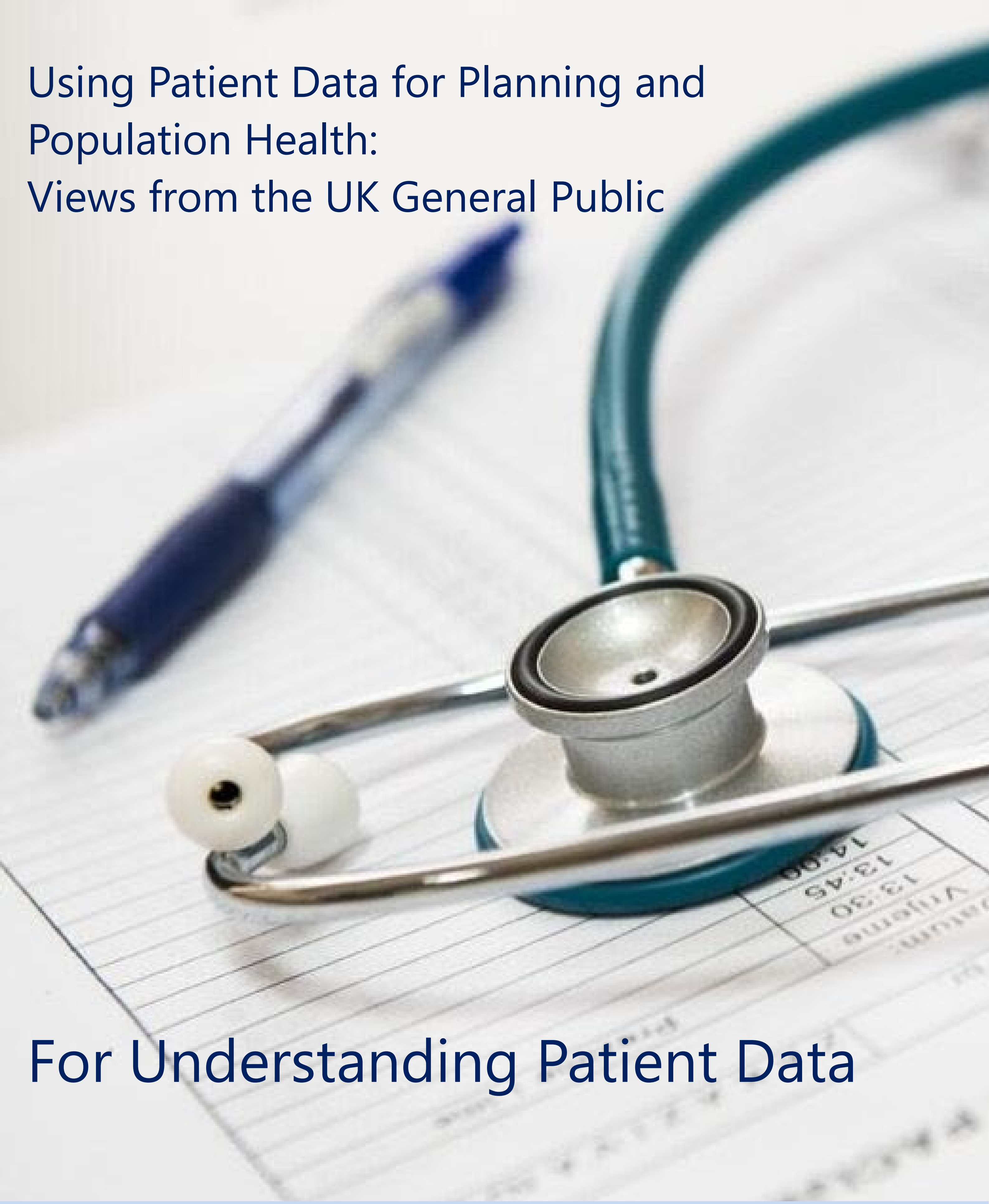
Using Patient Data for Planning and Population Health: Views from the UK General Public



For Understanding Patient Data

18th April 2024

MRS Evidence Matters™ Company Partner

QaResearch

Contents

1. Executive Summary

Research aim

This research project set out to understand public awareness, understanding and views towards the use of patient data for the specific use cases of planning and population health.

Methodology

The research consisted of two elements:

1. Quantitative online survey conducted with a nationally representative sample (N=1000) of the general public from all four UK nations.
2. Qualitative online workshops with members of the general public from all four UK nations. 31 participants took part across 4 workshops, grouped into age brackets.

Key findings

Awareness of patient data uses

Awareness of the use of patient data in the NHS was generally low, and participants demonstrated lower levels of awareness of the use of data for planning and population health than for research or individual care. Uses of data that participants could personally relate to garnered higher levels of awareness.

Overall levels of awareness about how the NHS uses patient data were low. A majority (54%) of survey respondents said that they knew *'nothing'* or *'a little'* about how the NHS uses the patient data it collects.

Respondents were less familiar with the use of patient data for 'planning' (66%) and 'population health' (68%) compared to 'research' (71%) and 'individual care' (86%), in both the survey and workshops.

The workshops revealed that whilst people were generally not familiar with the terminology of 'planning' and 'population health', they were familiar with, and understood, specific 'real-life' examples of how patient data was used for these purposes, e.g. managing hospital capacity or vaccine programmes.

People tended to be most familiar with examples of using patient data for planning and population health when they could personally relate. For example, a high proportion (65%) of survey respondents said they knew something about using patient data to help with *'delivering vaccination programmes'*, an example which has become more familiar to members of the public in the wake of the Covid-19 pandemic.

Support for different uses of data for planning and population health

Overall, participants reported consistently high levels of support for sharing their data for planning and population health purposes, and each use case was seen to be fair and essential to the running of the NHS.'Monitoring patient outcomes to understand how services are performing' and 'Analysing A&E admission data to manage demand for services' received the highest levels of support in the survey.

When presented with different examples of how patient data is used for planning and population health, the vast majority of people were supportive and stated that they would be happy to share their data for these purposes.

In the survey, around 90% of respondents stated that they would 'support' or 'strongly support' sharing their data for each example that was provided, compared to 84% of respondents who agreed with the general statement *'I am supportive of the use of patient data in the NHS'*, which might suggest that people are slightly more supportive of the use of data for planning when presented with specific examples of patient data uses compared to a broader statement.

The examples which garnered the highest levels of support in the survey were *'Monitoring patient outcomes to understand how services are performing'* (94%) and *'Analysing A&E admission data to manage demand for services'* (94%), while the example with the least support *'Analysing data to identify groups of people with similar lifestyles or risk factors'* still received high levels of support (89%) among respondents.

In the workshops, where participants were able to discuss and consider the different uses of patient data for planning and population health in more detail, there was widespread support for the NHS to use patient data for all of these purposes. Participants felt these uses were fair and logical, as well as being essential to the smooth running of the NHS.

People from older age groups were more likely to support the use of their patient data for planning and population health purposes, with 85% of over 55s supportive of all the examples we shared, compared to 18-34s (69%) and 35-54s (75%). The online workshops suggested that older people had a closer proximity to the NHS, having used (or expecting to use) health services more as they got older, and were therefore more invested and more willing for their data to be used to help improve the health service.

When asked about their data being used to support planning and population health at a local and national level, participants felt more comfortable with their data being used at a national level. Specifically, many participants placed emphasis on how using data on a larger scale is important for predicting what services will be needed overall in the future and where funding should be allocated, and that by using national data it is far less likely for individuals to be identifiable.

Attitudes towards benefits and risks of using patient data for planning and population health

Example benefits of using data relating to making the NHS more efficient, improving access to treatment and reducing costs were seen as the most convincing reasons to use data for planning and population health. Concerns around unauthorised access to data or data breaches were perceived as the biggest risks of the use of data. For the majority of participants, benefits were perceived to outweigh the risks.

When presented with potential benefits of using patient data for planning and population health purposes, people generally agreed with them. In the survey, each potential benefit was reported by a majority (70%+) to make them more supportive of sharing their health data for planning and population health.

People believed that the most useful benefits of using patient data for planning and population health purposes were those that revolved around making NHS services more efficient, improving access to care and cutting costs. *'Speeding up access to treatment and reducing waiting lists'* (87%) and *'making the healthcare system more efficient and saving the NHS money'* (82%) were selected as the most important reasons for using data for planning and population health.

The risks that most concerned people about the use of data for planning and population health focused on data security and privacy, with *'someone having unauthorised access to my health data'* (31%) or *'accidental or deliberate data breach'* (31%) being reported as the top reasons that might influence respondents to not want to share their data.

For most people, the benefits of using patient data for planning and population health were perceived to greater than the potential risks. Generally, participants in the workshops did not see the potential risks as a 'dealbreaker' and were supportive of sharing their patient data to help the NHS. This was reflected in the survey: 78% of respondents thought that the benefits outweighed any potential risks, however there are still 8% who felt the risks were too great and outweighed any benefits, and a further 14% who didn't know how they felt.

Views on identifiability and choice

A majority of participants strongly or somewhat preferred the use of de-identified data (as opposed to identifiable data) for planning and population health purposes. However, the use of identifiable data was perceived as acceptable as long as appropriate safeguards are in place and the use of identifiable data is limited.

There was limited awareness of the choices that people have in how their data is used. The findings from the workshops demonstrated that people in England were largely unaware that they could opt-out of their confidential patient information being used for secondary purposes (with some exceptions) through the National Data Opt-Out.

When given the option, people preferred de-identified data to be used for planning and population health purposes, with a majority (54%) of survey respondents strongly or somewhat preferred de-identified data to be used. Workshop findings echoed this, driven by participants' feeling that there is less risk associated with the use of de-identified data.

Whilst de-identified data was preferred, the majority of workshop participants were happy for their identifiable data to be used for planning and population health in instances when data cannot be entirely de-identified. Participants felt that as long as safeguards were in place and the NHS used as little identifiable information as possible, this would reduce concerns about the use of identifiable data.

There was a sizeable minority (19% of survey respondents) who thought that the NHS should not have automatic access to <u>any</u> type of data for planning and population health purposes, essentially suggesting that these should be 'opt in' rather than 'opt-out'. The verbatim responses from the survey and the workshop findings suggest that many who respond in this way do not necessarily oppose sharing their own data with the NHS, but would like to be given a choice on principle.

2. About this report

In December 2023, Understanding Patient Data (UPD) commissioned Qa Research to deliver a research project to explore public understanding and views on the use of patient data for planning and population health.

This mixed method project was carried out by Qa Research in February - March 2024 using an online survey and a series of online workshops. This report sets out findings from the survey and workshops, conclusions and avenues for future research.

This project was carried out in the context of developments in the use of health data across the UK to aid health service planning and improve population health, such as the commissioning of the Federated Data Platform and Integrated Care Systems having a mandate and increased expectations to use data for these purposes in England, and investments in data platforms across all four nations of the UK. On top of this, public discussion about the use of data during the data collection period means there were several possible influences on public opinion around the use of patient data. Results should be considered in this context.

About Understanding Patient Data

Understanding Patient Data is an independent initiative, hosted by the NHS Confederation, which aims to make the use of patient data more visible, understandable and trustworthy for patients, the public and health professionals. The initiative seeks to bring transparency, accountability and public involvement to the way patient data is used.

About Qa Research

Qa Research are an independent market and social research organisation with experience of delivering comprehensive insights into the health and social care sector.

A note on terminology

The NHS (National Health Service) was referred to throughout the survey for those living in England, Scotland and Wales. For those living in Northern Ireland, the term "NHS" was substituted with "HSC", referring to Health and Social Care, the publicly funded healthcare system in Northern Ireland. For ease of understanding, we will only refer to the NHS throughout the rest of this report.

This report will use the term "individual care", rather than "direct care", to refer to data that is used to prevent, investigate or treat a patient's health problem, in line with research conducted by Understanding Patient Data on the best words to use when talking about data.

3. Introduction and background

In recent years, a number of studies have explored public views on patient data uses. This area of research has become more salient as patient data plays an increasingly important role in governments' plans for improving and futureproofing the health service. The experiences of previous health data initiatives such as care.data and the halted roll-out of General Practice Data for Planning and Research (GPDPR) also highlight the importance of public support when setting policy on the use of patient data in the NHS.

Earlier research has shown relatively low levels of public awareness about the different uses of patient data. Whilst members of the public are generally aware of patient records and what kind of information is held in these records, awareness of specific uses of routinely collected patient data is low.[1,2] One study found that 61% of respondents knew very little or nothing at all about how the NHS uses the patient data it collects.[3] Another study found that only 33% of survey respondents had heard a great deal or fair amount about how the NHS is using health data.[4] Even when surveyed members of the public have heard of some uses of patient data, they do not tend to state that they understand fully what such uses entail. An NHS Digital study of public opinions about GPDPR found that a majority of respondents had heard of the scheme, but few actually understood the concepts surrounding it.[5] Lower understanding of how data is used has been found to be associated with higher levels of concerns about how patient data is used,[6] making improving public understanding of the uses of patient data a key consideration for policymakers setting health data policy.

A range of studies have found that people are generally supportive of the use of patient data for different purposes within the NHS.[7] A survey conducted by BCG's Centre for Growth found that a majority of respondents supported their health data being used for all use cases polled. The NHS consistently ranks at the top of the list of organisations people support using their health data, with the same BCG study finding 90% of people support sharing their health data with the NHS.[8] Whilst support for the NHS using health data remains high, research shows a relatively small but persistent minority of people, variously estimated at around 15-20%, that is unsupportive of all uses of their data.[9,10] There is also some evidence that levels of support for the NHS using patient data are declining, with Healthwatch finding in 2021 that 83% rate the NHS as very or moderately trustworthy on data (down from 92% in 2018), and 53% saying they were happy to share their data for planning and research (down from 73% in 2018).[11]

One systematic review of the existing research around public attitudes towards the use of patient data for research purposes found that respondents across a range of studies were typically supportive of sharing their data because they acknowledged that it would benefit the "public good". Whilst they were generally willing to share their data, concerns were raised that sharing their data would risk harm and breaches in their privacy.[12] Similarly, NHS Digital's study into public attitudes around GPDPR found broader benefits, such as improving NHS services, tended to be most convincing, whilst data security and access were perceived to be the most concerning risks of data sharing.[13]

Lower levels of awareness about the use of health data amongst individuals have been found to correlate with increased concerns about the use of health data.[14] However, it should also be noted that when levels of public awareness are raised this does not necessarily lead to more support from the general public. Research conducted by Healthwatch in 2021 in the midst of public discussion about GPDPR found that the public were more aware about health data uses due to media coverage of the issue, but were less willing to share their patient data than they had been in previous years.[15] Many previous studies into public attitudes towards patient data uses were conducted during a period of heightened public awareness in the wake of care.data or GPDPR. Our research will explore whether public views have changed since. However, it is worth noting that the research was conducted during a period of time following some controversy around the Federated Data Platform (FDP) in England along with the other possible influences on public opinion mentioned in section 2 – 'About this report'.

Whilst many studies have covered public understanding and attitudes about the use of health data generally, there is less information available on views about specific use cases. Many studies that focus on views about secondary uses of health data do not distinguish between research, planning, and population health, which leads to a lack of understanding about how levels of understanding and support compare between use cases. Many other studies focus solely on attitudes towards the use of data for research, perhaps because this use case is more likely to involve third-party actors such as universities or pharmaceutical companies.

There is relatively limited information available regarding the level of public awareness, understanding and support of utilising data specifically for the purposes of planning and population health, with some notable exceptions such as the OneLondon deliberation,[16] which highlighted a notable lack of research into people's views of data used for service planning. This research aims to contribute to the literature by filling this knowledge gap. Where relevant, this report will compare findings with existing evidence on views about data for planning and population health. The research also aims to look at views on the identifiability of data and views about the choices people have about how their data is used for planning and population health, which have limited coverage in existing studies.

Considerations for this research methodology

The lack of knowledge and comprehension among the public regarding the use of data for planning and population health was a theme repeated throughout the literature. This underscored the importance of building a clear picture of the current use and purpose of patient data throughout our qualitative and quantitative fieldwork exercises. The 2020 OneLondon Citizens' Summit was a deliberative event held over two weekends in 2020,[17] and we reviewed it in particular for its methodology in how to communicate complex concepts around patient data.

Reviewing the OneLondon materials and other literature had implications for our methodology as we knew to expect a range of existing knowledge and digital literacy levels as well as some potentially heightened emotions around threats to privacy.

The way we articulated both the concepts and the technological information would have an impact on participants' ability to provide informed opinions. Therefore, we tried to be clear, simple and concise in explanations using visual explainers from UPD and gaining inspiration from the OneLondon materials. We started at a very basic level, not assuming any prior knowledge and building in knowledge testing activities at different stages. In the survey, images were included to explain particular concepts and cognitive testing was carried out to ensure the survey was clearly understood.

4. Methodology

The research consisted of two strands:

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

4.1 Quantitative stage

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.

4.2 Qualitative stage

Sample and recruitment

In total 31 members of the general public took part over 4 online workshops. To account for participant drop outs, we over-recruited participants. Specifically, 32 participants were recruited (8 per group). Participants were recruited through free-find or pre-approved lists. The 4 groups were split depending upon age. See below for a breakdown of the sample:

Figure 3

UK Profile	**Final Sample**				
Gender	*Group 1 - Younger*	*Group 2 - Mid-age*	*Group 3 - Older*	*Group 4 - Mixed*	***Total***
Male	5	4	4	4	**17**
Female	2	4	4	4	**14**
Age					
18-35	7	0	0	2	**9**
35-49	0	8	0	3	**11**
50+	0	0	8	3	**11**
Nation/Region					
North East - England	1	1	0	0	**2**
North West - England	1	0	1	1	**3**
Yorkshire and Humber - England	0	1	1	1	**3**
East Midlands - England	0	0	1	1	**2**
West Midlands - England	1	1	1	0	**3**
East - England	0	1	0	1	**2**
London - England	1	1	1	0	**3**
South East	1	1	1	1	**4**
South West	0	1	1	1	**3**
Wales	0	0	1	1	**2**
Northern Ireland	1	0	0	0	**1**
Scotland	1	1	0	1	**3**
Ethnicity					
White British or Irish	5	5	5	5	**20**
Any other ethnic group	2	3	3	3	**11**
Social Grade					
ABC1	3	4	4	4	**15**
C2DE	4	4	4	4	**16**
Total	***7***	***8***	***8***	***8***	***31***

Online Workshop Method

All participants engaged in an online workshop, guided by a semi-structured discussion guide and a stimulus presentation designed to initiate discussions. The online workshops had a duration of 90 minutes, and participants were provided with a £60 cash incentive for taking part.

Online workshops were selected as the most appropriate and cost effective method due the target population for this research being the general public. The accessibility and flexibility provided an opportunity for individuals from diverse regions and demographics to participate over zoom.

Validation

Participants were validated in two key ways. First, validation and confirmation calls were carried out ahead of the online workshops where demographic information was checked. Second, interviewers confirmed participants' identity at the beginning of the online workshop.

Discussion guide and stimulus

A discussion guide with a semi-structured format was created to guide the online workshops. The guide featured themes similar to those in the survey but employed distinct sets of questions. The online workshop covered the following sections:

- General attitudes towards the health services and use of data
- Introducing data for planning and population health
- Support for different uses of patient data for planning and population health
- Benefits and risks of using data for planning and population health
- Views on identifiability and choice

The discussion guide was supported by stimulus material, where 14 showcards were created to visually depict the text and enhance understanding. The stimulus materials included content to inform participants. A full version of the discussion guide and showcards can be found in the Appendix.

Analysis

The qualitative team employed a thematic analysis approach to the data. Initially, all four online workshop recordings underwent transcription using software, and interviewers reviewed their own transcripts, making notes. Subsequently, the team hosted a collaborative analysis session to discuss, debate and shape themes into a cohesive report narrative. The quantitative lead also participated in this session to compare and contrast qualitative findings with the survey findings.

Please note that the outcomes of qualitative research cannot be projected and generalised onto the overall population. Instead, it gives depth and colour to the views people have of the NHS using patient data for planning and population health.

Limitations

The main limitation of this methodology was that it did not include many members of the public who were not technology literate as all methods were online. Only 4% of survey respondents disagreed that they were ‘confident using technology’, suggesting a wider range of viewpoints could have been gathered from people less confident. The qualitative element was all online so only involved those able to use Zoom. Possibly as a result, the findings may have over-represented positive views. The range of opinions are more varied in the survey, but still heavily weighted in favour of using patient data. Future studies may wish to redress this balance.

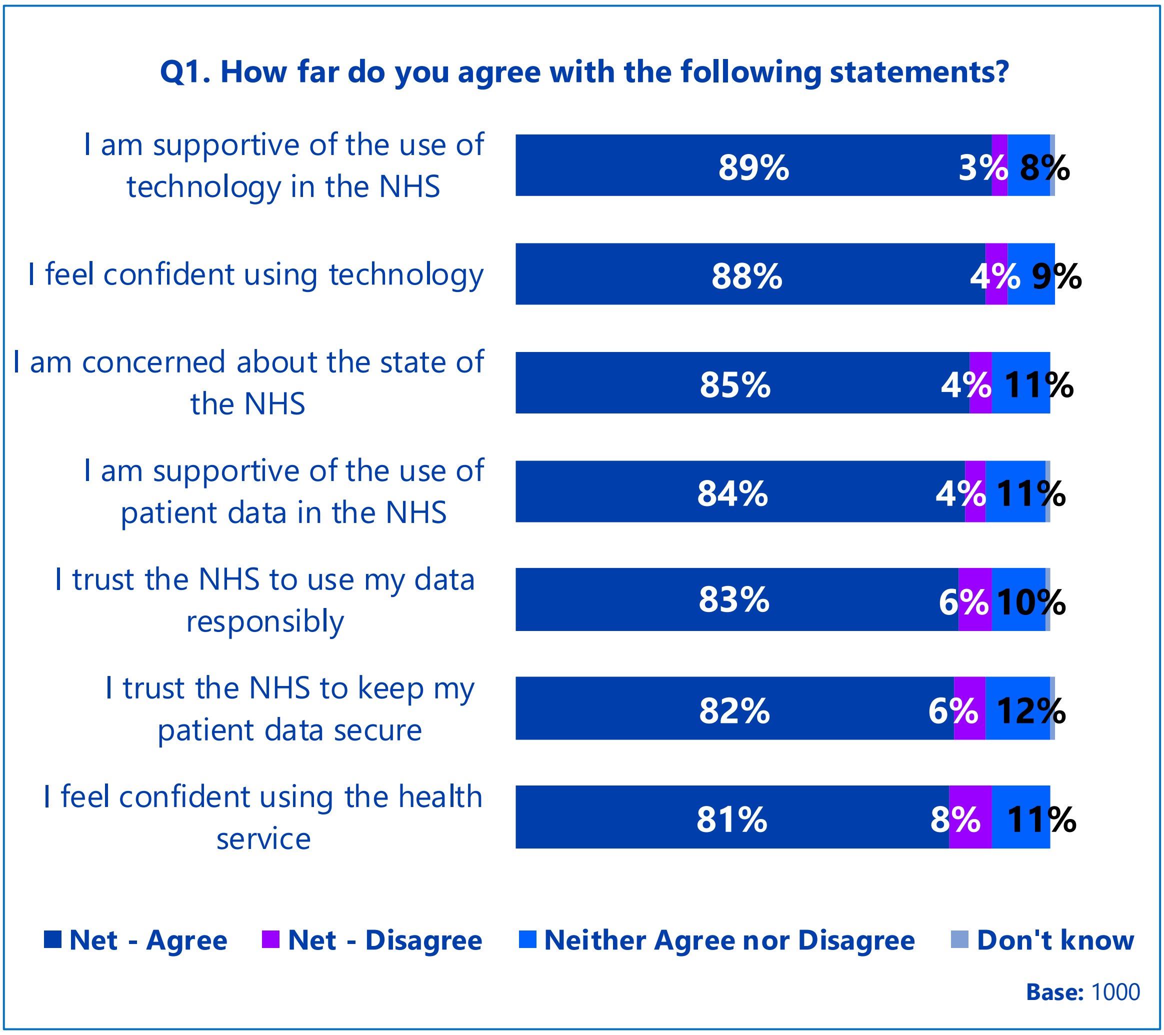
5. Findings

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

In the research, people were firstly asked about their general attitudes towards the NHS, and the use of patient data within it, in order to provide a wider context to their answers on later questions about the use of data for planning and population health purposes. These questions were also intended to allow comparisons between people's general attitudes, and their specific views on planning and population health. As such, in the survey findings, respondents' answers have been cross-tabulated and any significant differences have been highlighted.

Survey respondents were asked the extent to which they agreed with a series of general statements about the NHS, the use of patient data, and themselves. Over 80% answered *'agree'* or *'strongly agree'* for each of the statements.

Figure 4



Support for the use of patient data in the NHS

Overall, most people in the survey agreed with the general statement *'I am supportive of the use of patient data in the NHS'* (84%).

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 5

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				

These findings around levels of support are in line with existing research. Studies have found that people from minority ethnic backgrounds, such as Black and South Asian backgrounds, are slightly less willing to share their patient data.[18] Research has found that general levels of trust vary by socioeconomic group, with those from C2DE social grades more concerned about the use of their personal data.[19] Existing research also shows that older people are more likely to trust the NHS with their data, when compared to younger people.[20]

Trust around the use of patient data in the NHS

General levels of trust around the NHS using patient data are high. 83% and 82% of survey respondents agreed or strongly agreed with the statements *'I trust the NHS to use my data responsibly'* and *'I trust the NHS to keep my patient data secure'* respectively.

The table on the next page shows that were differences in levels of trust between some demographic groups.

Figure 6

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

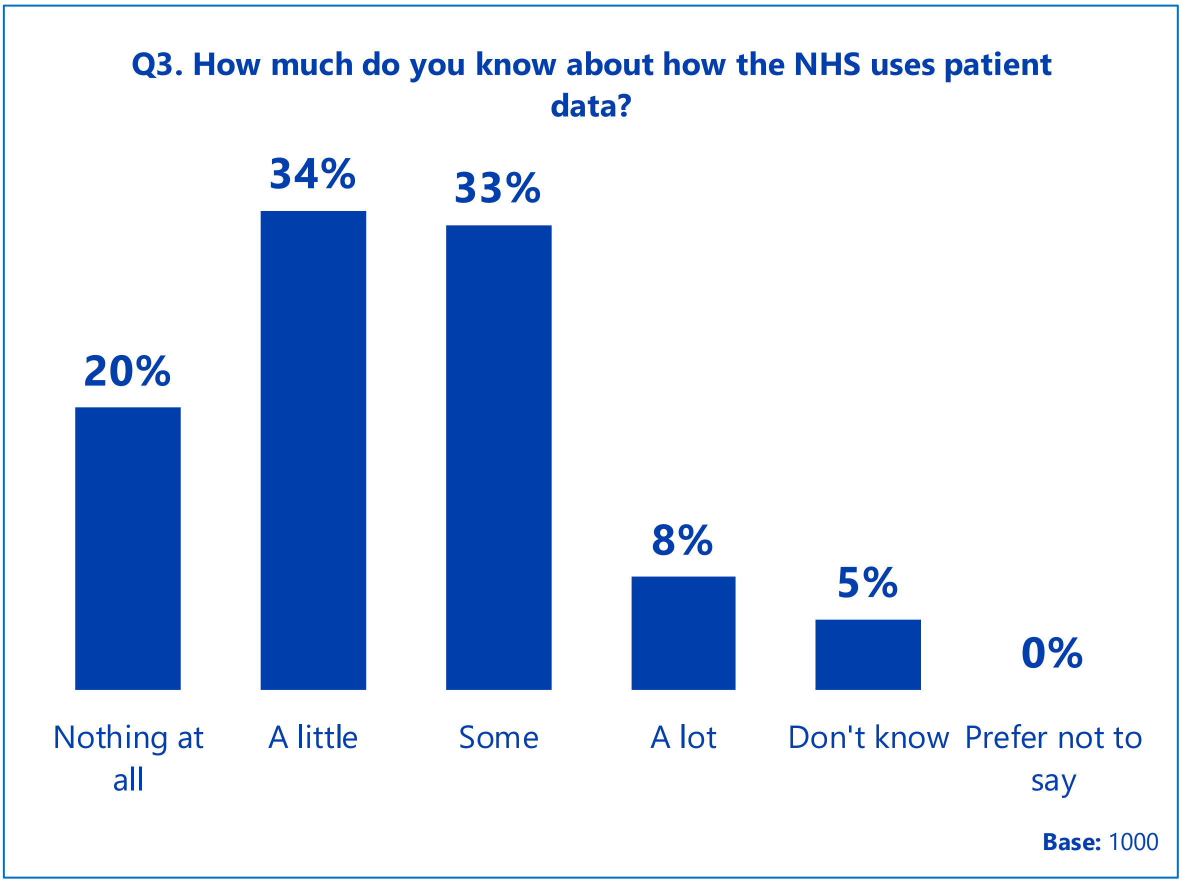
Section 2: Awareness of patient data uses in the NHS

Awareness of patient data in general

When asked how much they knew about how the NHS uses the patient data it collects, more than half (54%) of survey respondents said that they knew *'a little'* or *'nothing at all'*. This suggests levels of general awareness surrounding patient data uses are low, even before the more specific uses of patient data for planning and population were explained. Alongside low knowledge levels, this could also suggest people are not confident when talking about patient data, which was a sentiment echoed in the qualitative workshops.

A third of survey respondents (33%) said they knew *'some'* about how the NHS uses patient data. A much lower proportion (8%) stated that they knew *'a lot'* about how the NHS uses the patient data it collects.

Figure 7



The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. Younger people, people from a minority ethnic background, and people from social grades ABC1 were more likely to suggest that they knew *'some'* or *'a lot'* about how the NHS uses patient data.

Figure 8

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					

Workshop participants universally stated they understood the concept of 'patient data' and found it straightforward, after workshop facilitators defined the term as data that is routinely collected when somebody interacts with the NHS. Some participants had already heard of the term through interactions with GP surgeries, receptionists and nurses, and some were capable of specifying various forms of data collected by the NHS, such as medical conditions, address, and NHS numbers.

> *"[Patient data is...] your own confidential data as in your contact details, date of birth, things that are unique to you, your NHS number." Group 3*

None of the types of data listed were unexpected or contentious; all were presumed to be integral to the functioning of the NHS. After becoming familiar with the list of data that is collected, some participants could articulate ways they imagined the NHS might utilise this data, such as for research purposes or to track past prescriptions of medications for patients.

> *"Probably for their own research... you know whether you're Asian, white, black and then see what sort of medical problems you have." Group 4*

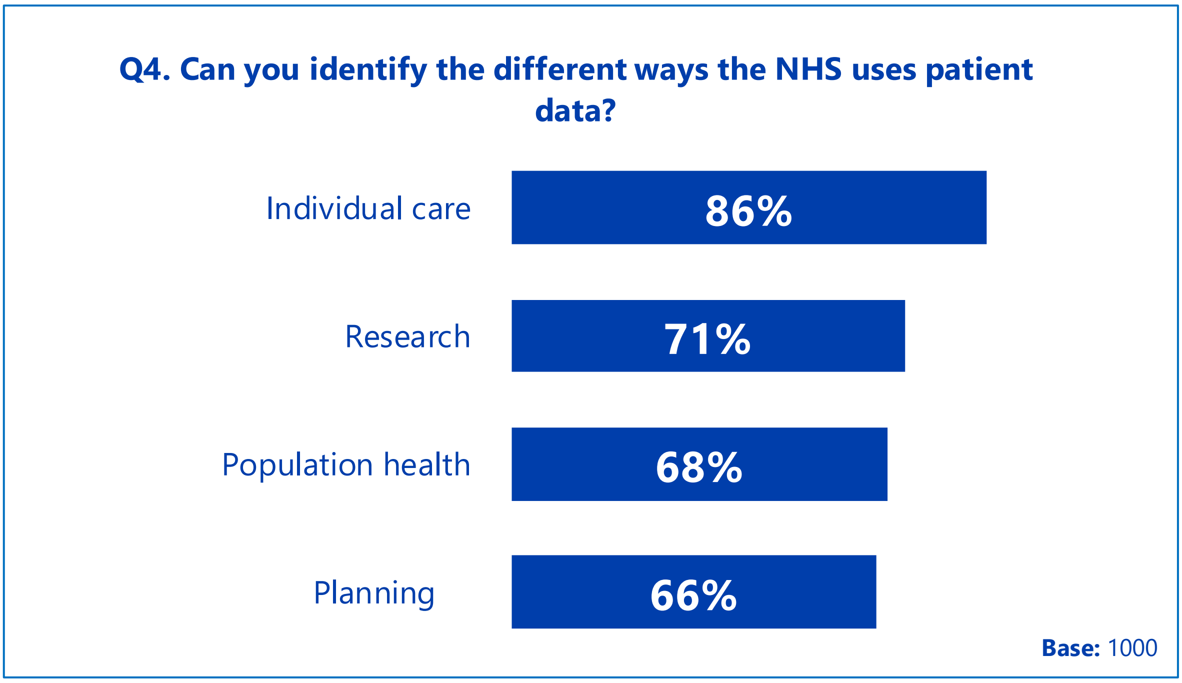
This being said, patient data was noted as a term that was not naturally thought about. Although the different types of data collected, once articulated, were acknowledged and understood, the actual term itself was initially perceived as ambiguous and unclear at first glance for the majority of participants. A lack of certainty about the term was evident in the limited amount of comments participants had to share, despite the moderator asking questions about patient data. This hesitation is equally reflected in Figure 7., which shows that over half of respondents knew *'a little'* or *'nothing at all'*.

> *"It's vague, no one actually tells you what exactly it is, you might have a rough idea but they just say it as an all-encompassing term." Group 4*

Identifying use cases

Survey respondents were provided with a list of different use cases of patient data within the NHS: individual care, research, population health and planning. Each use case was accompanied by a broad example for clarity (full survey questions can be found in the appendix). Respondents were asked if they believed the NHS uses patient data for these purposes. Just over half (51%) correctly identified that the NHS currently uses patient data for all four purposes, the rest got one or more correct.

Figure 9



Respondents were most likely to identify that the NHS uses patient data for *'individual care'* (86% of respondents selected this option), whereas they were less likely to identify *'planning'* (66%), *'population health'* (68%) or *'research'* (71%) as a way that patient data was used by the NHS.

Responses varied by demographic group. As the table below shows, older people, people from a White ethnic background, and people from social grades ABC1 were significantly more likely to identify the different use cases.

Figure 10

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				

Additionally, those who said they knew *'some'* or *'a lot'* about how the NHS uses patient data (56% and 55% respectively) were slightly more likely than those who said they knew *'nothing'* (48%) or *'a little'* (49%) to correctly identify all four uses.

In the workshops, very few participants could spontaneously come up with ways in which the NHS utilised their data, with the examples they provided primarily revolving around individual care and research, which aligns with the quantitative findings (as shown in Figure 9). However, after the four use cases were briefly outlined, they all "made sense" and were not unexpected; it was presumed that such activities were essential to provide the most effective treatment for patients.

> *"I know it goes on, but it has never been brought to my attention."*
> *Group 3*

Some participants also mentioned that they have previously been exposed to various use cases when presented with the four definitions, albeit not expressed in the precise terminology we provided.

> *"Not [heard of individual care] in that terminology no." Group 2*

The workshops then elaborated on these definitions, expanding on the concepts like 'individual care' with real-life examples and an opportunity to ask questions, which meant that all participants were able to recognise and understand this as a fundamental aspect of the NHS. In contrast, only 86% of survey respondents identified 'individual care' as something the NHS did, which could be attributed to the less interactive manner that the use cases were explained in the survey.

Awareness of planning and population health

Although workshop participants did not express familiarity with the terms 'planning' and 'population health' initially, all were able to understand the concepts without difficulty; one person went as far as to say that these terms were "*common sense*".

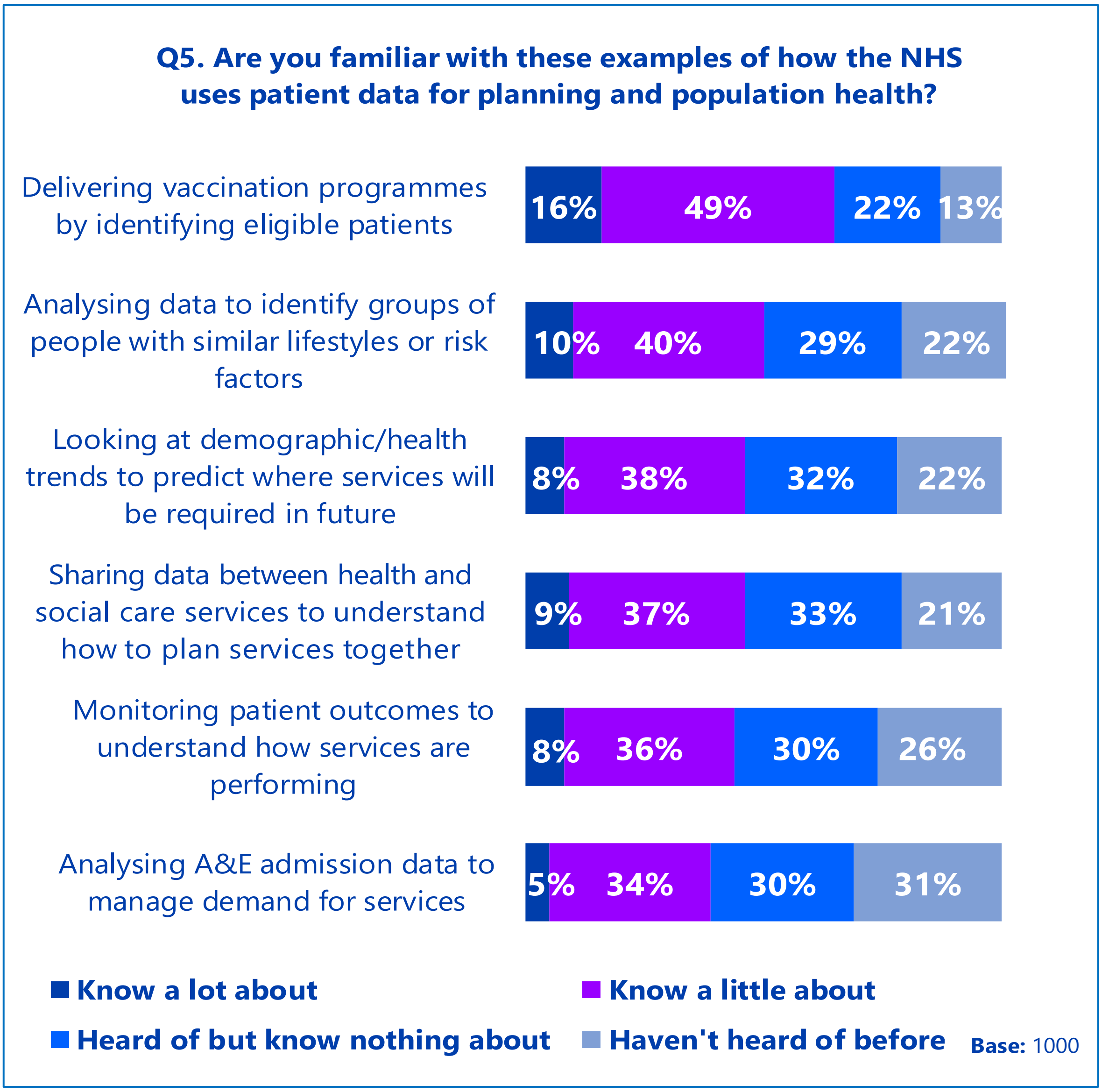
In general, only a minority of participants were able to confidently discuss various examples of planning and population health without prompting, and even they were not fully familiar with the terminology used during the workshop. The majority of participants could only 'hazard a guess' about examples of these use cases. Generally speaking, the use cases seemed logical and people assumed that this occurred in the NHS already, though again they had never really thought about this. This supports existing literature that finds people expect these as a given, and believed the NHS has already used data for these purposes.

> *"I think there was something that you had to give consent for? And I think I did, so this seems kind of familiar, but I'm not 100% sure."*
> *Group 2*

Specific use case examples

Survey respondents were asked to focus on planning and population health specifically, and were asked how familiar they were with six examples showing how the NHS uses patient data for planning and population health. Results are shown on the chart on the next page.

Figure 11



Survey respondents were most familiar with the use of patient data for *'delivering vaccination programmes'*. Only 13% hadn't heard of using patient data for this purpose before, whilst a majority (65%) said that they knew at least a little about it.

With the rest of the examples of using patient data for planning and population health, levels of familiarity were comparable. The chart above shows that a similar proportion of respondents knew about each example, with between 40-50% of respondents stating that they knew *'a little'* or *'a lot'* about each. This means that over half knew nothing about each example, aside from using patient data to deliver vaccination programmes.

Younger people were more likely to suggest that they were aware of the different ways the NHS uses patient data for planning and population health. 20% of people aged 18-34 said they knew at least a little for every example, compared to 13% of those aged 55 and over.

24% of people from a minority ethnic background said they knew at least a little for every example, compared to 15% of people from a White ethnic background.

Within the workshops, among every workshop there were slightly higher levels of familiarity with population health than planning. The awareness of using patient data for this objective appears to have gained a stronger profile due to the media attention during COVID-19. Similarly, many shared awareness of the topic through the use of examples that are close to people's lives, such as the increased prevalence of diabetes in minority ethnic background and outbreaks of measles due to lower MMR vaccination rates. This further supports the findings shown in Figure 11.

> *"I remember just after lockdown, there was a case where certain communities suddenly had a rise in MMR again like measles… they've got to be able to react straight away." Group 3*

> *"I know there's been a big drive in diabetes support for Black communities." Group 2*

Awareness of planning was more limited, with few participants being able to provide examples of this use case. Some acknowledged they had "*heard about it but don't think about it*", while others "*understand it, but I haven't really heard about it.*" Only two participants could draw upon examples, largely due to their proximity to the NHS; one having worked in social care and another with recurrent health problems.

> *"Well, planning, I would suggest that we'll need to do that to see if they've got enough staff to cover certain things." Group 3*

Differences in viewpoint between groups

Notably, some workshop participants from minority ethnic backgrounds indicated more awareness of population health than from White backgrounds, finding the concept more significant to their lived experiences.

When discussing using demographic data and identifying common characteristics, some of these participants could readily relate to examples illustrating its relevance to their lives. This aligns with findings from the survey, wherein 62% of people from a minority ethnic background knew something about *'analysing data to identify groups of people with similar lifestyles or risk factors'*, compared to only 46% of people from a White ethnic background. This was likewise evident though nonverbal cues, such as some participants nodding profusely when mentioning population health, or when others gave specific examples related to their communities.

> *"Me being Asian, we're more likely to, you know, be diabetic. So looking at those demographics is really important for the future." Group 4*

We also observed some differences by age in views towards using patient data among workshop participants, a distinction that became evident from the outset of the workshops. However, it is difficult to say this for certain given the low numbers of people included. Older participants said that they tended to feel more invested in the use of their data for improving the NHS, as they felt more likely to require the health service in the near future. Some said their views have changed with age and would have been different when they were younger.

Interestingly, one respondent from the younger group stated the belief that the older generation would be more inclined to oppose the use of their data by the NHS, though our research findings exhibit the opposite. Younger respondents were generally less aware of the internal mechanisms of NHS but openly expressed they were probably less supportive due to their limited interaction with the NHS and healthcare being less of an imminent priority in their lives.

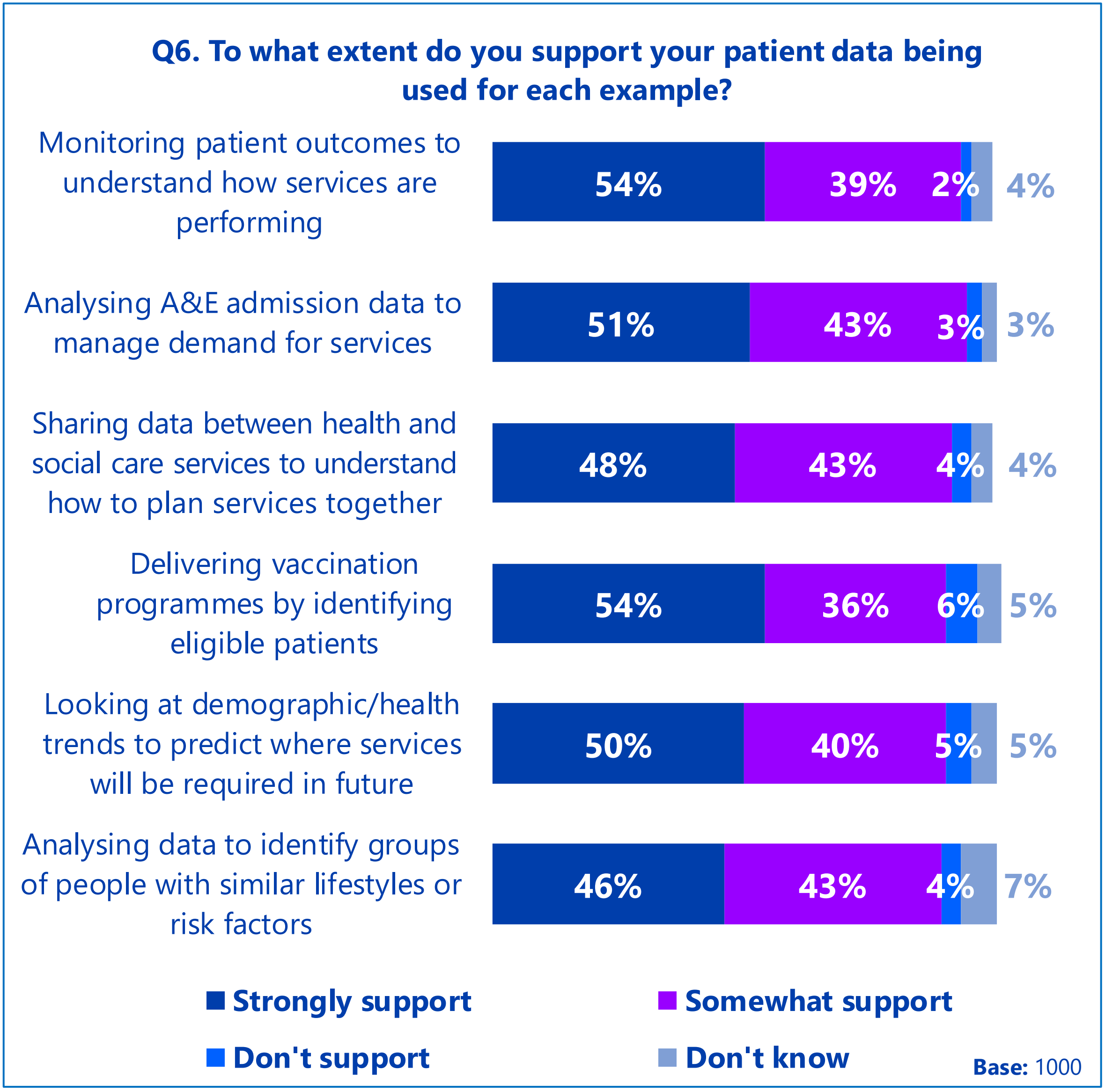
> *"I think for certain demographics, maybe towards like the elderly or the very sick… that it would be important but for some of them, I don't think it's very top of my mind." Group 1*

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

Support for specific use case examples

Survey respondents were shown the same list of examples demonstrating different ways the NHS uses patient data for planning and population health. This time, they were asked if they supported their patient data being used for each example.

Figure 12



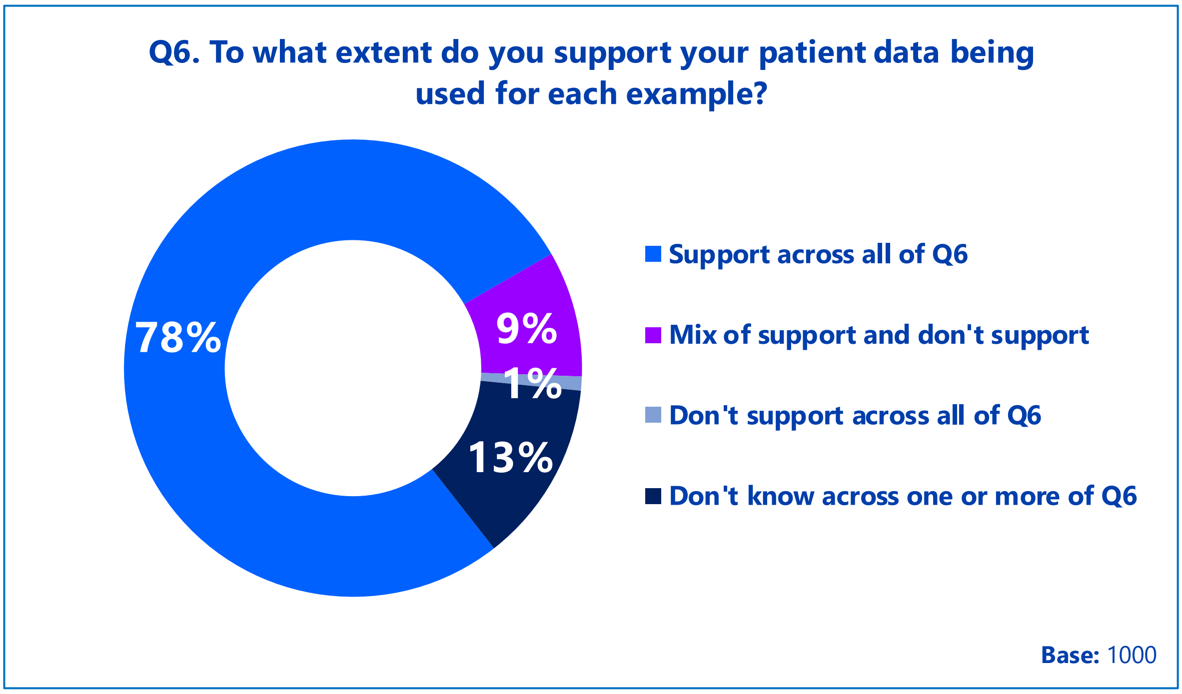
Every example of using patient data for planning and population health received high levels of support from respondents, with each one receiving around 90% net support – *'strongly support'* or *'somewhat support'*. Each example had around half of respondents stating that they would *'strongly support'* their patient data being used for this case. Whilst there is limited research available on levels of support for data for planning, the evidence that does exist supports this, such as a report from Joined Up Yorkshire and Humber which found that 88% of respondents supported using their health data to *"help plan the best services"*.[21]

When asked earlier in the survey about their support for the use of patient data, 84% of respondents net agreed with the statement *'Generally speaking, I am supportive of the use of patient data in the NHS'*. With each specific example here receiving around 90% net support or higher, this could suggest that when people are presented with specific examples explaining how the NHS uses patient data, they are slightly more likely to lend their support than when asked about the use of data in the abstract.

This could be due to low levels of awareness about how patient data is used. As this research, and previous studies, have shown, the majority of the public are largely unaware about how patient data is used within the NHS.[22] It may be that they are less likely to support the use of data in the NHS because they do not know what it entails. Therefore, it could be the case that, when people are presented with specific examples, they are more likely to offer their support.

Across the entirety of this question, 78% of respondents answered that they would strongly support or somewhat support their patient data being used for <u>all</u> examples.

Figure 13



Only a very small proportion of respondents (1%) answered *'don't support'* for every example. This contrasts with previous research, which had larger proportions of respondents stating that they would refuse to share their patient data. One study found that 14.9% of respondents were not willing to allow their anonymised personal health information to be used for any reason, whilst a study conducted by the Health Foundation found that 21% of the public would not be happy with their data being used for anything beyond individual care.[23]

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

Figure 14

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				

The table shows that, where support is lower amongst demographic groups, such as younger people, people from minority ethnic backgrounds, and people from social grades C2DE, this is often because respondents were more likely to answer *'Don't know'* rather than *'Don't support'*.

Levels of support for planning and population health examples

Workshop participants were shown the following six statements, which reflect the examples used in the quantitative survey (as shown in Figure 12). They laid out different examples of how patient data could be 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

- Monitoring and evaluating patient outcomes to understand which services are performing well and which ones need additional support, ensuring patients receive effective care.
- Sharing data between health and the local authority to improve services
- Studying how the nation's health is changing to predict what services are going to be needed where
- Using patient data to deliver vaccination programmes and issue invitations
- 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

Initially, participants were unfamiliar with these specific uses of data, but each one was generally positively received once explained. Even in the context of delivering vaccination programmes, which was at the forefront of people's minds following the mass Covid-19 vaccination programme, many had not previously connected this with the usage of their patient data.

When asked in a general sense if they supported these statements, all participants found them rational and common-sense; there was unanimous support across all groups. While this consensus corresponds with the high levels of support evident in Figure 12, the workshops allowed further discussion and more examples which may explain why support levels in the qualitative groups appeared to exceed the 78% support rate found in the survey. Some even questioned 'who would be against any of these statements?'

Despite supporting this in a general sense, some respondents expressed reservations upon being made aware of specific examples. Concerns were raised by a minority of participants about the use and analysis of their data, with questions as to why the depicted statements did not translate into the expected outcomes in the NHS and what was going wrong in the process. One participant voiced apprehension over where the data was actually going, given the perception that the NHS was 'disjointed'.

> *"You wonder where your data is going, if they're trying to improve services… I just feel like my data is disappearing." Group 2*

> *"All you hear is a shortage of staff and hospitals, back up staff, ambulance drivers but they're getting the data, is it funding again? Or is it bad management and they don't use it (the data) appropriately." Group 4*

Conversely, the majority of participants came to the realisation that without the use of data for these purposes, their concerns would be exacerbated, potentially leading to a deterioration of the NHS beyond its current challenges. This realisation and enhanced understanding emerged organically from the discussions during the workshops; the inability in the survey setting to discuss thoughts with others and expand on examples could explain the reasoning behind the higher levels of 'don't know' answers in the survey (see Figures 12 and 13). One participant mentioned that using data for these purposes was supported conditionally, depending on the NHS being able to justify why access is necessary.

> *"I think even though the NHS is struggling, I really can't see how any of anyone could do their job without the data, I think it would just be even it would be like a million times harder if they didn't have access to the data." Group 4*

> *"I'm always happy as long as it's like, they've got a reason to access it. And they have to prove that. So not just, it's open for anyone just to tap into it and just get any information they want from you, you have to have a good valid reason to" Group 2*

Support for specific use case examples

Upon reviewing the six examples, workshop participants showed more enthusiasm towards these specific examples compared to the abstract concepts of 'planning' and 'population health', aligning with the survey findings of higher levels of support for specific examples than the ideas in the abstract.

Participants were tasked with choosing one example out of the six they deemed most crucial. Whilst all examples garnered high levels of support, responses differed based on the individuals' priorities and proximity to certain issues. Specifically, distinctions based on age and ethnicity were prominent.

Older participants prioritised the case for 'sharing data between the health service and local authority to improve services', which they stated was influenced by their first-hand experiences of hospital discharge and their close proximity to the NHS, where they were able to see why improving these services is of high importance. This aligns with the quantitative findings, as support among older respondents was higher for sharing data to improve services across both the survey (94% of respondents aged 55+) and workshop compared to support from younger generations.

Likewise, this demographic placed significant emphasis on 'using patient data to deliver vaccination programmes and issue invitations to groups of people', a priority many could relate to. One respondent went further, sharing the importance of risk stratification through their personal experience of early cancer detection, which without an invitation to get checked based on their demographics would have gone undetected. Spontaneous examples such as the flu and shingles jab also resulted in strong support for this statement among the older generation. This aligns with findings from the survey that using patient data to deliver vaccination programmes was higher supported among those aged 55+ than other groups.

Younger participants expressed more varied responses, often depending on how close they were to certain issues. However, young people placed a notable emphasis on the importance of using data to evaluate patient outcomes. Many added that they would like to see patient reported outcomes incorporated into the evaluation and improvement process, which drove additional support for this example.

> *"Before that dropped on my doorstep, me and the wife, wouldn't have even considered doing a bowel cancer test. You know, they're on the ball with where your personal data goes and your age group, and maybe could be linked to your demographic of where you are and whatever. But doing that is a huge improvement on what it used to be, like mammograms for women catching it early - the way they use your data and your age and all the rest of it has caught my wife's breast cancer a long time before it could have got serious, now years ago she'd have been dead" Group 3*

> *"It's good to obviously get patients' feedback, because it's really important that they hear our side of as well, as you know, just looking at normal data." Group 2*

One participant in the younger group raised concern about the accuracy of 'targeting support', questioning its precision in reaching the right cohorts of patients when using data for population health, and its ability to not overlook patients who need support. Despite this, even when some participants posed questions and raised concerns about how these data use cases were implemented, this did not sway their overall support levels.

National vs local use of data

In the workshops, there was some difference in opinion regarding levels of support for the use of data for planning and population health purposes at a national or local level, though support for using data on a wider, national level was more prevalent. Specifically, many participants placed emphasis on how using data on a larger scale is important for predicting what services will be needed overall in the future and where funding should be allocated, and that by using national data it is far less likely for individuals to be identifiable. The significance of focusing on 'equity over equality' for certain demographics, geographies and hospitals who need the support more was similarly acknowledged.

> *"I think it's fair, because obviously, like you're saying certain places got more deprivation and more issues than others. So it's sort of like helps to level up everywhere." Group 2*

> *"I think it makes more sense to look at it in a broader spectrum as well. So you can know what the biggest outcome and risks are going to be and then obviously, provide more money to that." Group 1*

Discussion regarding identifiability arose spontaneously at this point, with scrutiny directed towards using data at a local level. Concerns were raised over the potential identifiability of data within local hospitals, causing worry among some participants. This is because participants felt that data used to support planning and population health nationally was more likely to be aggregate statistical data, whereas data used locally is assumed to be more identifiable. This is an important factor to be aware of: concern about being identifiable and not wanting others in their community to know details about their health.

> *"Where I was brought up was a very, very small town and I feel like maybe data will be easily identifiable." Group 4*

It was interesting to see that many participants felt more comfortable with the use of data for planning and population health nationally than locally, as a Health Foundation report[24] found that GP practices and local hospitals had slightly higher levels of support than national NHS organisations. However, equally, concern was raised over data falling through the gaps if shared solely on a national scale and not being able to truly address the nuances of local communities.

> *"I feel like I'd be more comfortable with it being on a national scale than a local although I know it's still anonymised [at a local scale]." Group 4*

Despite this, overall consensus emphasised the usefulness of employing data on both a national and local level. Across all groups, participants were generally happy to share on whichever scale was most effective and advantageous for the NHS.

> *"There's always a slight worry about, maybe misuse of your data. But at the same time, everything else, I think we're used to so many things in our lives now being kind of connected, whether it's tech stuff or wherever. So if this is a way to make healthcare more efficient, then definitely go for it." Group 2*

> *"Think it's really important at every level because without the local data, it wouldn't feed up to the national picture. And if you want to identify the pockets of difference in what's working and what's not, you need to start at the micro level." Group 3*

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

Benefits of sharing patient data

Survey respondents were asked to select, from the list shown in the table below, which potential benefits would make them more supportive of sharing their patient data for planning and population health within the NHS.

Over half (56%) selected *'All of the above'*. In the table below, respondents who selected *'All of the above'* have been included in the proportion of respondents who selected each benefit.

Figure 15

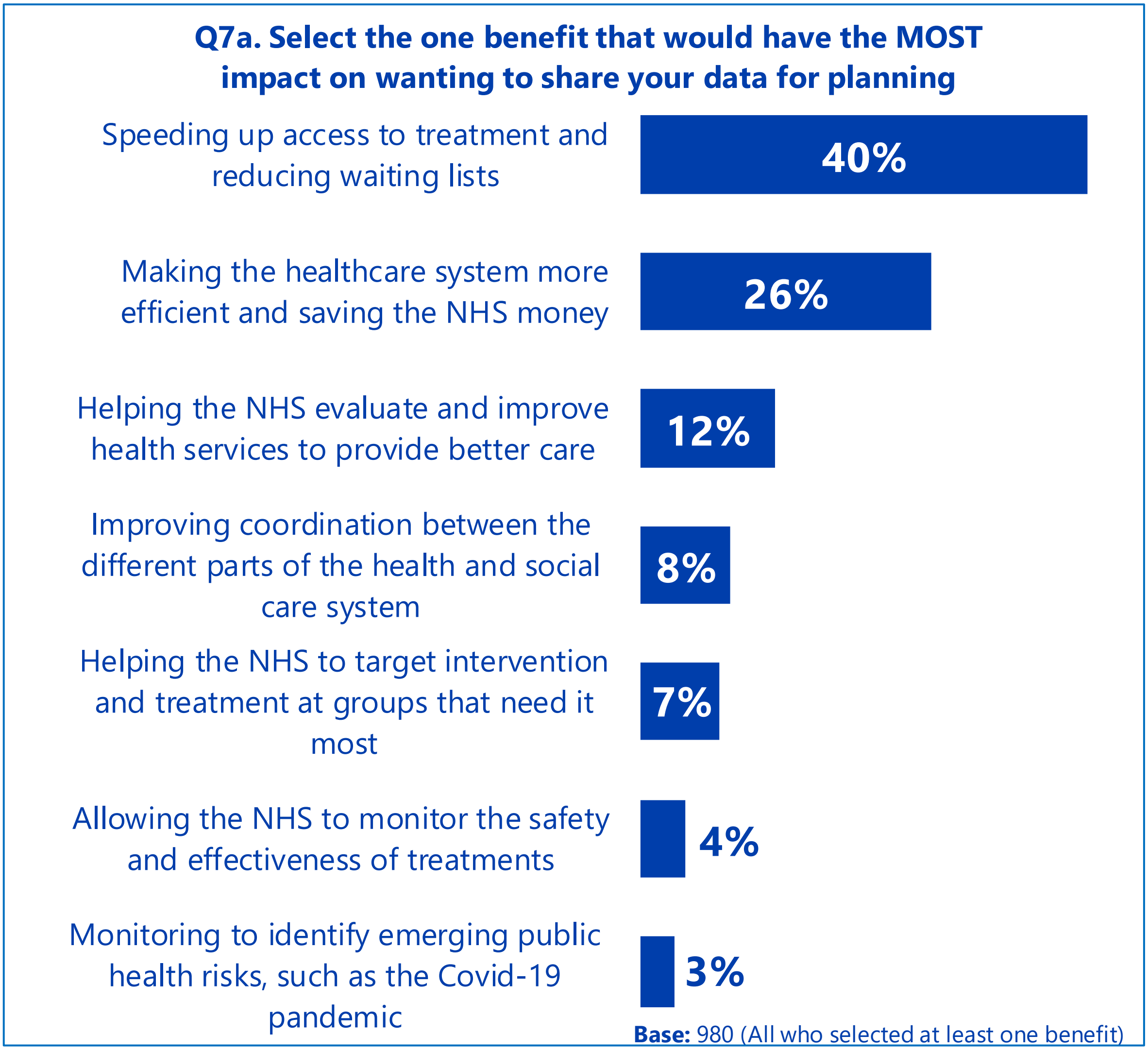
Q7. Benefits of sharing data	**%**
Speeding up access to treatment and reducing waiting lists	87%
Making the healthcare system more efficient and saving the NHS money	82%
Helping the NHS evaluate and improve health services to provide better care	76%
Monitoring to identify emerging public health risks, 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	

Only a very small proportion of respondents (2%) did not select any of the benefits, agreeing with the statement *'I wouldn't want to share my data with NHS to support planning and population health'*. Whereas, every benefit was selected by a high proportion of respondents (at least 70%).

Respondents who chose at least one benefit (n=980) were then shown the list of benefits they had selected. They were asked to select the benefit that would have the most impact on their decision to share their patient data to support planning within the NHS.

The most compelling benefits of using patient data for planning purposes were the ones which would make NHS services more efficient, improving access to care and cutting costs. The chart overleaf shows that respondents most commonly identified '*Speeding up access to treatment and reducing waiting lists*' (40%) as the benefit which would have the most impact on their decision to share their patient data to support planning. This factor may have been at the forefront of many respondents' minds due to high NHS waiting lists, which have been made more salient by media reports, personal experience waiting for care, and efforts by the government to tackle waiting lists and elective care backlogs.

Figure 16



Base: 980 (All who selected at least one benefit)

A large proportion, around a quarter (26%), of respondents selected '*Making the healthcare system more efficient and saving the NHS money*'. This is an interesting finding as prior research on people's views on using data to allocate resources or drive efficiencies has shown middling support at best. In one study, 60% of people supported using data to 'plan which locations need extra health services', an example which ranked in the bottom three out of twelve.[25] The OneLondon public deliberation held in 2020 found that whilst some supported using data to allocate resources and find cost savings, others were not as supportive as it brought to mind budget cuts and reduction in services[26]. It is likely that current media attention on financial pressures on state budgets and the NHS may have contributed to respondents being more sympathetic to this cause.

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.

The table shows that those who knew less about the use of patient data in the NHS were more likely to select *'Making the healthcare system more efficient and saving the NHS money'* and *'Speeding up access to treatment and reducing waiting lists'* as the most impactful benefit. Whereas, those who said they knew a lot were more likely to select *'Improving coordination between the different parts of the health and social care system'* and *'Helping the NHS to target intervention and treatment at groups that need it most'*.

Figure 17

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					

Some demographic groups were more likely to identify certain benefits as the most impactful:

- **Gender:** 44% of those who identified as female selected '*Speeding up access to treatment and reducing waiting lists*', compared to 35% of those who identified as male
- **Ethnicity:** 13% of people from a minority ethnic background selected *'Helping the NHS to target intervention and treatment at groups that need it most'*, compared to 6% of people from a White ethnic background

Workshop participants were presented with the top three benefits of sharing data for planning and population health selected by survey participants, as shown in Figure 16. All benefits were deemed positive outcomes. However, when discussing which might be the ‘most important benefits’, participants gravitated towards their views of the most pressing priorities for the NHS and their own personal experiences as a patient or potential patient. Older participants shared more personal experiences with waiting lists and therefore found it more impactful, reflecting the data shown in Figure 16, where those in older age groups were more inclined to select this benefit. However, younger respondents also showed concern around waiting lists.

Workshops discussed and acknowledged that waiting lists have increased in prominence and concern over recent years due to strong media focus on the Covid-19 backlog, which may explain the high rate of respondents selecting this benefit as ‘most important’ in the survey. One participant explained that if speeding up waiting lists was set as a key priority, other benefits would arise as a result of tackling this hence the significance of this benefit.

> *“One is fundamentally important, and if you take care of 1 [waiting lists], then perhaps you are helping 2 [cost saving to NHS] as a consequence, because it is therefore more efficient”. Group 3*

> *“I mean, they're positive. I think so if they work, they're really positive and speeding up reducing waiting lists. I mean, that's a big one really, isn't it? Because we all know about the wait lists for operations and things like that. So if it works, then they're all good benefits.” Group 4*

The discussion uncovered the importance of seeing the outcomes of using patient data to achieve these benefits in practice. While some identified that this was not a problem with data analysis and more to do with the allocation of resources needed to enact change within the confines of NHS funding, others found themselves uncertain and distrusting, especially given negative current perceptions of the NHS and its performance. This hesitation could explain the 13% in the survey who did not think speeding up waiting times was a benefit of using patient data. The challenge here is to ensure the public understand the distinction between how their data is analysed and the NHS’s capabilities for acting on that analysis; misunderstanding of this could lead to reduced support for using patient data.

> *"This doesn't happen at all, people are on waiting lists for god knows how long for everything and anything…but there's nothing speeding up is there, we're constantly waiting for treatment…They say, oh yeah we're doing this, we're doing that to speed things up, but nothing ever gets done. Nothing has been done…Nothing changes." Group 2*

> *"Whether they happen, you know, in practice, there's probably things going against them so that they don't happen in practice, but I think they are a good a good idea". Group 3*

Risks of sharing patient data

Survey respondents were asked to select, from the list shown in the table below, which potential concerns they felt posed a risk or would make them less supportive of sharing their patient data for planning and population health.

Figure 18

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	

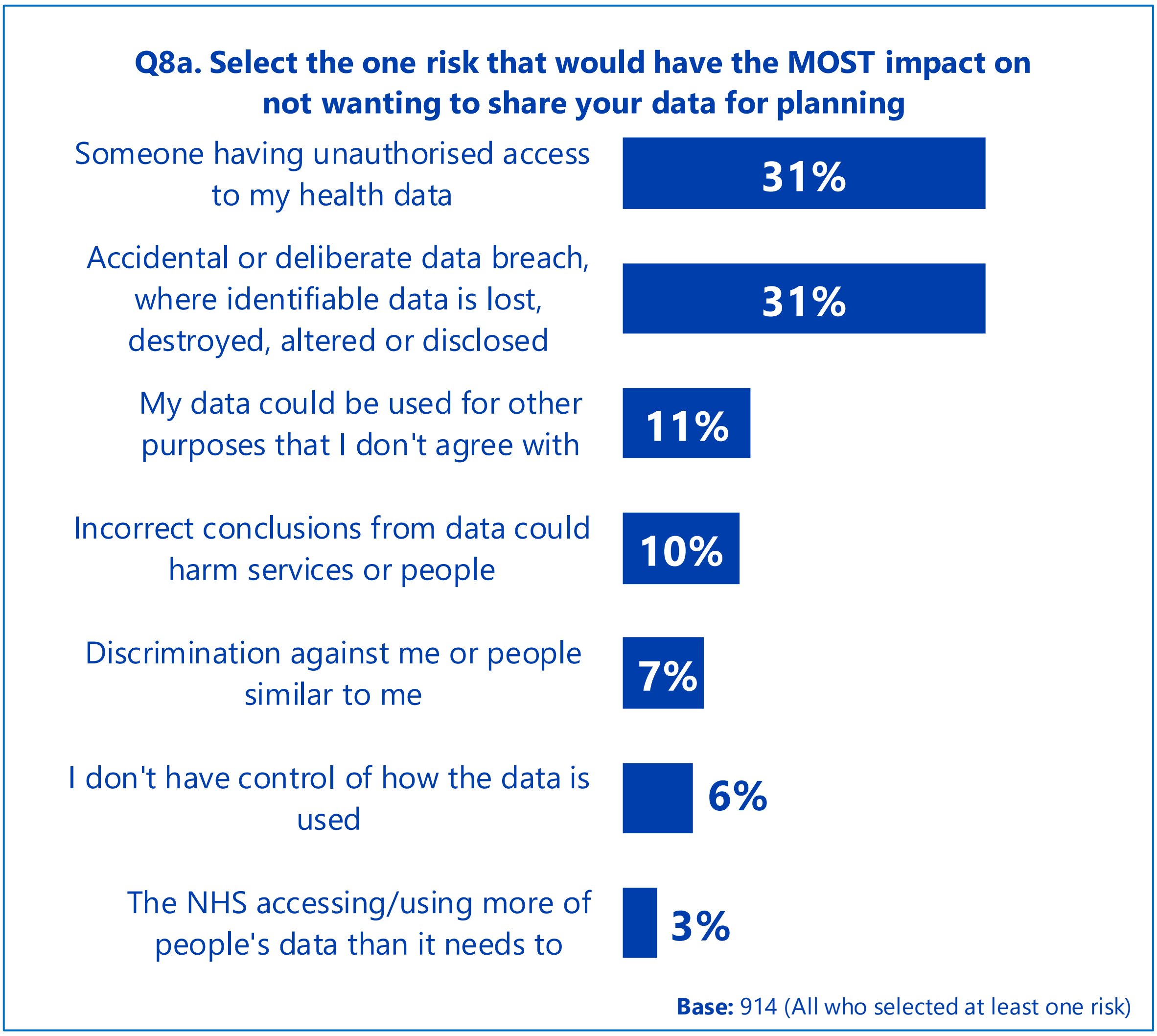
Survey respondents who selected *'All of the above'* have been included in the proportion of respondents who selected each potential risk. For this question, 22% of respondents selected *'All of the above'*, a much lower proportion than those who selected all of the benefits at the previous question.

Whereas each benefit in the previous question was selected by at least 70% of respondents (see Figure 15), each potential risk had a lower proportion of respondents. People were most concerned about *'Someone having unauthorised access to my health data'* or an *'Accidental or deliberate data breach'*, with 66% and 64% identifying these as potential risks which would make them less supportive of sharing their patient data for planning respectively.

Around one in ten respondents (9%) did not identify with any of the potential risks, instead opting for *'None of the above – these do not concern me'*.

Survey respondents who chose at least one risk (n=914) were then shown the list of potential risks they had selected. They were asked to select the risk that would have the most impact on their decision to not share their patient data to support planning and population health within the NHS, results shown in the chart below.

Figure 19



Data privacy and security were the biggest concerns for people. The chart above shows that a clear majority of respondents chose either *'Someone having unauthorised access to my health data'* (31%) or *'Accidental or deliberate data breach'* (31%) as the risk that would have the most impact on their support. In comparison, the next most-selected potential risk was only selected by 11% of respondents.

These findings echo existing literature on the perceived risks of data sharing and the perceived risk of data breaches or unauthorised access in particular.[27,28]

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

Figure 20

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%)

This may suggest that those who are more supportive tend to look towards factors that are perceived as external risks such as data breaches and hacking, whereas those who are less supportive are more likely to worry about risks internal to the NHS.

Looking at the workshop findings on the same topic, participants were then presented with the top three risks of sharing data selected by survey participants (see Figure 19) and asked their views on which were most concerning or would make them reluctant to share their data. In line with the findings depicted in Figure 19, potential data breaches and unauthorised access were seen as the biggest issues.

Consistently across all groups, there was heightened concern regarding data being sold to a third party and subsequently misused for marketing purposes, to defraud them, or hassle them with letters and phone calls. This concern was stated as being exacerbated by media attention around data leaks, as well as media reporting on AI and unknown aspects of its capabilities.

> *"But with AI and all this happening, maybe they can use it for something I don't really yet know what I understand, and then it'd be out there, all my information would be out there." Group 4*

> *"Like, you know, if you've got my birthday, my name, my full name, my date of birth, my postal address? I mean, because someone can open a credit card under my name." Group 1*

New concerns around children's data were also raised by one respondent, who expressed concerns about the absence of consent and control over their data. They questioned the ethical implications around utilising data to target children without parental consent.

> *"There are rising amounts of people whose children are actually receiving letters for all sorts of medical treatments, including the last that the latest vaccine, and this is getting sent out and parents don't know about it. So that's bad data of children." Group 2*

However, across the board, there was more enthusiastic discussion of the benefits than the risks, aligning with the survey results.

For most, the risks weren't deemed daunting or a 'dealbreaker'; instead, they were embraced as inherent to technology and the modern world. The risks of the NHS using and sharing patient data were seen as no riskier than engaging in online transactions, password breaches or consenting to cookies; and the benefits were deemed worth the associated risks.

> *"You put your credit card number and you put your details in your name, address etc … this breach of security in the NHS isn't such a threat." Group 3*

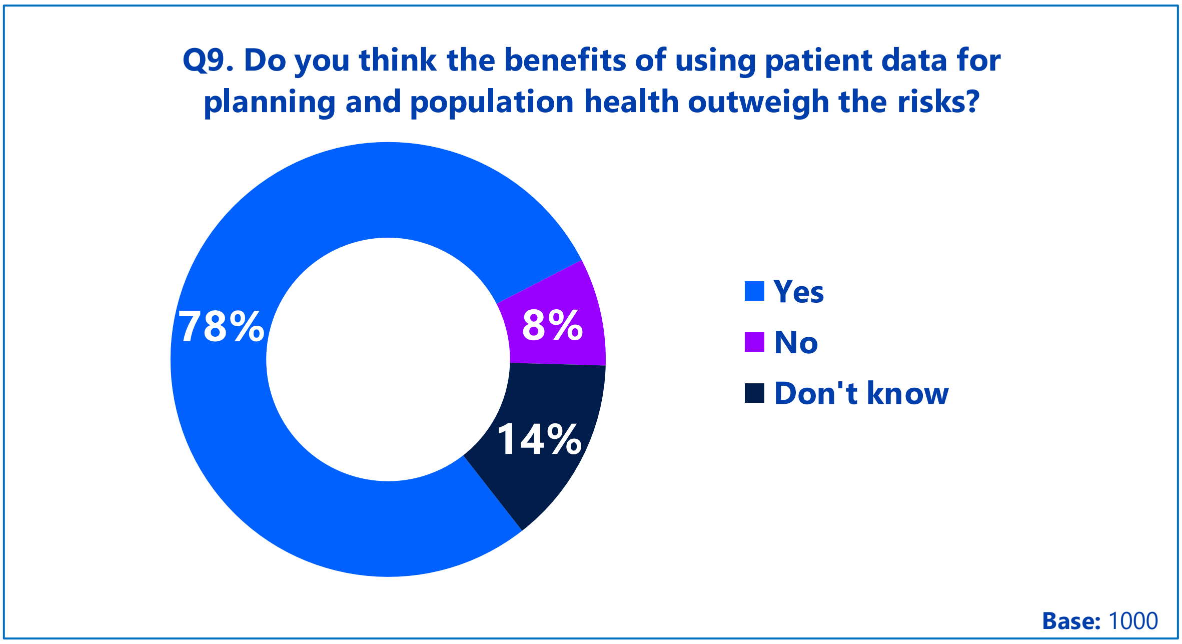
> *"At the end of the day, the only thing that you could get screwed over by is finance. You know, anything else, you get bombarded with letters through the door, it doesn't matter." Group 3*

It is important to note that because the methodology for this project was entirely online, it logically follows that the participants were likely to be more comfortable with online risks. There are likely to be members of the public who are not able to rationalise the risk of data breaches in this way, who were not able to participate in this research.

Do the benefits outweigh the risks?

After considering the potential benefits and risks of using patient data for planning and population health in the previous questions, survey respondents were asked whether they thought the benefits outweighed the potential risks.

Figure 21



Almost four in five (78%) thought that the benefits outweighed the potential risks. A larger proportion of respondents answered *'Don't know'* (14%), than those who thought the potential risks outweighed the benefits (8%). The sizeable proportion of respondents answering *'Don't know'* could be due to this question being shown on a different screen to the preceding questions about benefits and risks so respondents could not see the list of potential benefits and risks to when answering.

As the table below demonstrates, there were some demographic differences in the perceived balance of benefits and the risks. Any statistically significant differences are highlighted in blue.

Figure 22

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			

Workshop findings on the topic were similar. Not only was it implicit from the discussions that the benefits outweighed the risks due to how enthusiastically participants discussed the benefits and how moderate they were with the risk; the vast majority of respondents explicitly stated that the benefits of using patient data far exceeded the risk. This supports the survey findings shown in Figure 21.

While the risks were duly acknowledged and posed doubt in some participants' minds, the majority of workshop participants recognised the inherent risks associated with various aspects of life and accepted these. Some made statements to the effect of 'we need the NHS to run effectively, so we must trust it in the long run and accept the risks for what they are.' Both the workshops and Figure 21 show that even when clearly outlining both the risks and benefits to the public, generally, this does not alter people's opinions massively.

> *"You have to trust it in the long run, hope for the best. I mean, that's maybe a silly thing. But you have to try and try see the benefit in the long run." Group 2*

> *"I think the benefits do outweigh the risks because I can't see any other way to improve the system without having lots of data." Group 1*

> *"It's got so much potential with the benefits, but it's difficult because sometimes we don't see those benefits in practice. But I think, you know, the way they could use data could really help and transform." Group 4*

None of the workshop participants expressed uncertainty in how they feel about the benefits and risks, unlike the 14% who selected 'don't know' (see Figure 21), which could be down to the more open forum for debating and building understanding in the workshop.

One out of thirty-one participants stood out as an anomaly, expressing very strong beliefs that the risks outweighed the benefits. Through their heightened awareness of the NHS data usage during the pandemic, they had strong concern and opposition to data sharing in what was described as our 'espionage society'. This was exacerbated by media stories negatively publishing articles about the use of patient data during the pandemic. Increased knowledge of patient data uses therefore can, in some cases, have detrimental implications on support levels. Views such as these could contribute to the 8% who said the 'risks outweigh benefits' (see Figure 21).

> *"I disagree, I think because I felt as if... I didn't like the idea when I had COVID, when I had to test for it, I was really uncomfortable about posting something so personal. If somebody has been convicted of something they have to be asked beforehand, before any DNA swabs are taken, and I'm sending something off that somebody potentially has all my genetic information sitting in a post bag." Group 2*

Extent of awareness raising

Through explicitly asking workshop participants what information should be publicised about use of their patient data, it was apparent that wide publicity around the uses, benefits and risks might not always be beneficial and was in some cases deemed unnecessary. Providing excessive information in certain cases can potentially cause negative consequences. Some people felt that presenting members of the public with the risks, without an opportunity to address the unlikeliness of this occurring, could adversely affect the number of people comfortable and willing to consent to their data being used.

> *"I think just leave is as this is, you know, your data can be used, this is what it's used for. I feel like when you start putting in risks to things, although it's good to make people aware, I don't know whether certain people would it not necessarily understand it too much and just opt-out anyway." Group 3*

> *"Sometimes too much information isn't necessarily a good thing" Group 3*

> *"I think you could spend an awful lot of time and money trying to explain things to people who potentially are not interested anyway. I think you have to do the basics" Group 3*

Several participants reflected that the information should be made available to the public as it is crucial to inform them, but there was little need to excessively emphasise this. There were concerns expressed about the potential waste of money and resource on a large awareness-raising campaign. However, it was emphasised that having some clear information for those who are interested or concerned was important.

Safeguards

The following safeguards and reassurances were presented to workshop participants, questioning whether hearing these would make them more comfortable with having their data used 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 NHS is transparent about what data has been accessed, who has accessed it, and why

Raising awareness of safeguards to protect data, such as ensuring staff are appropriately trained, reduced concerns among participants. Participants also placed emphasis on improving the technical side such as firewalls and data security, which they explained would reduce their worry about data breaches. Across all groups, participants assumed these safeguarding procedures already occurred, but welcomed the affirmation that safeguards were in place.

Some participants also spontaneously brought up identifiable data at this point, stating the importance of these measures in ensuring personal data is as de-identified as possible. Another example provided by a participant of additional safeguards that would make people feel more reassured was the explanation that the NHS uses as little identifiable data as possible, only when strictly necessary for the piece of analysis.

> *"I think for me, personally, it's more the technical side. I know you see a lot of big companies and stuff like that nowadays are getting hacked left, right and centre." Group 1*

> *"[Safeguarding is positive] as it prevent it being sort of like identifiable, I think that's really important." Group 4*

> *"I would imagine to have that in place already. Like the other gentleman said, everything's hackable. So I just think, you know, they can do what they can do. But if someone's going to hack any bank, business, it's going to happen. So I'm quite assured, I'm quite happy." Group 3*

Despite these safeguarding procedures rarely being brought up prior to them being explained by the moderator, all of the procedures were deemed essential and reassuring. This supports the OneLondon study[29], which concluded it was necessary to set out conditions to accessing health and care data for those that need this data to perform their role, and highlighted the importance of safeguarding procedures, confidentiality agreements and accountability in accessing data. These findings suggest publicising the safeguarding procedures put in place would be positively received.

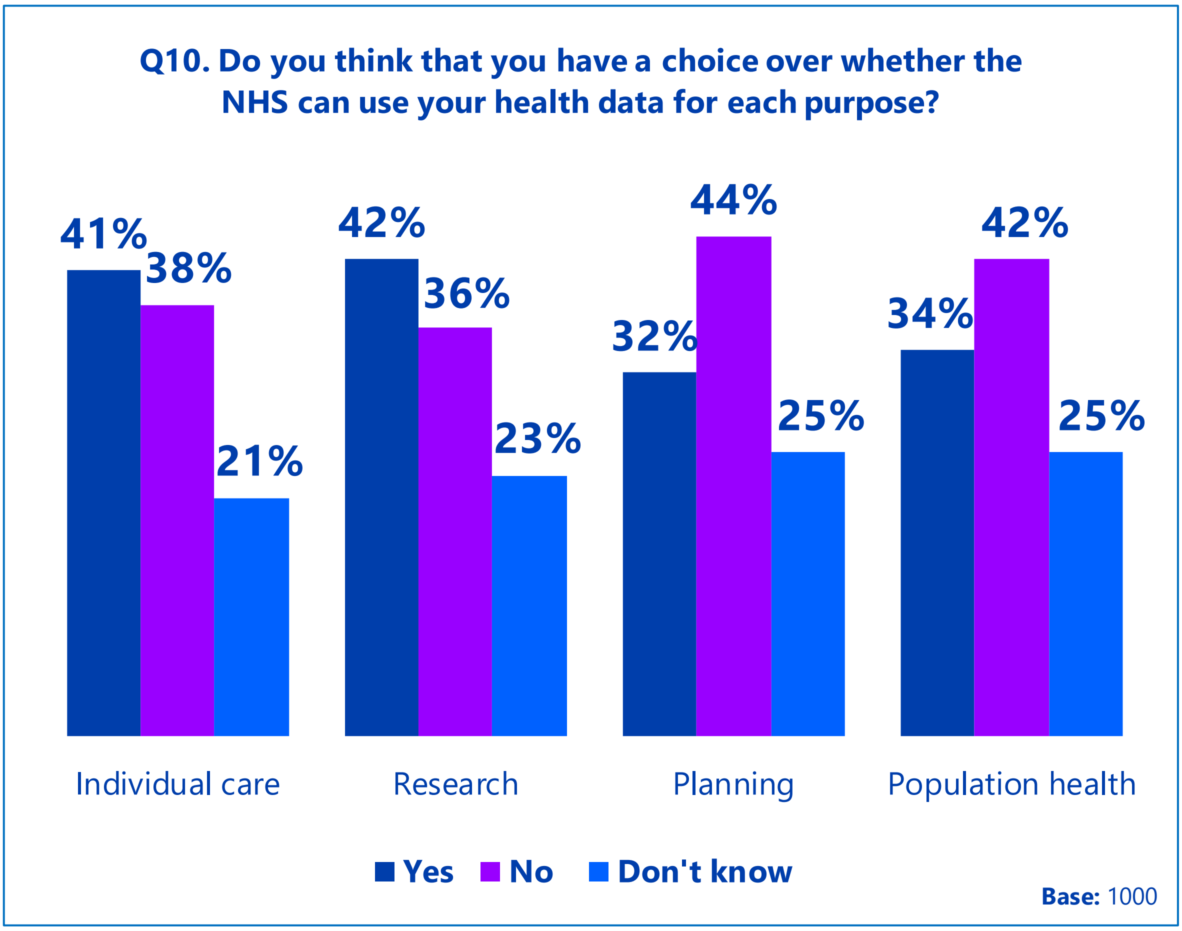
Section 5: Views on choice and identifiability in the use of patient data

Awareness of choices

Survey respondents were shown four different use cases for data within the NHS: individual care, research, planning and population health. They were asked if they thought that they currently had a choice over whether the NHS could use their health data for each category. In England, patients can opt-out of their identifiable data being used for secondary uses, with some exceptions. Patients can, however, not opt-out of their de-identified data being used and shared.

Respondents were more likely to think that they had a choice over whether the NHS could use their health data for individual care and research, compared to planning and population health. 41% and 42% of respondents thought that they had a choice over their data being used for *'direct care'* and *'research'* respectively, whilst a smaller proportion of respondents thought that they had a choice over their data being used for *'planning'* (32%) and *'population health'* (34%).

Figure 23



For each category, between a fifth and a quarter of respondents selected '*Don't know*'. The sizeable proportion of *'Don't know'* for each question, combined with more respondents thinking that they had a choice over the use of their patient data for individual care and research rather than planning and population health, suggests there is some level of confusion. It appears that when it comes to opting-out of the NHS using patient data for different purposes, including for planning and population health, people are not aware of the choices available to them. This aligns with existing research, which suggests that awareness of the National Data Opt-Out scheme is low amongst the general public.[30]This aligns with existing research, which suggests that awareness of the National Data Opt-out scheme is low amongst the general public.[31]

Among workshop participants, there was very limited awareness that the National Data Opt-out in England was a policy allowing patients to opt-out of their data being used for research and planning purposes. Some participants raised awareness of the concept of opt-out systems in a general sense, and primarily in connection to the unrelated example of being able to opt-out of organ donations, but no reference was made to data, planning and research, or population health. At earlier points in the workshops, some participants spontaneously raised the point that "*you should be able to opt-out of this*", unsure on whether or not this was legally possible. This lack of certainty supports the survey findings (see Figure 23) and could account for the sizeable proportion of *'Don't know'*.

> *"I wasn't aware that you could, that was even an option. But I do think it should be advertised more that it is an option." Group 1*

> *"I didn't know that [you could opt-out]. I think I heard about this a few years ago that you could actually say to your surgery, that you didn't when your data shared, Is that correct?" Group 4*

> *"I didn't know, I didn't even think about it" Group 4*

This being said, one participant stated that the Covid-19 pandemic made them aware of the ability to 'opt-out' of the NHS using their data, prompting their decision to opt-out. However, they expressed frustration at feeling 'hounded' by telephone calls even after choosing to opt-out. This case highlights how heightened awareness to the opt-out system in general can in some cases result in people opposing to the use of their data altogether.

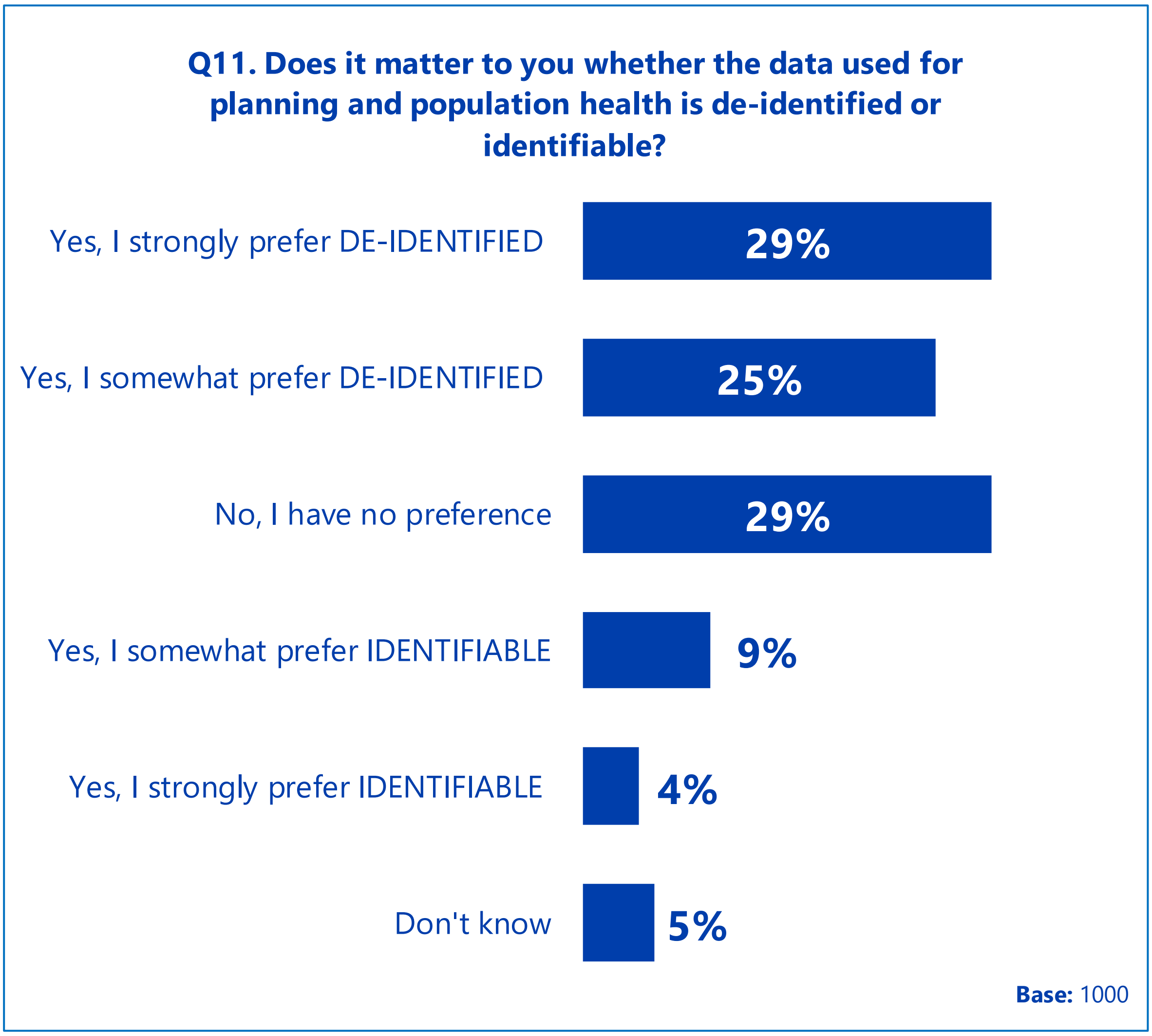
> *"I choose not to partake, or to participate in the treatment or the vaccine that was offered at the time [for covid] and I felt as if I was being hounded quite a bit is no different from somebody trying to sell me carpets or Windows, I didn't like that side of it. And I noticed that more than ever. So I think that's the bad data." Group 2*

It must be noted that this research wasn't able to go into the detail of whether the opt-out policy applied to such calls, and therefore whether they were appropriate or not, but there were additional rules, such as COPI notices, at the time which enabled and mandated the use of health data. This individual's experience could potentially suggest there is some confusion about what the opt-out does, as it does not mean an individual has opted out of being contacted by the NHS, that people assume opt-out policies apply when they don't, or that wider ecosystems of choice infrastructure, such as how communication preferences with regards to direct care, can impact how people feel about the use of their data for planning.

Identifiable vs de-identified data

Survey respondents were then shown an explanation of identifiable data and de-identified data. This was accompanied by two images which visually conveyed the differences between identifiable and de-identified data. They were asked if it mattered to them whether the data used by the NHS for planning and population health was de-identified or identifiable. Results are shown on the next page in a chart.

Figure 24



A majority of survey respondents (54%) either *'strongly'* or *'somewhat'* preferred the use of de-identified data for planning and population health purposes. Only a small proportion of respondents (12%) preferred identifiable data to be used, whilst a larger proportion (29%) stated that they had *'no preference'* between the two types. This echoes research conducted by The Health Foundation, which found that support for different uses of health data drops when the data used is identifiable, rather than anonymised.[32]

As the table on the next page demonstrates, there were significant differences between demographic groups. A higher proportion of younger people, people from ABC1 social grades, and people from Scotland and Northern Ireland preferred de-identified data to be used.

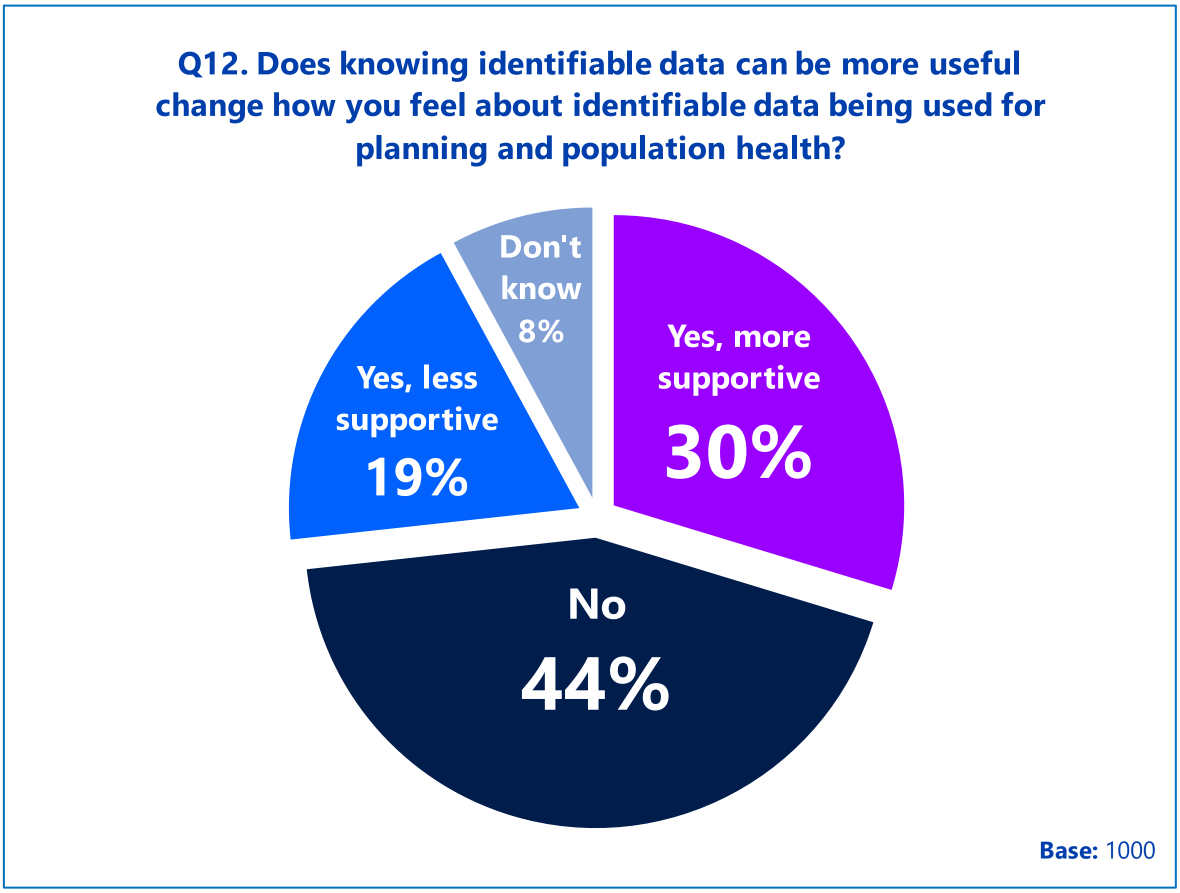
Figure 25

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				

A much higher proportion of survey respondents who disagreed with the statement *'Generally speaking, I am supportive of the use of patient data in the NHS'* at Q1 preferred de-identified data to be used. 70% of those who disagreed preferred de-identified data to be used compared to 53% of those who agreed.

It was then explained in the survey that the NHS used both identifiable and de-identified data to support planning, and that in some cases the analysis can only be done using identifiable data, or that it is more useful to use identifiable data because it is more detailed. They were then asked if this changed how they felt about identifiable data being used for planning, shown in the chart on the next page.

Figure 26



The chart shows that survey respondents most commonly stated that it did not change how they felt (44%). Amongst the respondents who stated that it did change how they felt, a higher proportion (30%) felt it made them more supportive of using identifiable data for planning. Just under one in five (19%) felt that the information they were shown made them less supportive of using identifiable data for planning.

The answers given to this question tend to correlate with survey respondents' attitudes towards identifiable data. Those who said that they preferred identifiable data to be used in the previous question were more likely to state that they were now more supportive, than those who preferred de-identified data to be used or had no preference (53% vs 30% and 22% respectively). Consequently, 28% of those who preferred de-identified data to be used in the previous question stated they were now less supportive of using identifiable data for planning, compared to 6% of those who had no preference and 12% of those who preferred identifiable data.

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

Figure 27

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				

A higher proportion of younger people, and people from a minority ethnic background, felt that knowing that identifiable data was used for planning and population health would not only change how they felt about it being used, but actually change it to make them less supportive. Whereas, a higher proportion of older people, and those from a White ethnic background, felt that this information did not change how they felt.

In workshops, the 54% preference for de-identified data shown in Figure 24 from survey respondents matched up with the predominant attitude among workshop participants initially. Workshop participants tended to gravitate towards de-identified data as it conveyed heightened security and fewer risks.

However, workshops allowed for discussions on the nuances of ‘identifiability’ and ‘de-identified’ data, which the survey format did not allow. Through explaining that identifiability exists on a spectrum from highly identifiable data to aggregate statistics, it gave participants an enhanced understanding. Once clarified and acknowledged that the NHS tends to use as little identifiable data as necessary and primarily uses de-identified data for population health and planning, concerns about identifiable data were reduced. Even in cases whereby members of the public would not be entirely de-identified, the majority of participants were content knowing it would be hard to re-identify them, and they were not completely identifiable.

Further, upon being informed of the potential benefits of using more identifiable data and being asked whether this would change their mind, the majority of participants were happy for their data to be used under the condition that it was deemed necessary and used sensibly. Citing examples within the workshop that resonated closely with participants daily lives, the majority recognised the potential advantages of identifiable data. Similar findings were reflected in the survey results, where individuals felt more content knowing that the data could improve the effectiveness of the NHS

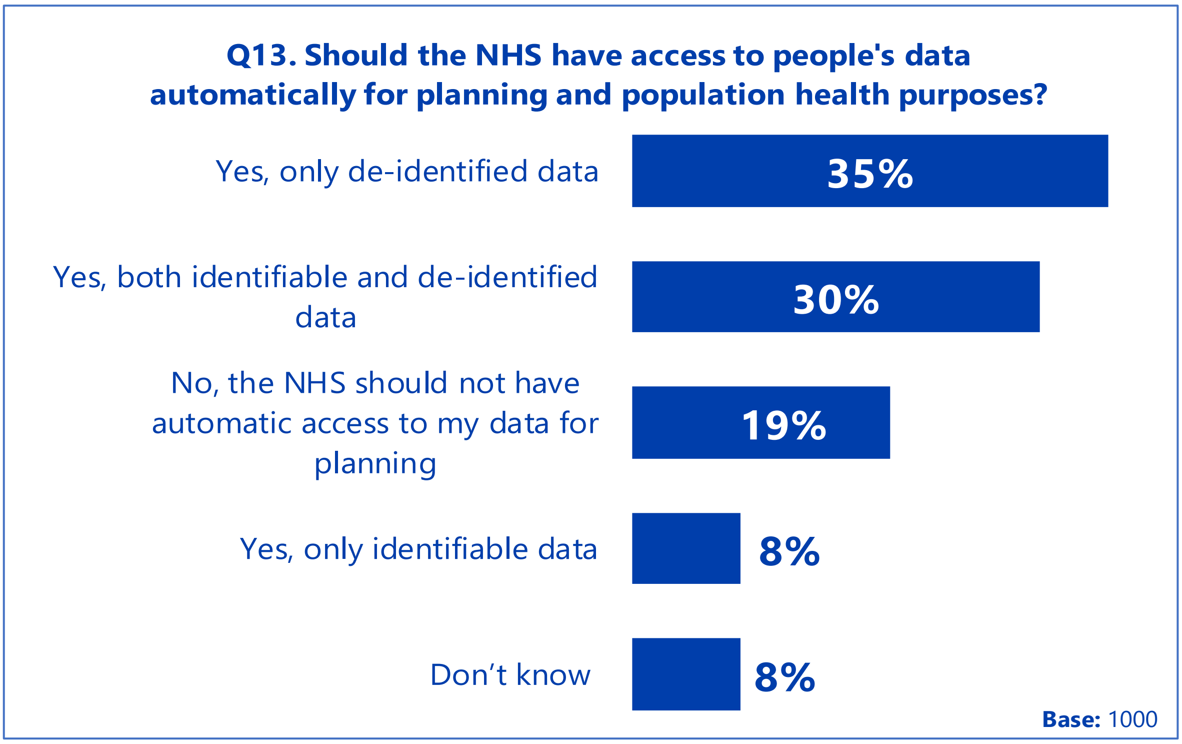
Nevertheless, the introduction of additional examples of national and local-level data raised concerns among certain participants about the extent of information available to their local hospitals. Some leaned towards preferring the use of national, de-identified data, unless there was a clear and essential need to utilise more identifiable data at a local level.

> *"I feel like to people working in there you can maybe be easily identifiable, but I understand it's probably anonymised [at a local level]." Group 4*

Automatic access to data

Survey respondents were asked if they thought that the NHS should have access to people's data automatically for planning and population health purposes.

Figure 28



More than a third of people (35%) thought that the NHS should only have automatic access to patient data when de-identified data is used. A sizeable proportion of survey respondents (30%) felt that the NHS should have automatic access to both identifiable and de-identified data for planning and population health purposes.

There was also a notable minority of survey respondents (19%) who felt that the NHS should not have automatic access to any of their data for planning and population health purposes, and that people should have to opt in or give permission for their data to be used. Whilst they are in the minority, this is a sizeable portion of the population which needs to be considered.

People's attitudes towards automatic access and choice seem to correlate with their levels of support in the survey. 43% of people who disagreed with the statement *'Generally speaking, I am supportive of the use of patient data in the NHS'* at Q1 said that the NHS should not have automatic access to their data for planning and population health purposes. Whereas, only 16% of those who agreed with the same statement said that the NHS should not have automatic access to their data.

Similarly, attitudes also correlate with survey respondents' knowledge levels. Those who said they knew *'nothing at all'* about how the NHS uses patient data at Q3 were more likely to state that the NHS should not have automatic access to their data for planning and population health than those who said they knew *'some'* or *'a lot'* (25% compared to 17% and 11% respectively). Whereas those that knew *'a lot'* were more likely to say that the NHS should have automatic access to both identifiable and de-identified data than those that said they knew *'nothing at all'* (40% compared to 26%).

Answers varied by demographic group. The table on the next page highlights any statistically significant differences between demographic groups in blue.

Figure 29

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					

Survey respondents were then asked why they gave the answer they did in the previous question. The verbatim answers given by respondents have been coded and grouped together. The tables below show the top five answers given in response to each answer at Q13 in rank order.

Those who thought that the NHS should only have automatic access to patient data when de-identified data is used (n=354) felt that de-identified data was preferable because of the lower risk associated with it. A third (33%) felt de-identified data was less likely to reveal personal information or be misused.

Additionally, a quarter of respondents (25%) felt that identifiable data should not be required for planning purposes. These results are seen in the table below (figure 30).

Figure 30

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		

Amongst those who thought the NHS should have automatic access to both identifiable data and de-identified data (n=300), many stated it would help improve NHS services through planning Results are in the table on the next page (figure 31).

Others were happy for both types of data to be used because they trust the NHS or because they do not mind the NHS using their data for whatever purposes they require. This suggests that there is a sizeable portion of the population who are broadly happy to share any type of data to support the NHS.

Figure 31

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		

Survey respondents who thought that the NHS should not have automatic access to <u>any</u> patient data for planning and population health purposes (n=191) wanted people to have more choice over how their data is used (figure 32). Whilst respondents did not want the NHS to automatically access their data, it is important to state that they did not necessarily feel that the NHS should not be using patient data for planning or population health purposes. Rather than data being automatically accessed by the NHS, they felt that people should be given a choice over whether their data is used.

Figure 32

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		

The small number of people who thought that the NHS should have automatic access to only <u>identifiable</u> data for planning and population health purposes (n=77) provided answers which suggested there was some confusion over the different types of data (see figure 33 overleaf). They supported automatic access to identifiable data to help the NHS as they believed it could improve planning and support the provision of services.

It is unclear from these answers why respondents thought that the NHS should only have automatic access to <u>identifiable</u> data, rather than both types of data, as the latter option would automatically include de-identified data. This suggests there was some confusion over identifiable and de-identified data. Perhaps the respondents who selected *'only identifiable data'* believed they were being offered a binary choice between the NHS using de-identified and identifiable data, as identifiable data would give the NHS more useful information.

This is supported by the verbatim responses. For this question, and others, some respondents were clearly unsure about what each type of data referred to.

Figure 33

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		

Moving onto the workshop findings, participants were asked about the same six example uses of data for planning and population health that they viewed earlier, but in this exercise were questioned for each purpose if the NHS should:

- Be able to use people's data by default, and you should NOT 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

Support for removing choice/automatic access to data

Interestingly, participants in the older group were unanimously supportive of removing choice and believed that the majority of use cases should be automatic, without an opt-out option. Notably, due to their more frequent use of the NHS, they perceived the benefits as necessary, and felt reassured by the responsible and beneficial use of data.

They used reverse logic to discuss the repercussions of withholding such data from the NHS and were primarily concerned with the risks of data gaps through providing an opt-out choice. Collectively, they agreed that the decision of using data should be entrusted to the NHS. That said, some participants in this group expressed understanding with regard to why certain people would want the option to opt-out.

> *"Well it's common sense, because you think what would happen if they didn't have it." Group 3*

> *"I think some people would prefer to opt-out if they can. I'm happy with the automatic, but I can see where some people will resist this" Group 3*

A similar viewpoint was voiced by one participant in another group, who raised concerns about the data gaps resulting from opting-out, highlighting how this could render the data meaningless or exclude certain individuals. However, the issue of opting-out became highly controversial for some, who emphasised the right to make a choice and how this choice is a basic human right.

> *"If you're opting-out, you're therefore creating another data subset somewhere else, whether that's by AI or whatever else, but then that has to then be carved out. That's another action to be had, whereas, if everyone is in by default, and you can't opt-out, then that is the dataset and it is anonymised." Group 4*

Interestingly, the younger group suggested that there may be an influx of opting-out among the older generation, while the younger generation might be more accepting of such measures, though our research shows the opposite. This, in combination with answers to previous questions, shows that younger people may assume that they are more comfortable with the NHS using their data due to assumed higher technological literacy levels, despite this not being borne out in the research.

This echoes findings by the Health Foundation that older survey participants (79%) were more likely to trust NHS organisations with their data than younger cohorts (57%)[33]. Nevertheless, it is important to consider only online literate older participants were spoken to, and less technologically literate older people may have different views that are not reflected in this research.

Support for opt-out

When workshop participants were questioned about various uses of data for planning and population health, the majority of participants across the groups wanted to maintain the status quo. Generally, there was a consensus that the ability to opt-out was fair and constituted a basic 'human right' – the importance of maintaining the opt-out system appeared to be viewed more as important on principle rather than because participants indicated they wanted to opt-out. Despite being supportive of the ability to opt-out, almost all participants indicated they would not personally opt-out, although interestingly, they did acknowledge that family members might. This aligns with the number of verbatim comments in the survey which emphasised the importance of choice (see Figure 32). Some participants also drew parallels to organ donation and argued that having an opt-out system is beneficial as a whole.

> *"It should be done by default. And then you should be able to opt-out if you want to, it's just giving you the option isn't it' Group 2*

> *"Opting in, from work experience, it's too complicated. It's too much extra work for a lot of people. Opting-out, or being automatic that you're all opted in, is so much better. I think they did that recently with organ donation. I think that's so important. Because actually, if you don't bother to opt yourself out, why shouldn't they have your organs?" Group 4*

> *"By taking that option away from people, like they might not even know that they've got the option, but to not have that there, I think that's like, I don't know, like a human rights issue. You can't do that, I don't think so, they've always got the option." Group 3*

Support for opt in

Support for opt-in in the workshops was minimal, with only a minority of participants suggesting that in some cases where the use of data was not essential, there could be an opt-in system. However, this viewpoint was rarely raised across the groups. This slightly contradicts the survey findings where 19% of respondents did not want the NHS to have automatic access to any data. Conversely, one participant stood out as an anomaly, suggesting that opting in should be approached in a parallel way to accepting cookies – there should be consent every time. Questions were raised regarding why data should be shared with the NHS when individuals would not readily disclose this information with strangers on the street. Therefore, it is important to recognise that although this perspective is not prevalent, it still exists among the general public.

> *"That's quite alarming who people are quite happy to sort of hand over stuff about their actual blood tests, inheritance and things that can work seriously against them. I don't know, I think a patient should have a right every time… do you want this to be used for this, for that…" Group 2*

Threats to people's trust in using data

In the workshop, it become clear that people have become increasingly aware of the spread of misinformation and the prevalence of fake news, particularly on social media platforms. Consequently, many participants shared they felt less trusting in general and had heightened privacy concerns. For most, this didn't impact their personal willingness to share data, but they could see how it would for others. They regarded this phenomenon as a potential threat to the NHS and use of data, as heightened awareness and publicity regarding the topic through social media could adversely impact opt-out rates. Participants emphasised that careful consideration must be given to how this information is communicated to minimise misinformation and misinterpretation.

> *"The thing about the social media is that if everyone in the world saw this kind of thing, that's fine, but people also are less trusting because there's so much misinformation which as we know all this you know fake news this and that. So giving so many people the option to opt-out maybe people's right, but you also face the risk of it. You're not getting enough participants because there's so much misinformation." Group 2*

Changing the opt-out

The Data Saves Lives strategy (England's health and care data strategy) has committed to 'simplifying the opt-out' and undertaking in-depth engagement on the future of the National Data Opt-out. This topic has also received some media attention during the announcement of the Federated Data Platform supplier. Findings from the workshops indicate that minimal change is required to the opt-out system as the majority favoured the system as it was. However, when splitting opt-out choices into different examples of using data for planning and population health purposes, a few participants did vary their opinion depending on the specific examples provided. Therefore, there is some appetite to separate opt-out choices into different use cases, although further research into the national data opt-out would be needed. Though, on the whole, the idea of opting out in a more granular way led to concern over practicalities.

Awareness raising about opt-outs

Without prompting, some participants within one group suggested that individuals should be provided with a small amount of information about their right to opt out (as opposed to a significant amount), similar to the way that some felt publicising the risks of using data was unnecessary and potentially unhelpful. One participant remarked that 30 years ago, before the advent of social media, systems like the NHS were functioning effectively. However, now that people have a platform to voice their opinions, it was felt that nothing seems to work anymore. Heavy publicising was therefore cautioned against, as in a lot of cases it was stated as having negative implications.

> *"Ignorance is bliss. Sometimes I think that's probably best"*
> *Group 2*

> *"This might be completely off the topic…years ago, we didn't have an option of opting-out. But because all of a sudden, it's more people are aware of what's going on, people are opting-out, things aren't working. You know, a lot of people say the crime rate has gone through the roof, actually, it is probably the same as it was 20 years ago. It's just that more people know about it now because of social." Group 2*

Interestingly, this conversation sparked a new line of thinking for some participants who had previously emphasised the need for the opt-out system. There was a sudden realisation that if a large number of people were to opt-out, it could result in inaccurate data.

> *"You won't get the true demographic would you? What if people are opting-out of everything and only opt in certain things you're not going to get the true demographic of dementia." Group 2*

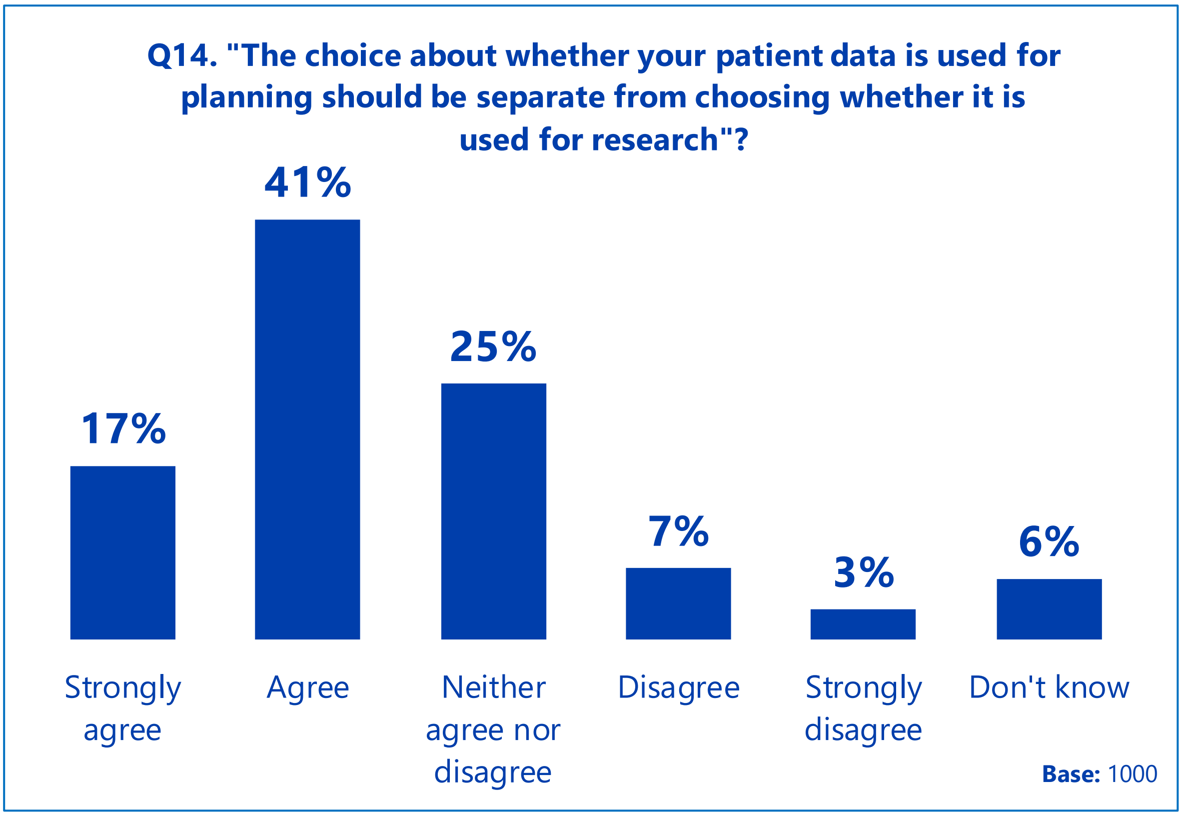
At the end of the group, participants were asked about the workshop's impact on their opinions. Despite the idea of '*ignorance is bliss*' being expressed both explicitly and implicitly, evidenced by nods of agreement, all participants stated their feelings were either more positive or unchanged. Though, those who stated they felt unchanged clarified that they felt positive prior to the discussion.

Interestingly, despite participants suggesting that 'less is more' in terms of what information should be presented to members of the public, researchers noticed when reflecting on the workshops that participants' levels of understanding dramatically increased as more information was provided. Conversely, when less information was presented, participants were more likely to misinterpret or misunderstand the question. The contrast in the amount of information provided in the workshop could explain why the use of data for planning and population health gained more support in comparison to the survey results.

Choices about particular uses of data

In the next survey question, respondents were firstly reminded what the terms *'research'* and *'planning'* referred to. They were then asked to what extent they agreed with the statement: *"The choice about whether your patient data is used for planning should be separate from choosing whether it is used for research"*.

Figure 34



A majority *'strongly'* or *'somewhat'* agreed (59%) that they should be given separate choices over the use of their patient data for planning and the use of their patient data for research.

Only a small number (10%) *'strongly'* or *'somewhat'* disagreed with the statement, with the remainder selecting *'neither agree nor disagree'* (25%) or *'don't know'* (6%).

The large proportion of survey respondents who opted not to agree or disagree with the statement suggests there could be some confusion over the level of choice people should have when it comes to their data being used within the NHS. It could be possible that some respondents did not feel they were informed enough to come to a decision, or that they simply didn't mind either way.

As the table below shows, some demographic groups were more likely to agree or strongly agree with the statement *"The choice about whether your patient data is used for planning should be separate from choosing whether is used for research"* than others. Respondents from younger age groups, minority ethnic backgrounds and social grades ABC1 were all more likely to (net) agree ('strongly agree' or 'agree').

Figure 35

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

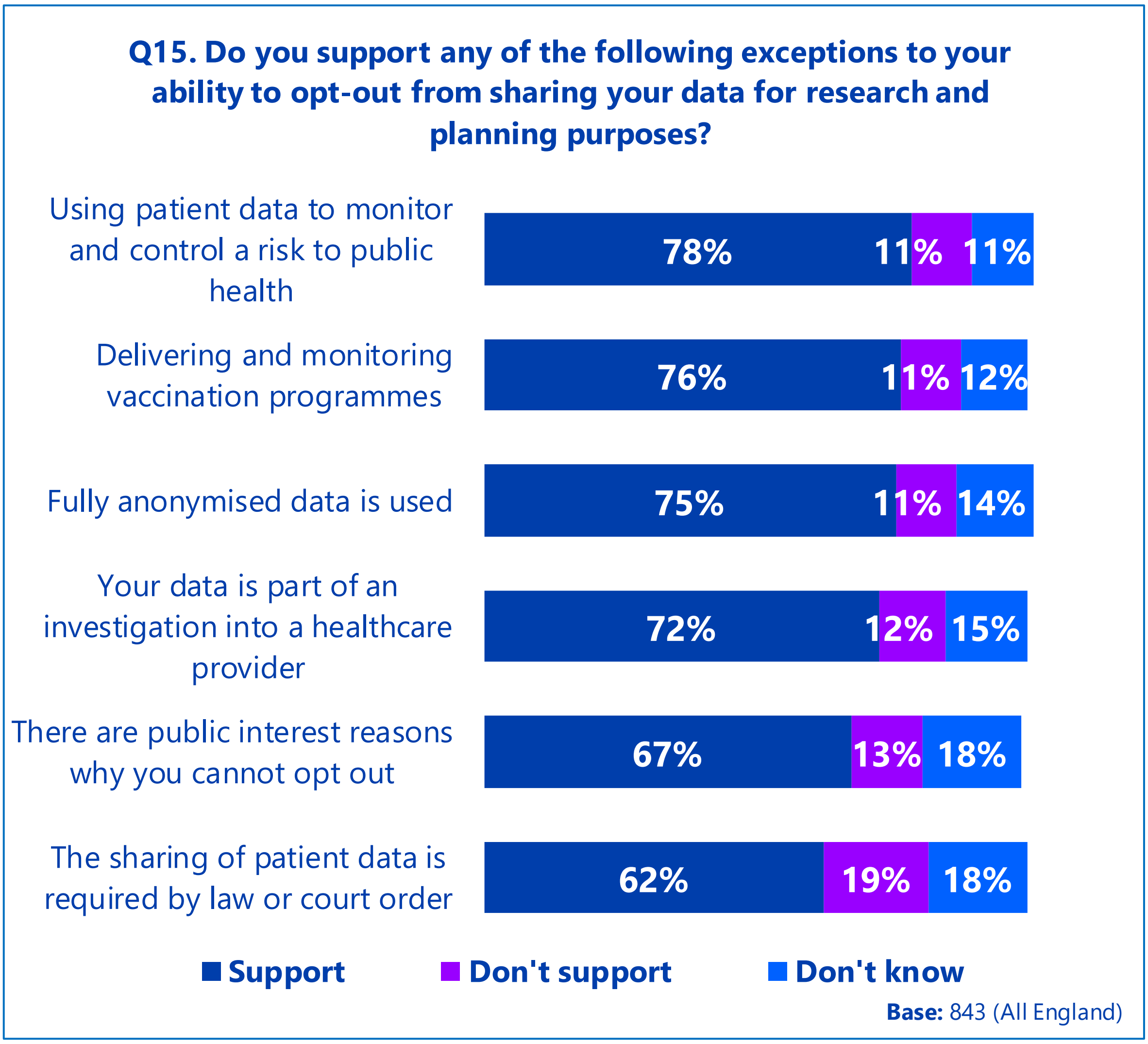
Survey respondents from England were informed that although they could choose to opt-out of their identifiable data being shared for research and planning purposes, there are certain exceptions. They were shown a list of exceptions to their ability to opt-out and asked if they supported each one. Results are shown overleaf in figure 36.

There was majority support for each exception to their ability to opt-out. People were more likely to support exceptions which related to public health. More than three-quarters supported opt-out exceptions *to 'monitor and control a risk to public health'* (78%) and to *'deliver and monitor vaccination programmes'* (76%).

Where support was lower for each exception, it tended to be because more survey respondents answered *'don't know'*, rather than stating that they *'don't support'*. The only statement that didn't follow this trend was *'The sharing of patient data is required by law or court order'*, with 19% selecting *'don't support'*, whilst 18% chose *'don't know'*.

The sizeable proportion of *'Don't know'* for each exception could suggest that people are currently uninformed and do not know what these exceptions mean or why they exist.

Figure 36



Survey respondents were then 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)	

Most people (82%) could not think of any other circumstances where they would support exceptions to the current opt-out system.

Amongst those who could think of more circumstances, there was a variety of responses, often reflecting or emphasising personal concerns. 5% were happy for the NHS to use patient data to monitor and control a risk to public health, despite this being an exception listed in the previous question. A few wanted exceptions for patient data to be used to research specific illnesses. Others stated that they were happy to share any form of their data to help the NHS or benefit other people.

Section 6: Methodological findings

Questions identified

Throughout the fieldwork (particularly qualitative), some common questions were asked by participants, which may be useful for Understanding Patient Data to consider in their work:

- Who is allowed access to my data?
- In what circumstances can the NHS share my data with third parties?
- Is there a limit to how many times the NHS can use my data?
- What do third parties do with my data – can it ever be used to sell to me?
- What happens if a third party breaks the rules of handling my data?
- Is most data analysis done on anonymous or aggregated data?
- What could the consequences of a data breach or hack be?
- What would happen if the NHS didn't have access to patient data?
- If I opt-out of data sharing for planning, does the NHS still store my data and can it still be hacked?

Reflection on explaining patient data in research

Different types of engagement and participatory activities serve different purposes. Sometimes it is assumed that a lengthy deliberative exercise over several hours/days is needed in order for participants to give informed views on patient data. Whilst this type of deliberation has many benefits and perhaps the most informed views (due to spending extra time on the educational content), this level of intensive research can exclude participants who are unable or unwilling to give up this much time, therefore it's important to also conduct research at different levels with different time commitments.

The concern for this research was ensuring that there was enough information to give informed judgements, and that this information was presented in a way that 'sunk in'. Across the different methodologies there were some key learnings:

- The most successful explanations involved an opportunity to ask questions and develop understanding through discussion. The workshops were the best example of this, and as a result more informed and nuanced discussions took place based on this sound understanding.
- The survey explanations were developed based on cognitive testing interviews, where participants could critique the survey and suggest improvements to the explanations. Cognitive testing is a key element to

doing survey work on this topic, and it flagged a number of areas where the explanation needed improving. The findings from the cognitive testing also flagged topics where the research team might need to spend more time during the workshops to explain and provide information.

- Concrete and relatable examples are crucial when explaining data uses. Rather than ‘delivering public health programmes’, explanations could say ‘delivering public health programmes, such as bowel cancer screening programmes for groups identified as being at higher risk of these cancers’.
- Simple language is important, stripping out any jargon and explaining as if it was a conversation, rather than a policy document.
- Images and diagrams really help, for example the image illustrating identifiable and de-identified data was very helpful in explaining this quite complicated concept.

Ultimately, this shows that it is possible to do meaningful research into patient data in a non-intensive way which is more easily achieved on a smaller budget and still likely to result in a wide range of perspectives. However, it is still important to spend time challenging the explanations that are used and making sure they will land well.

Reflecting on the benefit of qualitative and participatory practices

While it is clear there are many opportunities to conduct quantitative research into public views on patient data, it should also be noted that the engagement and discussion in the workshops has clear benefits to not only research but for education and involvement purposes. Workshop participants were taken on a journey throughout the 90 minutes, with their knowledge being built up slowly and iteratively. We made sure that each section was understood before moving on to the next one, with opportunities to share concerns or questions and have these answered or at least discussed in a non-judgemental forum.

When comparing the sentiment of the workshops to the survey findings (which we assessed through looking at the tone of the verbatim comments as well as the statistics), it seemed that workshop participants were more positive towards patient data, possibly as they had had more time to develop and explore nuances in their views. Qualitative discussion has a dual purpose of gaining insights and also allowing members of the general public to become informed (and oftentimes supportive) of patient data uses.

Limitations of the research’s online focus

The main limitation of this methodology was that it did not include many members of the public who were not technology literate as all methods were online. Only 4%

of survey respondents disagreed that they were ‘confident using technology’, suggesting a wider range of viewpoints could have been gathered from people less confident. The qualitative element was all online so only involved those able to use Zoom.

Possibly as a result, the findings may have over-represented positive views. The range of opinions are more varied in the survey, but still heavily weighted in favour of using patient data. We know from other studies and from the minority of comments in this piece of research that there are still strong concerns among the general public around use of patient data.

Indeed, many workshop participants reflected that while they were highly positive, they knew friends or family members who would be much more critical and would rather opt-out. It is important to consider the conclusions in light of this, and that there are members of the public with strong and valid concerns whose voices weren’t reflected as strongly in this study.

It is also worth considering a piece of insight solely focused on those disengaged with technology to understand how far their views differ from the findings of this study.

6. Conclusions

- Public understanding and awareness of ‘planning’ as a concept was lower compared to all other use cases (individual care, research and population health). Even after expanding on this in the workshops, understanding remained lower for planning compared to population health, primarily due to the examples for population health being more relatable.

- This said, on the whole, there were high levels of support for using data for planning and population health, which was heightened by the use of examples of how data is used for these purposes. The examples that garnered the most support correlated with age; older participants prioritised the case for ‘sharing data between the health service and local authority to improve services’, while younger participants placed a notable emphasis on the importance of using data to evaluate patient outcomes.

- Covid-19 appears to have impacted the way the public perceive planning and population health, prompting members of the public to claim to be more aware of data use than before the pandemic. The recent pandemic example notably brought the population health use case closer to home, which boosted understanding but also support for this use case.

- Based on the workshop findings where participants described what was driving their feelings, we can assume that more frequent NHS use drives older participants to have higher awareness levels across the board as they were closer to the services. Similarly, some ethnic minority groups reported feeling a greater connection to population health examples due to their perceived proximity to heightened risk factors associated with their own communities. However, despite this proximity, many individuals had not previously connected this with their patient data being used, and the small number of participants taking part in the workshop limits the generalisability of these findings.

- While the potential benefits are seen as important reasons for sharing patient data with the NHS, seeing patient data deliver benefits in practice was a point of contention for participants. There were frustrations over the gap between the listed benefits of the use of data and the actual state of affairs within the NHS. This led some to doubt the claims made over patient data ‘improving’ the NHS as they don’t see these improvements in their own lives.

- The risks associated with data use and sharing were often likened to the risks inherent in every day online activities or accepting cookies; these were accepted as expected in the modern world and there was a bit of apathy around this.

While some consider these risks as inevitable and therefore accept them, there remains a minority for whom these concerns are ever-present and would make them unhappy with their data being used by the NHS.

- As a whole, participants tended to prefer the NHS to use de-identified data, which is aligned with findings from previous research. However, once the concept of identifiability existing on a spectrum was explained during the workshops, participants became more open to the idea of the NHS using some identifiable data. This perspective was supported as long as the analysis was beneficial to the NHS and that safeguarding measures were put in place. It is important to note that it took a fair amount of explaining and answering questions to get to this point, and that the initial reaction (of wariness towards identifiable data) is more likely to be the reaction of the general public.

- Awareness of safeguarding procedures is crucial in ensuring the public feel comfortable with their data being used. Participants liked knowing that the use of identifiable data is minimised as much as possible, and there are extra approvals required when it needs to be used. This emphasis on both safeguarding practices and the limited use of identifiable data is essential to instil confidence among the public.

- Using tangible, interactive, relatable and colloquial examples proved highly effective in conveying concepts and also resulted in participants showing greater support.

- The option to opt-out was deemed fair and regarded by the majority as a basic right. Reverse reasoning proved useful in explaining and evaluating the benefits of not opting-out. By questioning the potential impacts of opting-out, many participants came to the conclusion that such a decision could render the wider dataset meaningless and potentially have huge implications for the NHS. Again, this was only once they had a chance to weigh up and debate the options, not an instant reaction which is more likely to be how the general public feel.

- The research explored whether the current ‘broad-brush’ approach in England to opting-out of data being used for research, planning and population health was fit for purpose or if a more granular approach would be better. Findings were inconclusive as the concept of more choice sounded good to participants, but when considering the practicalities of having to understand each use and choose either way, this became less appealing.

- Findings suggest that providing an abundance of information about patient data could pose some risks, as individuals may not fully understand it and may lack support in trying to understand it, which could cause confusion and potentially negative opinions. Many stated that 'less is more' regarding information on risks and how data is used. However, workshops demonstrated that presenting less data resulted in higher risk of misinterpretation, therefore there is a balance to be struck about what level of information is available.

- Overall, there is a prevailing trust that the NHS will use patient data responsibly, and that such data has the potential to help and transform the NHS. However, participants expressed they had no option but to trust the NHS, as this trust is integral to the functioning of the healthcare service that they benefit from.

Recommendations

Based on this research, a number of recommendations for communication, public policy discussion and further research regarding the use of patient data for planning and population health emerged.

- When discussing the use of patient data for planning and population health purposes with members of the public, it should be considered that these terms are perceived to be abstract and are not fully understood. The research highlights that people often lack the confidence to talk about patient data uses in this way. Members of the public feel more able to discuss these topics when they are given relatable, tangible examples of what using patient data for planning and population health purposes means. Clear examples should be a central feature of any communications about the topic, whether this is in research or in wider communications.

- The survey results and the workshops also show that people are more supportive of patient data uses when they are conveyed as specific examples, rather than broad categories. More research could be conducted on the efficacy of using relatable, tangible examples, developing a deeper understanding of which examples have the most effect on people's levels of support and understanding. Explaining how the NHS uses patient data for planning through relatable examples like case studies could raise low awareness levels amongst the general public.

- This research engaged with participants online and therefore is very unlikely to have captured the views of people who are partially or completely disengaged from technology. Further research could engage with people who are digitally excluded, such as older demographic groups, whose views on patient data uses for planning and population health purposes might differ substantially. Such research could shed light on those who are most concerned about data sharing.

- The workshops demonstrated that people welcome reassurances about how the NHS uses, shares and stores their health data. People tend to assume the NHS is already taking steps to protect and use patient data safely and securely, but they respond positively when this is put into words and explained to them, as it provides reassurance by reiterating their own assumptions. Therefore, any potential reassurances that could be offered to the public about how the NHS protects and keeps patient data secure would likely be well-received.

- The workshops also uncovered a few concerns about patient data being used at the 'local level'. These participants believed that it would be easier for patients to be identified at this level due to the smaller pool of patients, leaving their personal information exposed. To overcome these concerns, people need to be assured that there are safeguards in place, and that the identifiability of data exists on a spectrum. People felt more comfortable with the use of their data when it was explained that de-identified and identifiable data are not binary. When discussing identifiability, it should be explained that health data exists on a scale and therefore 'identifiable' data does not necessarily include every piece of information that could identify a person. It would also be beneficial to note safeguards such as restricted access, which also helped ease concerns over identifiability.

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Project details

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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.

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