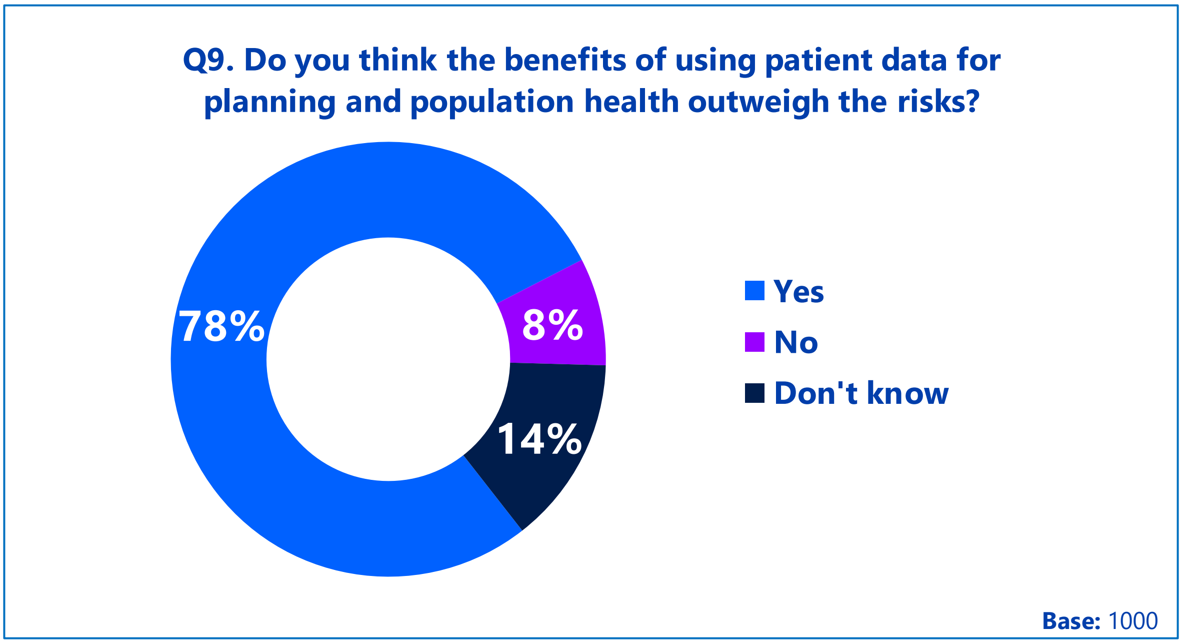
Q8a. Select the one risk that would have the MOST impact on not wanting to share your data for planning	**Someone having unauthorised access to my health data**	**Accidental or deliberate data breach**	**Incorrect conclusions could harm services or people**	**Discrimination against me or people similar to me**
Age				
18-34	28%	31%	8%	9%
35-54	**37%**	25%	8%	7%
55+	28%	**35%**	**14%**	5%
Ethnicity				
White ethnic background	31%	**33%**	11%	5%
Minority ethnic background	30%	24%	7%	**16%**
Base: 1000				

General support for using patient data overall (*Q1*) also correlated with different views on risk:

- **Unsupportive:** those who 'disagreed' about being supportive of the use of data in the NHS in general were more likely to be concerned about *'Someone having unauthorised access to my health data'* compared to those who were supportive (47% vs 30%)
- **Supportive:** those who 'agreed' about being supportive of the use of data in the NHS in general were more likely to see an *'Accidental or deliberate data breach, where identifiable data is lost, destroyed, altered or disclosed'* as the main risk compared to those who were not supportive in a general sense about patient data at Q1 (33% vs 18%)

Do the benefits outweigh the risks?

Figure 20



There were some demographic differences when it came to weighing up the benefits and the risks. Any statistically significant differences are highlighted in blue:

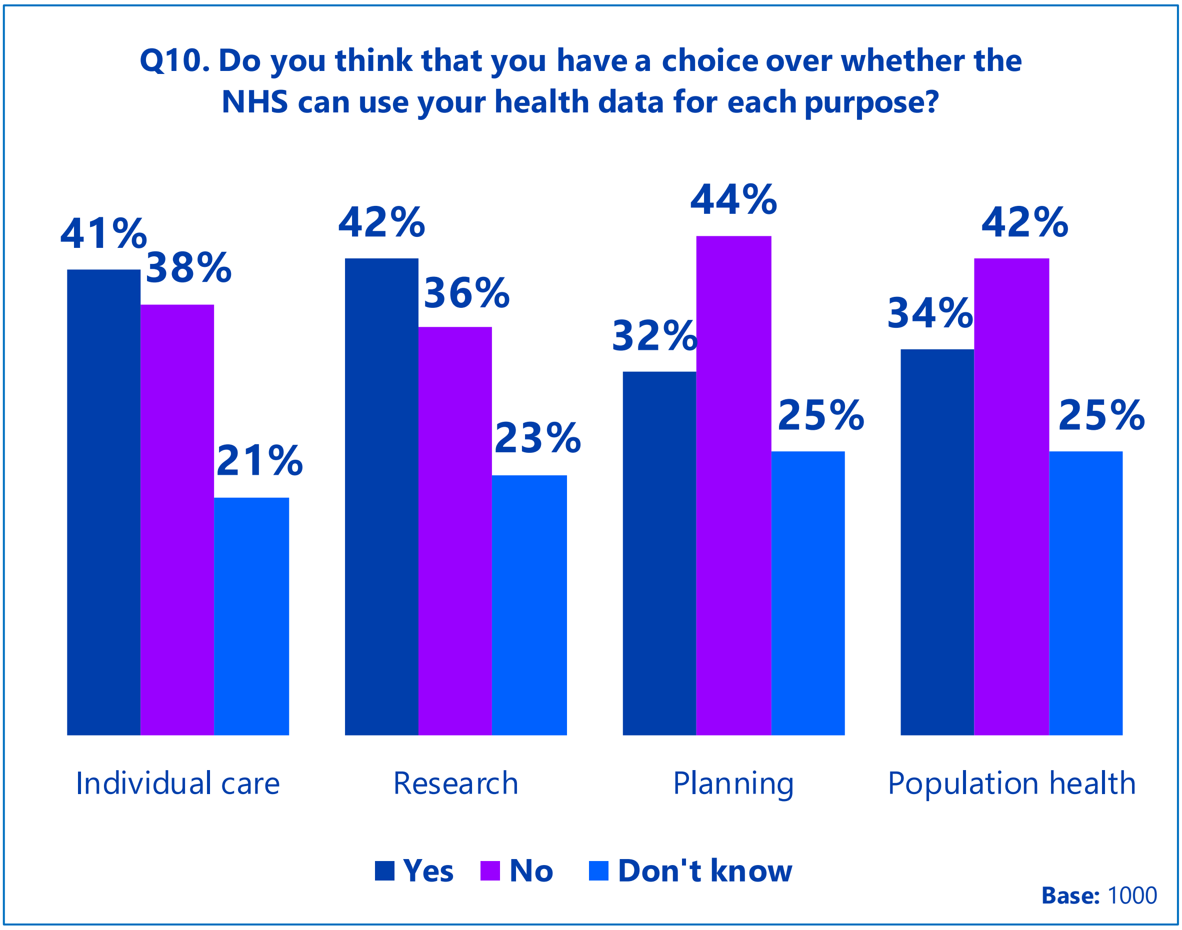
Figure 21

Q9. Do you think the benefits of using patient data for planning and population health outweigh the risks?	Yes	No	Don't know
Gender			
Female	74%	9%	**16%**
Male	**82%**	7%	11%
Age			
18-34	74%	**15%**	11%
35-54	75%	**9%**	16%
55+	**83%**	3%	14%
Ethnicity			
White ethnic background	**80%**	7%	13%
Minority ethnic background	72%	**13%**	15%
Nation			
England	77%	**9%**	14%
Scotland	**88%**	4%	8%
Wales	85%	4%	11%
Northern Ireland	77%	4%	19%
Social grade			
ABC1	**82%**	8%	10%
C2DE	73%	9%	**18%**
Base: 1000			

Section 5: Views on choice and identifiability in the use of patient data

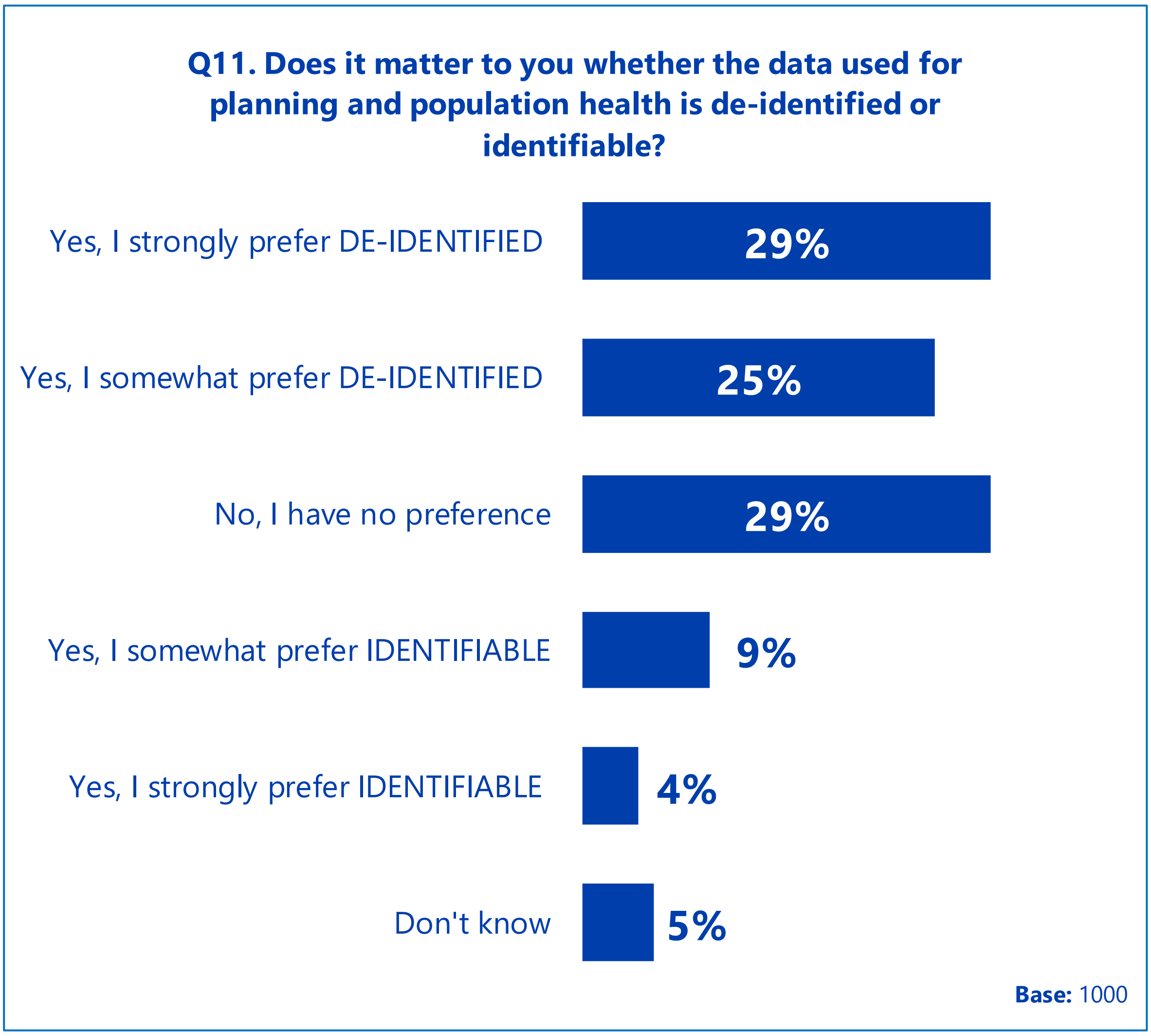
Awareness of choices

Figure 22



Identifiable vs de-identified

Figure 23

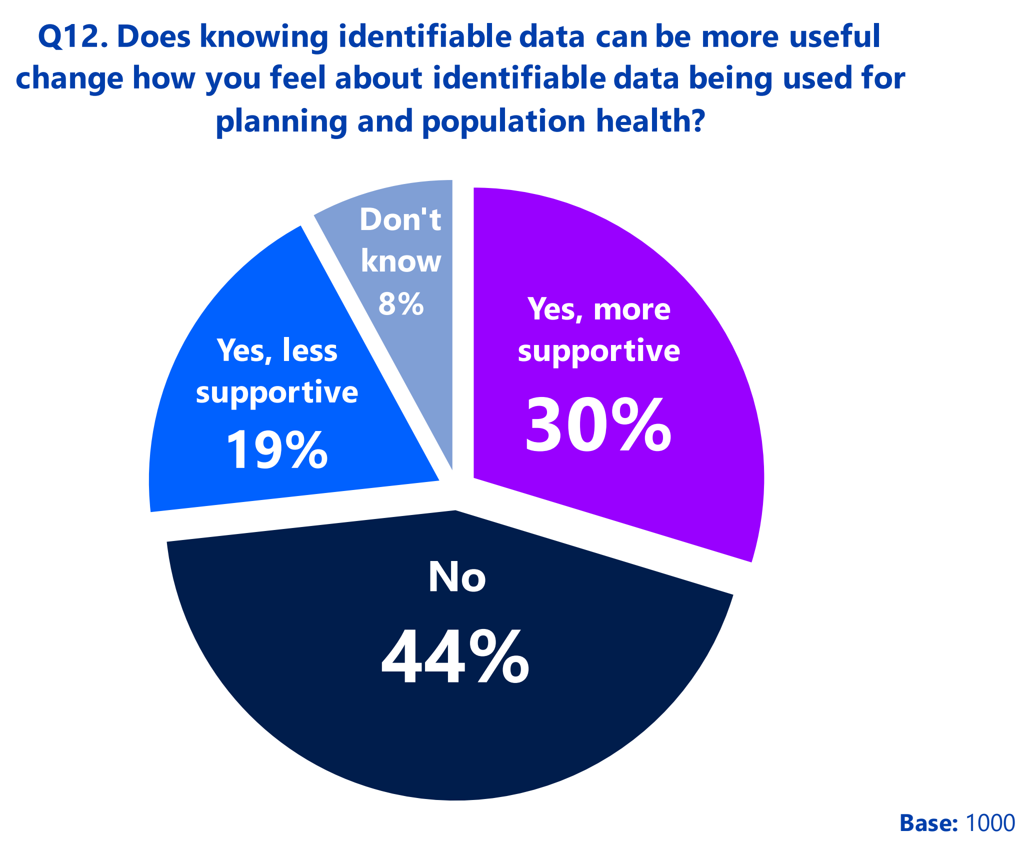


As the table below demonstrates, there were significant differences between demographic groups.

Figure 24

Q11. Does it matter to you whether the data used for planning and population health is de-identified or identifiable?	Prefer de-identified data (net)	No preference	Prefer identifiable data (net)	Don't know
Age				
18-34	**61%**	20%	15%	4%
35-54	53%	**30%**	11%	6%
55+	51%	**33%**	11%	4%
Ethnicity				
White ethnic background	54%	**31%**	11%	5%
Minority ethnic background	58%	20%	**17%**	5%
Nation				
England	53%	30%	12%	6%
Scotland	**67%**	21%	12%	-
Wales	55%	26%	15%	4%
Northern Ireland	**73%**	19%	8%	-
Social grade				
ABC1	**58%**	27%	12%	4%
C2DE	50%	30%	13%	6%
Base: 1000				

Figure 25


Q12. Does knowing identifiable data can be more useful change how you feel about identifiable data being used for planning and population health?
Don't know 8%
Yes, more supportive 30%
Yes, less supportive 19%
No 44%
Base: 1000

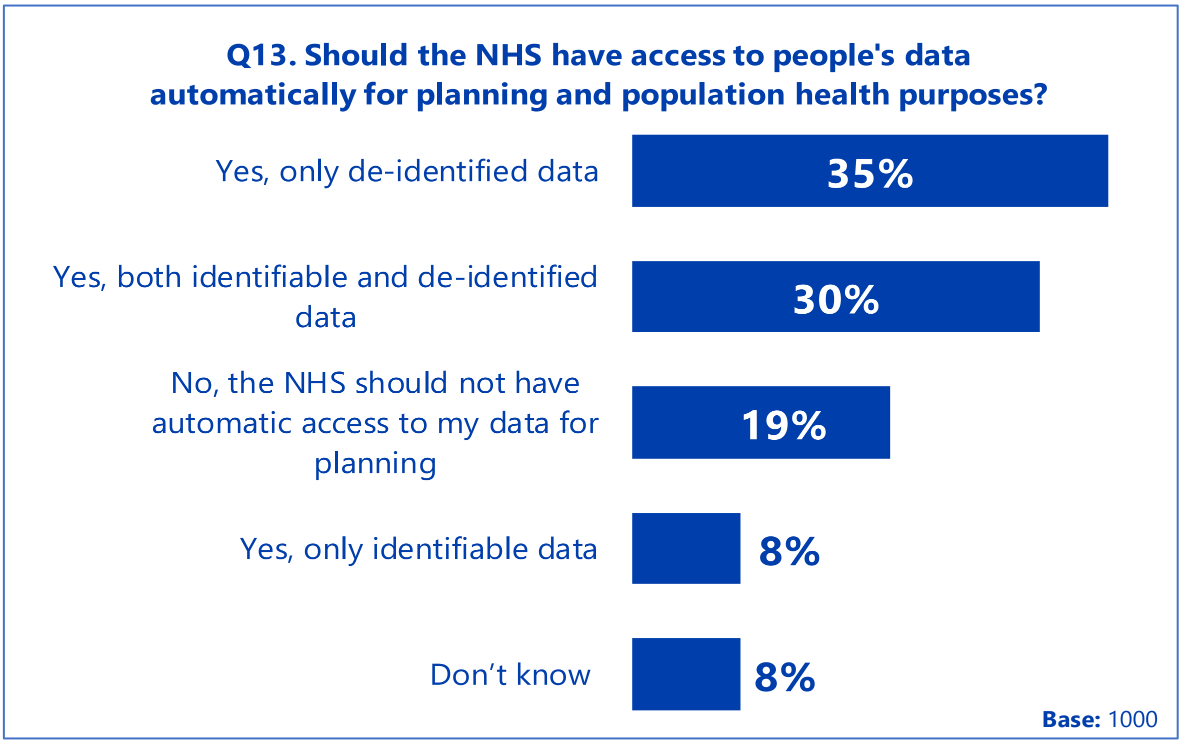
Answers varied somewhat by demographic group. Statistically significant differences are highlighted in blue in the table below.

Figure 26

Q12. Does knowing identifiable data can be more useful change how you feel about it being used?	Yes, more supportive	Yes, less supportive	No	Don't know
Age				
18-34	32%	**23%**	35%	9%
35-54	28%	**22%**	39%	10%
55+	28%	13%	**53%**	6%
Ethnicity				
White ethnic background	28%	17%	**47%**	8%
Minority ethnic background	34%	**28%**	29%	9%
Social grade				
ABC1	**32%**	20%	42%	6%
C2DE	26%	17%	46%	**11%**
Base: 1000				

Automatic access to data

Figure 27



Answers varied by demographic group. The table below highlights any statistically significant differences between demographic groups in blue.

Figure 28

Q13. Should the NHS have access to people's data automatically for planning and population health purposes?	**Yes, both identifiable and de-identified data**	**Yes, only de-identified data**	**Yes, only identifiable data**	**No, the NHS should not have automatic access**	**Don't know**
Gender					
Female	27%	35%	8%	**22%**	9%
Male	**34%**	36%	8%	16%	7%
Age					
18-34	25%	35%	**12%**	22%	6%
35-54	28%	37%	7%	18%	10%
55+	**35%**	35%	5%	17%	7%
Social grade					
ABC1	30%	**39%**	7%	18%	6%
C2DE	30%	31%	8%	20%	**10%**
Disability					
Has a disability	**37%**	27%	8%	22%	7%
No disability	28%	**38%**	8%	18%	8%
Base: 1000					

Figure 29

Yes, only de-identified data at Q13	**Count**	**%**
De-identified data is less intrusive, anonymous, and less inclined to be misused, so is the more acceptable option	117	33%
Identifiable data is not required for making broad planning decisions	88	25%
Each person should have the opportunity to choose	35	10%
Worried about a data breach	19	5%
Worried about fraud or scams	18	5%
Base: 354		

Figure 30

Yes, both identifiable and de-identified data at Q13	**Count**	**%**
Will improve the effectiveness & speed of NHS services	68	23%
If it helps improve NHS planning, then I am in favour of it	42	14%
Fully support & trust the NHS	35	12%
No problem with my personal data being used	33	11%
NHS needs to have as much information as possible to make informed decisions	33	11%
Base: 300		

Figure 31

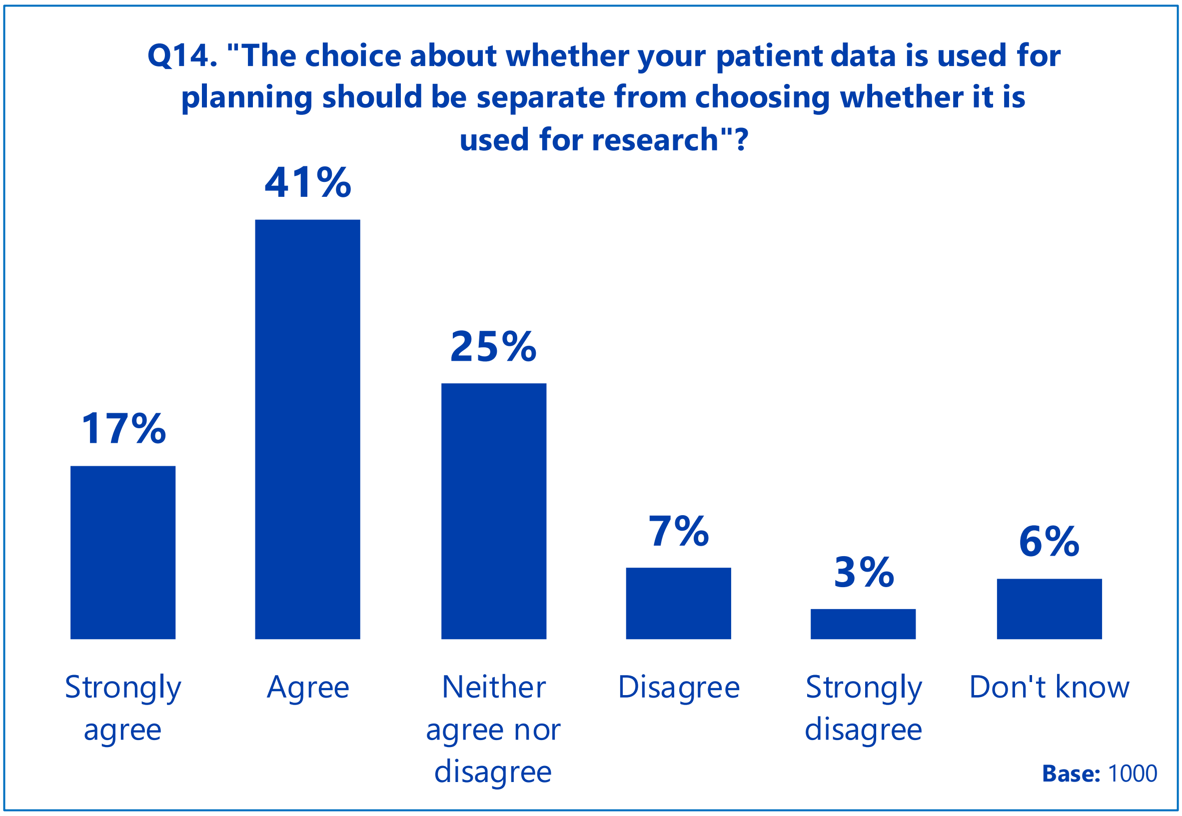
No, the NHS should not have automatic access to my data for planning at Q13	**Count**	**%**
Each person should have the opportunity to choose	61	32%
I want to decide when & how my own personal data is used as this makes me feel safer	58	30%
Suspicion that personal data will be used for inappropriate non-clinical purposes	19	10%
Data protection legislation already requires permission before personal data is used	14	7%
Worried about a data breach	11	6%
Base: 191		

Figure 32

Yes, only identifiable data at Q13	**Count**	**%**
If it helps improve NHS planning, then I am in favour of it	7	9%
Will improve the effectiveness & speed of NHS services	7	9%
Data is only valuable if it fully represents all groups within the population; opting out may skew the results	7	9%
Fully support & trust the NHS	5	6%
NHS needs to have as much information as possible to make informed decisions	4	5%
Base: 77		

Choices separating research and planning

Figure 33



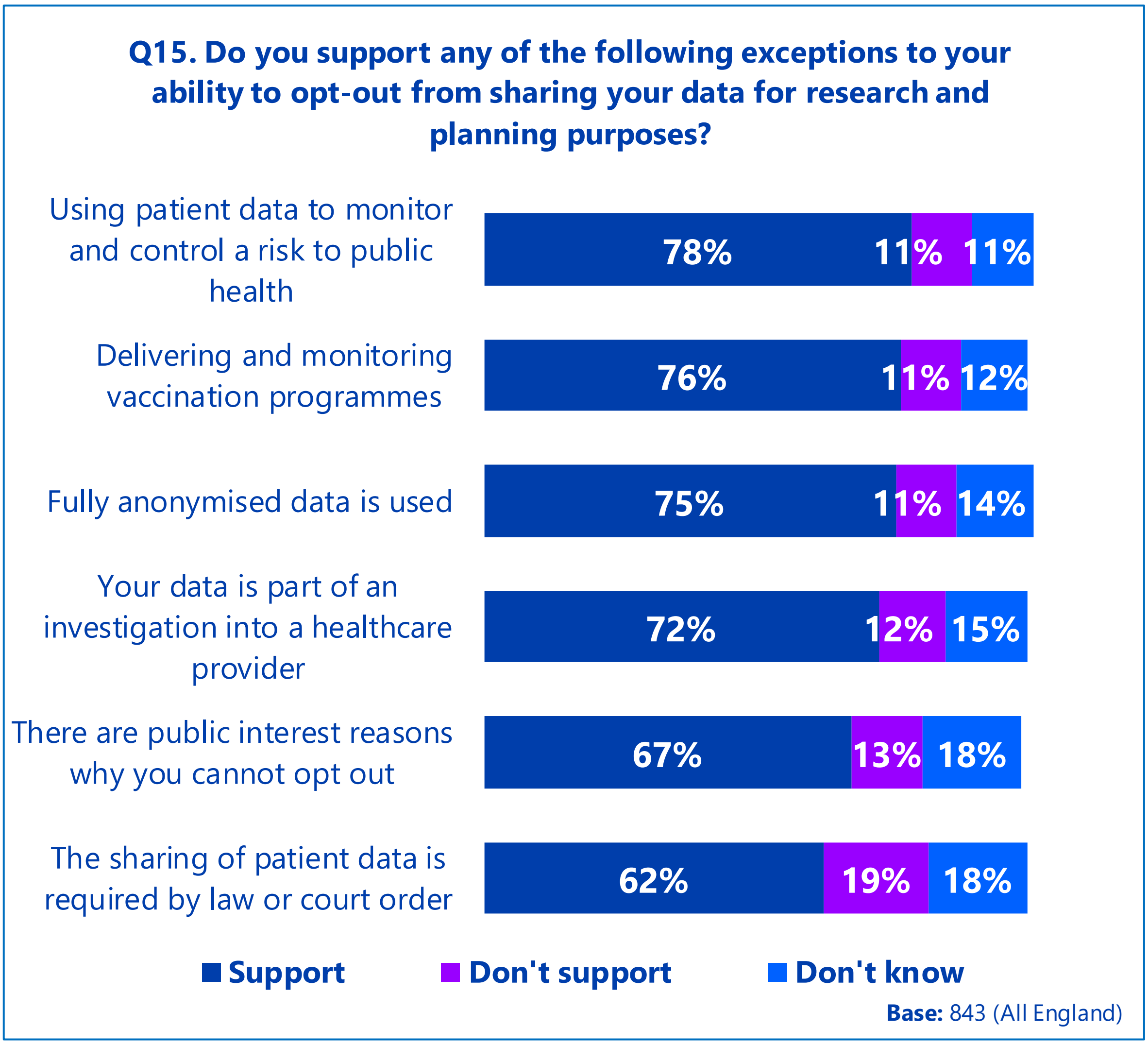
Answers varied by demographic group:

Figure 34

Q9. To what extent do you agree with the statement?	Agree (net)	Disagree (net)	Neither agree nor disagree	Don't know
Age				
18-34	**71%**	6%	20%	4%
35-54	**62%**	8%	23%	7%
55+	48%	**18%**	**30%**	7%
Ethnicity				
White ethnic background	57%	**12%**	**25%**	7%
Minority ethnic background	**67%**	6%	24%	4%
Social grade				
ABC1	**61%**	10%	24%	4%
C2DE	55%	10%	25%	**9%**
Base: 1000				

Exceptions to opt out

Figure 35



Respondents were asked if they could think of any other circumstances where they would be happy for the NHS to use patient data regardless of opt-out preferences. The verbatim answers given by respondents have been coded and grouped together. The table below show the top five answers given at Q16 in rank order.

Figure 37

Q16. Any other circumstances for exceptions?	**%**
None; no other circumstances	82%
Using patient data to monitor and control a risk to public health, such as an infectious disease, or other emergencies	5%
Medical research into physical & mental illness, including those affecting specific groups of people	3%
Anything to help the NHS	2%
Anything where the sharing of personal data can benefit other people	1%
Base: 843 (All England)	

3. Appendix

Appendix 1: Survey

Patient Data for Planning and Population Health Survey

This study is being conducted by Qa Research, an independent research company, on behalf of Understanding Patient Data, which is part of the NHS Confederation.

The purpose of this study is to understand people's views towards the different ways the NHS and health services use their patient data.

It should take around 10-15 minutes to complete.

Please click on the NEXT button to start the study.

This study will be carried out according to the Market Research Society's Code of Conduct and all your answers and information you provide will be treated as anonymous and confidential in accordance with the Data Protection Act.

Any personal data collected in this study will be held securely and will not be shared with any third party unless you give permission. You can read more about how your Personal Data is protected here (*https://www.qaresearch.co.uk/privacy/*)

Section 1 – About you

To ensure we gain views from a wide range of people we would first like to ask some questions about you.

S1. What gender do you identify with?
SINGLECODE
Female
Male
In another way (Write in)
Prefer not to say

S2. Which of the following age groups do you belong to?
SINGLECODE
Under 18 – ***Thank and close***
18-34
35-44
45-54
55-64
65-74
75+
Prefer not to say

S3. Which region of the UK do you live in?
SINGLECODE
North East - England
North West - England
Yorkshire and Humber - England
East Midlands - England
West Midlands - England
East - England
London - England
South East - England
South West - England
Wales
Northern Ireland
Scotland

S4. What is the first part of your postcode (e.g. YO16 6)?
OPEN

S5. Which of the following best describes your ethnic group or background?
SINGLECODE
Asian / Asian British
Bangladeshi
Chinese
Indian
Pakistani
Any other Asian background, please describe
Black / African / Caribbean / Black British

African
Caribbean
Any other Black / African / Caribbean background, please describe
Mixed / Multiple ethnic groups
White and Asian
White and Black African
White and Black Caribbean
Any other Mixed / Multiple ethnic background, please describe
Other ethnic group
Arab
Any other ethnic group, please describe
White
English / Welsh / Scottish / Northern Irish / British
Gypsy or Irish Traveller
Irish
Any other White background, please describe
Prefer not to say

S6. What is the occupation of the main income earner within your household?

If you share a house with others but have separate finances, do not include them at this question. Only consider those who have shared incomes / outgoings.

If the main income earner is retired and receiving a company pension, please indicate the last job they held before retirement

1. Housewife / house husband / looking after family ***(CODE AS E)***
2. Retired and only receiving state pension, not company pension ***(CODE AS E)***
3. Student ***(CODE AS C1)***
4. Casual worker without regular income, or unemployed for six months or longer ***(CODE AS E)***
5. Manual worker (e.g. Lorry driver, Holiday camp worker, Hotel Porter) ***(CODE AS D)***
6. Skilled manual worker (e.g. Silversmith, Plumber, Electrician) ***(CODE AS C2)***
7. Junior management or professional, or administrative (e.g. Most office workers, Accounts clerk, Secretary, Police Sergeant) ***(CODE AS C1)***
8. Intermediate management in large organisation, owner of small business, principal officer in civil service / local government ***(CODE AS B)***
9. Very senior management, top-level civil servant or professional (e.g. Surgeon, Partner in a law firm, Regional bank manager, Board Director of medium/large firm' ***(CODE AS A)***
10. Unemployed for 6 months or longer ***(CODE AS E)***
11. Prefer not to say

S7. The Equality Act 2010 defines a person as disabled if they have a physical or mental impairment, which has a substantial and long-term (i.e.

has lasted or is expected to last at least 12 months) adverse effect on the person's ability to carry out normal day-to-day activities.

Do you have a disability?
SINGLECODE
Yes
No
Prefer not to say
Don't know

Section 2 – General attitudes towards the NHS and use of data

This survey is about how the health service uses your data as a patient in different ways.

If England, Scotland and Wales –
When we talk about the health service we mean the National Health Service (NHS) which is the publicly funded healthcare system in *[TEXT SUB ACCORDING TO LOCATION]* **England / Scotland / Wales. We will use the term NHS throughout the survey.**

If Northern Ireland –
When we talk about the national health service we mean Health and Social Care or HSC which is the publicly funded health and social care system in Northern Ireland, although you may refer to it as the NHS. We will use the term health and care service throughout the survey.

We want to know your honest views towards how the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/Health and Social Care service use your patient data.**

When we refer to patient data, we mean the data that is routinely collected when someone interacts with the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC, such as visiting the GP or hospital. This includes information about the individual, their health and lifestyle and may include information such as height and weight, medical conditions, medication history and test results such as blood tests or MRI scans.**

This data is stored in your patient record and there are strict regulations in place to protect your data and confidentiality. Patient data is used to provide the best care for each patient, but it may also be used internally by the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC to help make the health service better, or to support research.**

Q1. How far do you agree with the following statements?
SINGLECODE
Strongly Disagree

Disagree
Neither Agree nor Disagree
Agree
Strongly Agree
Don’t Know

LOOP – RANDOMISE ORDER - table format radio buttons

I trust the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC to use my data responsibly**
I trust the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC to keep my patient data secure**
Generally speaking, I am supportive of the use of patient data in the *[TEXT SUB ACCORDING TO LOCATION]* NHS/HSC
Generally speaking, I am supportive of the use of technology in the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC**
Generally speaking, I feel confident using technology
Generally speaking, I feel confident navigating the health service
I am concerned about the state of the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC**

SHOW Q2 FOR EACH ANSWER WITH ‘STRONGLY DISAGREE’ RATING AT Q1

Q2. You said you strongly disagree that *[INSERT TEXT SUB FROM Q1]*, **can you tell us why you said that?**

OPENCODE

Section 3 – Awareness of patient data uses

Q3. How much, if anything, would you say that you know about how the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC uses the patient data it collects?**

SINGLECODE

Nothing at all
Very little
Some
A lot
Don’t know
Prefer not to say

Q4. The *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC uses patient data for a number of different purposes.**

Can you identify the different ways in which the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC currently uses patient data from the list below? Please tick any that you think apply.**

MULTICODE except ‘none of the above’ and ‘all of the above'

Direct care – e.g. using data to prevent, investigate or treat a patient’s health problem
Population health – e.g. using data to target health services to groups of people depending on the needs of different communities
Planning – e.g. using data to evaluate and predict hospital activity to improve capacity and target resources

Research – e.g. using data to understand health conditions better and develop new treatments
All of the above
None of the above

Section 4 – Levels of support for different uses of patient data

The survey will now focus specifically on your views on using patient data for planning and population health within the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC.**

Patient data can only be used for purposes beyond your individual care in specific circumstances, where there is a legal basis for using the data. Any use of patient data must benefit health and care.

The *[TEXT SUB ACCORDING TO LOCATION]* NHS/HSC uses data to support planning. This involves using data about patients to:

- **understand how health services are operating at the moment to help them improve**
- **predict what health services will be needed in the future and provide them with enough funding, staff and equipment**
- **coordinate health and social care services to ensure each sector has the information they need to provide care**

The *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC also uses data to improve population health. This involves using data about patients to:**

- **target health services to groups of people depending on the needs of different communities**
- **deliver programmes to improve the health of the population, such as the COVID-19 vaccine programme**

Q5. Listed below are some more specific examples of the ways the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC use patient data for planning and population health.**

To what extent, if at all, are you familiar with each of these examples of how the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC uses patient data?**
SINGLECODE
Haven't heard of before
Heard of but know nothing about
Know a little about
Know a lot about
LOOP – SAME ORDER
Analysing Accidents and Emergency (A&E) admission data to ensure the hospital has the right amount of staff and resources available to deliver care.

Monitoring and evaluating outcomes to understand which services are performing well and which ones need additional support, ensuring patients receive effective care.

Sharing data between health and social care services to understand how to plan services together and ensure people move between the two sectors smoothly.

Looking at demographic and health trends across the country to predict what services are going to be needed in the future and effectively target resources where they are most needed.

Using patient data to deliver vaccination programmes by identifying patients eligible for vaccines, targeting people for invitation by risk factors, and identifying groups who may be more hesitant about taking up the vaccine to provide with additional information.

Analysing data to identify cohorts of people with similar lifestyles or risk factors that may contribute to health conditions and targeting groups of people with different health interventions

Q6. To what extent do you support your patient data being used for each example?

SINGLECODE

Strongly support
Somewhat support
Don’t support
Don’t know

LOOP – SAME ORDER AS BEFORE

Analysing Accidents and Emergency (A&E) admission data to ensure the hospital has the right amount of staff and resources available to deliver care.

Monitoring and evaluating outcomes to understand which services are performing well and which ones need additional support, ensuring patients receive effective care.

Sharing data between health and social care services to understand how to plan services together and ensure people move between the two sectors smoothly.

Looking at demographic and health trends across the country to predict what services are going to be needed in the future and effectively target resources where they are most needed.

Using patient data to deliver vaccination programmes by identifying patients eligible for vaccines, targeting people for invitation by risk factors, and identifying groups who may be more hesitant about taking up the vaccine to provide with additional information.

Analysing data to identify cohorts of people with similar lifestyles or risk factors that may contribute to health conditions and targeting groups of people with different health interventions

Section 5 – Benefits and risks of using data for planning and population health

Q7. Listed below are a list of benefits of using patient data for planning and population health.

Can you select the benefits that you think would make you more supportive of sharing your patient data for planning and population health within the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC?**
MULTICODE
Making the healthcare system more efficient and saving the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC money
Speeding up access to treatment and reducing waiting lists
Improving coordination between the different parts of the health and social care system within the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC
Helping the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC to target intervention and treatment at groups that need it most
Helping the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC evaluate and improve health services to provide better care
Allowing the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC to monitor the safety and effectiveness of treatments
Monitoring to identify emerging public health risks, such as the Covid-19 pandemic
Something else (write in)
None of the above – I wouldn't want to share my data with the NHS to support planning and population health

ASK ALL EXCEPT – 'NONE OF THE ABOVE' AT Q7
Q7a. Now can you select ONE benefit that you think would have the MOST impact on wanting to share your patient data to support planning within the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC?**
ONLY SHOW THOSE SELECTED AT Q7 - SINGLECODE
Making the healthcare system more efficient and saving the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC money
Speeding up access to treatment and reducing waiting lists
Improving coordination between the different parts of the health and social care system within the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC
Helping the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC to target intervention and treatment at groups that need it most
Helping the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC evaluate and improve health services to provide better care
Allowing the ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC to monitor the safety and effectiveness of treatments
Monitoring to identify emerging public health risks, such as the Covid-19 pandemic
Something else (write in)

Q8. It's important to recognise that with the use of patient data there are some risks alongside the benefits. Below is a list of concerns people may have about the use of patient data.

Please select any potential concerns that you feel pose a risk or make you less supportive of sharing your patient data for planning.
MULTICODE
Someone having unauthorised access to my health data
Accidental or deliberate data breach, where identifiable data is lost, destroyed, altered or disclosed
Discrimination against me or people similar to me
My data could be used for other purposes that I don't agree with
The ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC accessing/using more of people's data than it needs to
Incorrect conclusions from data could harm services or people
I don't have control of how the data is used
Something else (write in)
None of the above – these do not concern me

ASK ALL EXCEPT – 'NONE OF THE ABOVE' AT Q8
Q8a. Now can you select ONE risk that you think would have the MOST impact on not wanting to share your patient data to support planning within the NHS?
ONLY SHOW THOSE SELECTED AT Q8 - SINGLECODE
Someone having unauthorised access to my health data
Accidental or deliberate data breach, where identifiable data is lost, destroyed, altered or disclosed
Discrimination against me or people similar to me
My data could be used for other purposes that I don't agree with
The ***[TEXT SUB ACCORDING TO LOCATION]*** NHS/HSC accessing/using more of people's data than it needs to
Incorrect conclusions from data could harm services or people
I don't have control of how the data is used
Something else (write in)

ASK ALL
Q9. On balance, do you think that the benefits of using patient data for planning and population health within the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC outweigh the potential risks?**
SINGLECODE
Yes
No
Don't know

Section 6 – Views on identifiability and choice

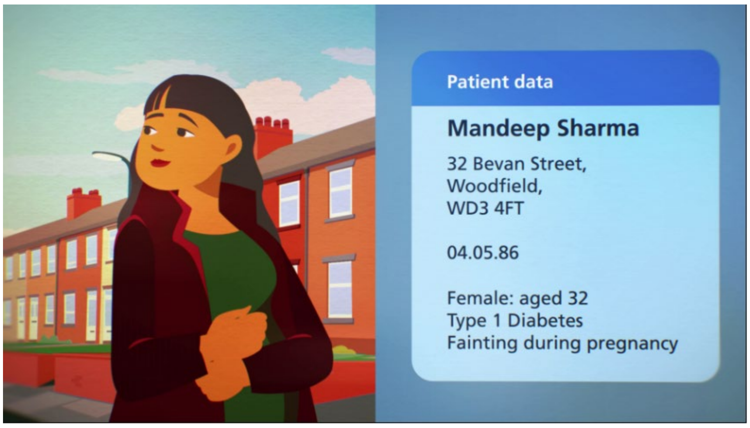
We're now going to talk about your choices over how the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC uses your patient data.**

Q10. Do you think that you currently have a choice over whether the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC can use your health data for each of the following purposes?**
SINGLECODE - table format radio buttons
Yes
No
Don’t know
LOOP – RANDOMISE ORDER
Direct care
Planning
Population health
Research
END LOOP

SHOWCARD: The *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC uses your data for different purposes. Some uses require your data to be identifiable. Personally identifiable data contains information that can be used to identify a specific person, such as your name, address, date of birth, and your** *[TEXT SUB ACCORDING TO LOCATION]* **NHS/Health & Care number. For instance, your medical professionals will use identifiable data to support your individual care.**

The NHS also uses de-identified data. De-identified data has had information that could directly identify you, such as your name or date of birth, removed or disguised. However, if de-identified data is not adequately protected or combined with different sources, it may be possible to identify an individual from this data.

Identifiable data:



Patient data

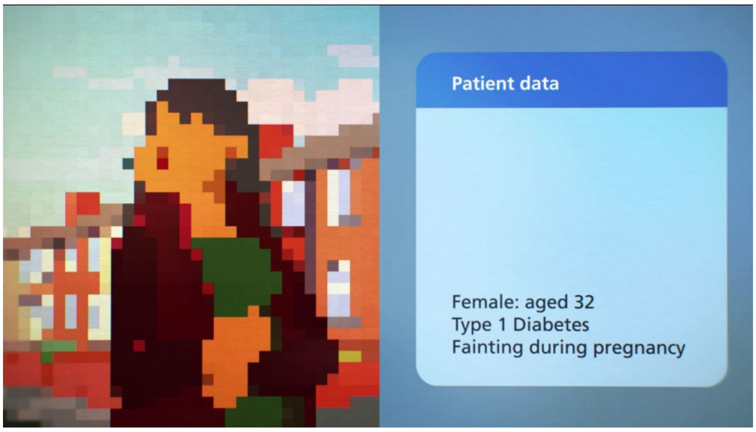
Mandeep Sharma

32 Bevan Street,
Woodfield,
WD3 4FT

04.05.86

Female: aged 32
Type 1 Diabetes
Fainting during pregnancy

De-identified data:



Patient data

Female: aged 32
Type 1 Diabetes
Fainting during pregnancy

Q11. Does it matter to you whether the data used by the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC for planning and population health is de-identified or identifiable?**
SINGLECODE – Sliding scale on screen
Yes, I strongly prefer de-identified data to be used
Yes, I somewhat prefer de-identified data to be used
No, I have no preference
Yes, I somewhat prefer identifiable data to be used
Yes, I strongly prefer identifiable data to be used
Don’t know

Q12. The *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC uses both identifiable and de-identified data internally to support planning. Sometimes identifiable data is more useful and in some cases the analysis can only be done using identifiable data.**

Does this change how you feel about identifiable data being used for planning?
SINGLECODE
Yes, I am more supportive of using identifiable data for planning
Yes, I am less supportive of using identifiable data for planning
No, this does not change how I feel
Don’t know

Q13. When it comes to the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC using data for planning and population health purposes internally, do you think the** *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC should have access to people’s data automatically, i.e. without you opting into it?**
SINGLECODE
Yes, both identifiable and de-identified data
Yes, only de-identified data
Yes, only identifiable data
No, the NHS should not have automatic access to my data for planning
Don’t know

Q13a. Why did you give this answer?
OPENCODE

If answered "England" at S3 –
Q14. Currently, you can choose to opt-out of your identifiable data being used for "research and planning" as a whole, but you cannot choose to opt-out of one but not the other.

As a reminder, 'research' refers to research that uses data about people's health and care. For instance, looking at population-level health data to understand risk factors for disease or identify ways to develop new treatments.

To what extent do you agree with the following statement: "The choice about whether your patient data is used for planning should be separate from choosing whether it is used for research"
SINGLECODE
Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree
Don't know

If answered "England" at S3 –
Q15. Although you can currently choose to opt-out of your identifiable data being shared for research and planning purposes, there are certain exceptions to this. For example, to deal with the major public health risk of coronavirus, patient data was shared within the NHS for a limited period of time, regardless of whether patients had chosen to opt-out.

Do you support any of the following exceptions to your ability to opt-out from sharing your data for research and planning purposes?
SINGLECODE
Support
Do not support
Don't know
Prefer not to say

LOOP
Using patient data to monitor and control a risk to public health, such as an infectious disease
There are public interest reasons why you cannot opt-out, such as reporting of gun wounds to the police
The sharing of patient data is required by law or court order
Your data forms part of an investigation into a healthcare provider, such as a General Medical Council investigation into a doctor's fitness to practice
Fully anonymised data, which cannot be traced back to an individual, is used
Delivering and monitoring vaccination programmes

If answered "England" at S3 –

Q16. Can you think of any other circumstances where you would be happy for the NHS to use patient data regardless of opt-out preferences?

OPENCODE

Q17. Do you have any other comments about the use of patient data for planning and population health by the *[TEXT SUB ACCORDING TO LOCATION]* **NHS/HSC?**

OPENCODE

Q18. Thank you for your time answering this survey. Just to double check for quality control purposes, please write your age in the box below

OPENCODE

Prefer not to say

THANK AND CLOSE

Appendix 2: Discussion guide

QaResearch

Understanding Patient Data

Data for Planning – Views and Expectations

General Public - Online Workshop Script

Respondent Profile:

- Demographic mix from across the UK
- Group 1 – Under 35's
- Group 2 – 35-49's
- Group 3 – 50+
- Group 4 – Mixed ages

Section 1: Introduction – 10 mins

Presentation: Welcome

- Qa - Welcome, thank you for coming
- Qa is doing this research on behalf of Understanding Patient Data, an independent initiative hosted by the NHS Confederation. The purpose of UPD is to make the way patient data is used visible, understandable and trustworthy, for patients, the public and health professionals.

Ground rules:

- Should last no longer than 90 minutes
- Video and audio recording
- Please have your cameras on but please mute when not speaking if possible
- £60 thank you payment transferred via bank transfer this week.
- Confidential – everything you say will be reported anonymously
- No right or wrong answers – just want your honest feedback
- No such thing as a silly question – if you're thinking it, chances are someone else is too
- Please be respectful of each other's views even if you do not agree with them
- To ensure we all hear what each of you has to say, please try not to talk over each other – but feel free to make comments in response to each other's points.
- Qa follows the MRS Code of Conduct which means you have the right to withdraw from the research at any time, and don't have to answer any question if you don't want to.

What is this online workshop about?

The online workshop is about the use of patient data for planning and population health purposes. Don't worry, we'll explain all you need to know. Throughout the workshop we'll show you slides and have discussions to build your understanding of using patient data for these reasons, and hear what your opinions are about it.

Discussion: Introductions

First, let’s go around the table and everyone introduce yourself.

- Name
- Where do you live? What do you like about it?
- What do you do for a living?

Section 2: General Attitudes Towards The Health Service and Use of Data - 10 mins

- We’re going to start with an explanation on what we mean by the ‘health service’ and ‘patient data’ and go from there. If there is anything you aren’t sure on, or you feel like we’ve missed, please ask questions!
- When we talk about the **Health Service** we are referring to the **National Health Service (NHS)** in England, Wales and Scotland and the Health and Social Care (HSC) in Northern Ireland. We will use the term ‘**Health Service’** throughout the workshop.
- When we refer to **patient data,** we mean the data that is routinely collected when someone interacts with the Health Service, such as visiting the GP or hospital. **SHOWCARD 1** - This includes information about the **individual, their health and lifestyle and may include information such as name, address, contact information, date of birth, next of kin, height and weight, medical conditions, medication history and test results such as blood tests or MRI scans**. This data is stored in your patient record and there are strict regulations in place to protect your data and confidentiality. This full record is used to help the different people involved in your health care give you the best care possible.
    - Are there any questions about these definitions? Do these make sense?
    - Have you heard of the term ‘patient data’ before?
    - If yes, where have you heard the term? What have you heard about it?

- We’re now going to look at some examples of how the Health Service *currently* uses your data…

SHOWCARD 2 – ‘Patient Data Uses’

- **Individual Care** e.g., using data to prevent, investigate or treat a patient’s health problem

  - **Research** e.g. using data to understand health conditions better and develop new treatments
  - **Planning**
  - **Population Health**

For this group we won't be covering individual care and research, instead will be focusing on planning and population health (**SHOWCARD 3**). We will delve into these further.

Section 3: Introducing Data for Planning and Population Health

- Patient data is used to provide the best individual care for each patient or for research, but today we are going to focus on how it **is used internally** by the health service to help make the health service better (called **planning**), or to understand and improve the health outcomes a particular population (called population **health**).

SHOWCARD 3

UNPROMPTED:

- Have you heard of either of these terms before? If so, which one?
- What are your first impressions of using data for population health / planning?
- What do you think about this?
- Can you think of any instances where the Health Service would need to use data for planning and population health?
- Where have you heard about these?
- Did you know that your data may be used to support planning and population health?

- We are now going to talk a little bit about what we mean when we talk about using data for planning. Don't worry if this is a little bit confusing, we will go over this in more detail later. But here is what using data for planning involves:

SHOWCARD 4 – Using Data to Support Planning

- Explain how the health service uses data for planning [based on slides]. Explain that we are going to go into more detail with examples shortly.
- *Understand and evaluate how health services are operating at the moment to help them improve* ***– for instance, looking at data about cancer care to understand where delays might be occurring and where initiatives or extra funding to speed up referrals might be implemented.***
- *Predict what health services will be needed in the future and provide them with enough funding, staff and equipment –* ***for instance looking at how the population is changing over time to understand what the demand is likely to be for stroke units so that national leaders can invest in new stroke units in hospitals.***

- *Coordinate between the health service and the local authority to ensure each sector has the information they need to provide care –* ***for instance sharing data between a hospital trust and the local authority about the number of patients that are medically fit to be discharged but need social care arranged, so that the local authority can prepare for when patients are moved from hospital into social care.***

SHOWCARD 5 – Using Data to Support Population Health

- Explain how the health service uses data for population health [based on slides]

- *Use data about groups of people to identify common characteristics that may impact health to anticipate the needs of different communities and allow the health service to respond–* ***for instance, a local health service looking at health data in combination with data about deprivation and social exclusion such as income and disability to anticipate how this might affect people's ability to access healthcare services or likelihood to suffer from poor health, so that health services can be tailored accordingly e.g. coming up with models of care that are easier to access or providing more anti-smoking services.***
- *Deliver programmes to improve the health of the population, such as the COVID-19 vaccine programme –* ***for instance, segmenting the population into different groups with different risk factors for COVID-19 to determine what groups of people should receive an invitation to get vaccinated first.***

    - Do you understand this?
    - Do you have any questions?
    - Do you agree with your data being used for this purpose?

SHOWCARD 6 – Planning and Population Health at Different Levels

- Explain that healthcare planning and population health management happens at many different levels. For instance, as shown by **SHOWCARD 5**, planning is done by your local hospital all the way to national organisations [like NHS England, the UK Health Security Agency, or others]

- Does this make sense?
- Do you have any questions?
- Looking at **SHOWCARD 6**, do you feel differently about your data being used for planning and population health locally or by national organisations?
- Why? Why not?
- Are there any health services you would trust more or less to use your data for planning and population health?

Section 4: Levels of Support for Different Uses of Patient Data for Planning and Population Health – 15 mins

- Now that we've defined what planning and population health, I am going to show you some more specific examples of how data is used for these purposes.

SHOWCARD 7 – 'Why Different People Need Access'

- These are some types of roles within the health service that might need to use data for planning and population health. It might also be contracted out.
- Does this sound familiar based on what we have just talked about?
- How do you feel about your data being used for this purpose?

We are now going to look at some more specific examples of how data may be used for planning and population health…

SHOWCARD 8 – Examples of How Data is Used for Planning and Population Health

- Analysing hospital admission data to ensure the hospital has the right amount of staff and resources available to deliver care – *for instance, forecasting when A&E services are likely to be busiest.*
- Monitoring and evaluating patient outcomes to understand which services are performing well and which ones need additional support, ensuring patients receive effective care. E.g., *NHS England analyse data from hospital trusts about how they are performing against targets like ambulance wait times, what proportion of patients take up cancer screening, how well the hospital trust is managing its budgets etc. If a trust is consistently far off these targets, this will prompt investigation and NHS England will work with the trust to understand where they might need additional support or guidance to get back on track. This support will look different depending on what the problems are.*
- Sharing data between health and the local authority to improve services… *e.g., hospital managers sharing data with local authorities to manage people being discharged from hospital to social care*
- Studying how the nation's health is changing to predict what services are going to be needed… *E.g., looking at population changes over time to target investment in new hospitals or analysing trends in stroke incidence to understand where in the country more hospital beds for stroke patients are needed.*
- Using patient data to deliver vaccination programmes. *For instance, identifying groups of people (e.g. numbers of people over age 50 in Bedfordshire) who would be eligible for the COVID-19 vaccine in a given area at a given time.*
- Analysing data to identify groups of people with similar lifestyles or risk factors that may contribute to health conditions, and reaching out to these groups to provide services that are targeted to their needs for improving their health… *E.g., local health analysts using data to identify people whose records indicate*

they are at risk of heart disease to be referred to social prescribing services like healthy eating advice

For each statement ask:

- How, if at all, familiar are you with your data being used for this purpose?
- Do you support your data being used for this purpose?
- If yes, why? If no, why?
- Is this important to you that your data is used for this purpose?

After reading all statements:

- Which of the examples would you say is the most important out of them all and why?
- Which example would you say you are most familiar with? Probe on: which ones are most relevant to you (*is it because of their proximity to vaccine programmes because of covid?)*
- Why do you say this?
- Are there any examples that you would not support/are concerned about?
- Why?
- What makes certain examples of data being used for planning and population health acceptable and others not?
- Depending on answers probe on:
    - Some of these involve sharing health data with other public sector organisations such as local authorities. How do you feel about this?
    - Do you feel more/less comfortable than if data were only analysed by the health service?
    - Do you feel differently about local services using data for planning and population health (e.g. hospitals forecasting demand for services) and national organisations (e.g. determining where to build new hospitals or central policymakers using data to find ways to save the health service money/be more efficient with its resources)?
    - If yes, why? If no, why?

Section 5 – Benefits and risks of using data for Planning & Population Health – 15 mins

We are now going to move on and look at some potential benefits and risks of using patient data for **planning and population health.**

- Unprompted: What do you think the benefits are of using data for planning and population health?
  …Why do you think this is a benefit?
- What do you think would be the biggest benefit of using data for planning and population health?

- **SHOWCARD 9** – Benefits of using patient data for Planning and Population Health
- *Providing more targeted care and resources to reduce health inequalities - The use of data helps the health service understand the needs of different groups of the population and to consider societal and environmental factors that impact health, which means they can provide targeted interventions to improve health outcomes and reduce health inequalities.*
- *Making the healthcare system more efficient and saving the health service money - by using data to understand where there is demand for services, leaders can know where to invest resources, for instance building new hospitals. By understanding how services are performing, they can also know which services are most cost-effective, saving the NHS money*
- *Helping the NHS evaluate and improve health services to provide better care - Patient data can be used to analyse how services (for instance maternity units across the country) are performing to make comparisons and understand where improvements can be made. For instance, looking at patient outcomes from surgery to make sure everyone receives good and safe care.*

    - Do you have any questions on any of these?
    - How do you feel about the list of benefits? Probe on: Positive / Negative? Confusing? Explore why
    - Are there any other benefits you can think of?
    - Which of the benefits are most relevant to you?
    - If you had to pick one benefit which is most important, which would you pick? Explore why
    - Do these benefits make you feel happier about sharing your data for planning and population?

Other benefits to call on if needed;

- *Improving coordination between the different parts of the health and social care system within the health service*
- *Helping the health service to target intervention and treatment at groups that need it most*
- *Allowing the health service to monitor the safety and effectiveness of treatments*
- *Monitoring to identify emerging public health risks, such as the Covid-19 pandemic*

- Unprompted: What do you think the risks are of using data for planning and population health?
- What are your personal concerns about sharing your data for this purpose?

- **SHOWCARD 10**– Potential Risks

- *Someone having unauthorised access to my health data - for instance, a health service staff member looking at my patient record even though they have no reason* *to. It is a criminal offence for healthcare professionals to look at someone's patient record when they do not need to in the course of their duties.*

- *Accidental or deliberate data breach, where identifiable data is lost, destroyed, altered or disclosed - for instance, your health data being shown or sent to the wrong person, or a hospital's IT system being hacked. Most data breaches in the health service are accidental and if there is a data breach, health service organisations have to report the breach to the Information Commissioners Office and tell you about it.*
- *My data could be used for other purposes that I don't agree with - for instance, your data is used for medical research you oppose or by actors you oppose, such as pharmaceutical companies.*

- Do you have any questions on any of these?
- How do you feel about the list of risks? Probe on: Positive / Negative? Confusing?
- What situations specifically worry you?
- Are there any other risks you can think of that concern you?
- If you had to pick one risk which concerns you most, which would you pick? Explore why
- Do these risks make you worried about sharing your data?

Other risks to call on if needed;

- *Discrimination against me or people similar to me*
- *The Health Service accessing/using more of people's data than it needs to*
- *Incorrect conclusions from data could harm services or people*
- *I don't have control of how the data is used*

- **POLL** on Zoom – do you think the benefits **outweigh** the risks for using patient data for planning and population health?
  - Those who said yes – why?
  - Those who said no – why? What would make you change your mind?

- Thinking about how your data is used, do you feel comfortable with what it is used for, and how it is kept safe?
  - Could the health service give more reassurance? In what ways?
  - Do you think the Health Service could do anything to help with making people more aware of how your data is used?

- What safeguards would make you feel more comfortable with the use of data for planning and population health?
  - The people accessing the data are appropriately trained and authorised
  - The use of data is lawful, in the best interests of patients and the public

    - The data has been processed to minimise the risk of identifying individuals
    - There are technical controls on who can access the data and the data is stored in a way that protects data against unauthorised use
    - Analysts and other people accessing the data can only see the data they need to see to complete their task (and nothing else)
    - The health service is transparent about what data has been accessed, who has accessed it, and why
- Something else?

Section 6: Views on Identifiability and Choice – 25 mins

- Thinking about how the health service uses your data for planning and population health… **SHOWCARD 11**
    - For most planning and population health analysis at a **national** level, the health service can use **de-identified** data where information that could directly identify you, such as your name or date of birth, has been removed or disguised.
        - **SHOWCARD 12** For instance, looking at population level data on how the health of the nation is changing to prepare us for future health challenges such as an increase in cancer incidence rates due to changes in diet and exercise. This can be data such as how the population is ageing, how many people have risk factors for heart disease, or trends in vaccination rates. The data is not identifiable and focuses on large trends or patterns.
    - **SHOWCARD 11** Sometimes **local** services use **identifiable** data – which can include identifying information about you such as address or date of birth – use identifiable data. They will use data with as little identifying information as possible but sometimes need to know who you are.
        - **SHOWCARD 12** For instance, for population health management, your local health service looks at patterns in data about large numbers of people to identify groups of people with similar risk factors for disease to be able to provide additional services to help them. To do this, they need to be able to identify you in order to contact you.
- Do you understand this?
- Do you have any questions on de-identified and identifiable data?

- **SHOWCARD 13** Different parts of the health service have access to your data automatically/by default, meaning that you do not have an ability to opt-out, do not have to opt in or actively choose to share your data for these purposes. Remember there are strict rules about who is allowed to access your data, and all uses must benefit patients and the public.
- *For instance, your pharmacist has access to a version of your health record so that they can give you your prescription and give you advice on how your medicine might interact with any others you are taking. Clinical researchers can request access to de-identified data for research projects, for instance looking at correlation between different risk factors and heart disease.*

- Thinking specifically about the use of data for planning and population health…
    - How do you feel about the Health Service having access to people's data automatically?
    - Positive / negative?
    - Why do you feel this way?
    - Do you have any concerns about the Health Service automatically having this data?
    - Would you choose to share data if you were provided with a choice?
    - Explore why

- **SHOWCARD 14**
- You cannot opt-out of having your data used by health and care organisations for your own individual care. However, depending on where you live in the UK, you may be able to opt-out of your data being used for secondary uses (which includes research, planning and population health).
- Thinking about the examples we discussed earlier of how your data may be used for planning and population health, we want to talk about what choices you think people should have…

- For each of the examples we discussed earlier, do you think the health service should:
        - Be able to use people's data by default, and you shouldn't be able to opt-out
        - Be able to use people's data by default, but you should be able to opt-out
        - Not be able to use people's data by default, you should have to opt in to your data being used this way
- Do your thoughts on this change depending on whether the data is identifiable or de-identified?
- Do you have any concerns about people opting-out?

    - (If no thoughts, prompt on e.g. datasets not being representative, there being less data available to help plan services etc…)

Section 7 – Final Questions and Thanks for Contributing

- Do you have any other comments you'd like to make at all?

Thank you everyone for your brilliant contributions today. Your £60 will be on its way to you this week.

CLOSE GROUP

Appendix 3: Showcard deck

Data for Planning Stimulus
Understanding Patient Data

Qa Research
Merchant House,
11a Piccadilly, York, YO1 9WB
01904 632039 www.qaresearch.co.uk

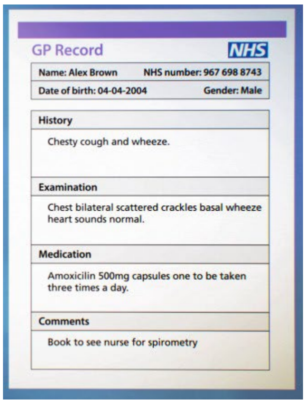
Ground rules

- No longer than 90 minutes
- Video and audio recording
- Cameras on but please mute when not speaking
- £60 thank you payment
- Confidential
- No right or wrong answers
- No such thing as silly questions
- Respect each other's views
- Try not to talk over each other
- MRS Code of Conduct

1. What patient data is collected about you?

Your patient record includes information such as:

- Name
- Address
- Contact information
- Date of birth
- Height
- Weight
- Next of kin information
- Medical conditions
- Medication history
- Test results, such as blood tests or MRI scans



GP Record

NHS

Name: Alex Brown NHS number: 967 698 8743
Date of birth: 04-04-2004 Gender: Male

History

Chesty cough and wheeze.

Examination

Chest bilateral scattered crackles basal wheeze heart sounds normal.

Medication

Amoxicilin 500mg capsules one to be taken three times a day.

Comments

Book to see nurse for spirometry

2. Patient Data Uses

1. Individual Care

2. Research

3. Planning

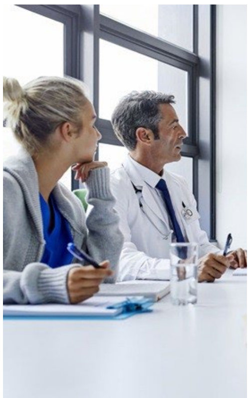
4. Population Health

3. Going forward, we'll talk about…

1. Individual Care
2. Research
3. Planning
4. Population Health

4. Using Data to Support Planning

The health service uses data to support **planning**. This involves using data about patients to:



- Understand and evaluate how health services are operating to help them improve
- Predict what health services will be needed in the future, including the funding, staff and equipment to support it
- Coordinate between the health service and the local authority to ensure each sector has the information they need to provide care

5. Using Data to Support Population Health

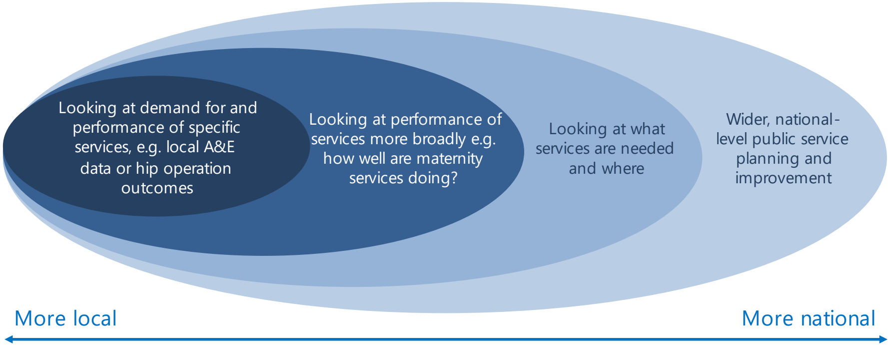
The health service also uses data to improve **population health**. This involves using data about patients to:

- Identify common characteristics that may impact health to anticipate the needs of different groups or communities and allow the health service to provide the service they need
- Deliver interventions to improve the health of the population, such as the COVID-19 vaccine programme

Population health aims to improve the health of a defined population, and takes into account the many social determinants of health that affect our wellbeing, such as geography, ethnicity, and social class.

6. Planning and Population Health at Different Levels

Healthcare planning and population health happens at many different levels.
For instance, this shows an example of the different levels of health system planning.



Looking at demand for and performance of specific services, e.g. local A&E data or hip operation outcomes

Looking at performance of services more broadly e.g. how well are maternity services doing?

Looking at what services are needed and where

Wider, national-level public service planning and improvement

More local

More national

Adapted from Ipsos |OneLondon Deliberative event- Day 3 Presentation | February 2020 | | Public |

7. Why Different People Need Access

Hospital Manager

I need to analyse Accidents and Emergency (A&E) admission data (*e.g., time spent in A&E*) to ensure that our hospital has the **right amount of staff and resources** available to deliver care.

Analyst (National)

I analyse demographic and health trends nationwide, trying to **predict the future demand for services**. This helps me strategically target resources where they'll be most needed.

Analyst (Local)

I analyse data to find groups of people who share similar lifestyles or risk factors that could contribute to health conditions. From there, local clinicians can **tailor health interventions for different groups to address their specific needs**.

8. Examples of How Data is Used for Planning and Population Health


1 Analysing hospital admission data to ensure the hospital has the right amount of staff and resources


2 Evaluating patient outcomes to understand which services need additional support so patients get effective care


3 Sharing data between the health service and local authority to improve services


4 Studying how the nation's health is changing to predict what services are going to be needed where


5 Using patient data to deliver vaccination programmes and issue invitations


6 Analysing data to identify groups of people with similar demographics or risk factors for outreach

9. Potential Benefits of Using Patient Data for Planning and Population Health


Speeding up access to treatment and **reducing waiting lists**

Making the healthcare system **more efficient** and **saving the health service money**


Providing more **targeted care** to improve population health and **reduce health inequalities**

10. Potential Risks of Using Patient Data for Planning and Population Health

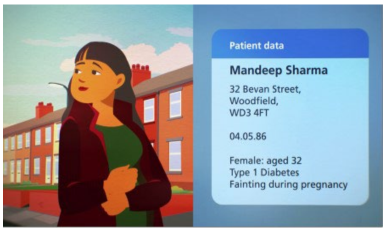

Someone having **unauthorised access** to my health data

Accidental or deliberate **data breach**, where **identifiable data** is lost, destroyed, altered or disclosed


My data could be used for other **purposes that I don't agree with**

11. Identifiable vs De-identified Data

Identifiable Data



Patient data

Mandeep Sharma

32 Bevan Street,
Woodfield,
WD3 4FT

04.05.86

Female: aged 32
Type 1 Diabetes
Fainting during pregnancy

De-identified Data

Patient data

Female: aged 32
Type 1 Diabetes
Fainting during pregnancy

12. How Identifiable and De-identified Data Could Be Used

Local Level

Identifying groups of people in the local community with similar risk factors for disease to be able to provide additional services to help them.

National Level

Preparing for future health challenges e.g., an increase in cancer rates due to changes in diet and exercise.

13. Who can access your data?

Different parts of the health service have access to your data for a number of purposes.

This happens automatically, without you needing to opt in to share your data.

Most of the time when your data is used for **secondary uses**, identifying information about you has been removed from it.

Secondary uses

Individual care
- GP
- Pharmacy
- Hospital

Research
- Clinical researchers

Planning
- Hospital managers
- Analysts (local)
- Health service managers/ analysts (national)

Population health
- Public health teams (local)
- Health analysts (local)
- Public health bodies (national)

14. Choices about the use of data for planning and population health

Should the health service…

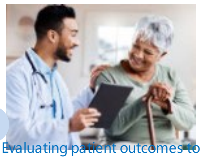
a) Be able to use people's data **by default**, and you **should NOT** be able to opt out

b) Be able to use people's data **by default**, but you **should** be able to opt out

c) **NOT** be able to use people's data by default, you should have to **opt in** to your data being used this way

1

Analysing hospital admission data to ensure the hospital has the right amount of staff and resources



2

Evaluating patient outcomes to understand which services need additional support so patients get effective care

3

Sharing data between the health service and local authority to improve services

4

Studying how the nation's health is changing to predict what services are going to be needed where

5

Using patient data to deliver vaccination programmes and issue invitations

6

Analysing data to identify groups of people with similar demographics or risk factors for outreach

Project details

Project number: HEALT04-9391 Patient Data Public Views

Location:
UPD_Quantitative_Resulhttps://qaresearch.sharepoint.com/sites/QaData_S-ProjectFiles/Shared Documents/ProjectFiles/U/Understanding_Patient_Data/HEALT04-9391_Patient_data_public_views/Reports/UPD_Quantitative_Results_V2.docxts_V2

Date: 18th April 2024

Report status: Final

Approved by: Georgina Culliford

Authors: Georgina Culliford, Hannah Penrose and Sam Shaw

Comments: georgina.culliford@qaresearch.co.uk

This research has been carried out in compliance with the International standard ISO 20252, (the International Standard for Market and Social research), The Market Research Society's Code of Conduct and UK Data Protection law.

Address
Qa Research,
Merchant House,
11a Piccadilly,
York, YO1 9WB
01904 632039

www.qaresearch.co.uk
Company registration: 3186539