Public Perspectives on GP Record Data: Exploring views and information needs about patient data held in general practice records in England

For Understanding Patient Data

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MRS Evidence Matters™
Company Partner

QaResearch

Contents

1. Executive summary

Research aim

This research project set out to explore public understanding, views, and expectations towards the data collected and held in general practice (GP) records in England. The research also aimed to gather insights which could be used to produce an informational resource explaining key facts about GP record data to the general public.

Methodology

The research consisted of three stages:

1. Quantitative online and CAPI survey conducted with a nationally representative sample (n=1104) of the general public in England
2. Qualitative online workshops and telephone interviews with members of the general public from across England.
    a. 40 members of the general public took part in 6 online workshops
    b. 5 digitally disengaged participants took part in telephone interviews
3. Qualitative online co-design workshops and in-person interviews with members of the general public from across England.
    a. 20 members of the general public took part in 3 online workshops
    b. 3 digitally disengaged participants took part in in-person interviews

Key findings

Content and storage of GP records

Overall, awareness of what data can be collected and held in a person's GP record was mixed. Both survey respondents and qualitative participants expected their contact details and information directly related to their medical care to be held in their GP record. Whilst people are not necessarily aware of the specific types of data collected, the information held in the GP record meets their expectations, meaning there are no surprises about the types of data that are collected.

Levels of awareness around the storage of GP records are generally low. Survey respondents largely expected that the GP record would be held digitally (95%), but there was little awareness around who is responsible for managing these digital records. Whilst the most selected option was '*Digitally, managed by the GP surgery*' (66%), over half incorrectly selected '*Digitally, managed elsewhere in the NHS*' (54%).

There are similar misconceptions around who provides the computer systems that store the data: only 28% of respondents correctly selected '*A private-sector company*'.

Additionally, a majority of survey respondents (61%) incorrectly believe that there is a single national healthcare record, containing all the data collected about them by the NHS. The same proportion of respondents (61%) would prefer for their GP record data be stored in a single national healthcare record controlled by a national body, such as NHS England, rather than in a record controlled by their GP surgery.

Accessing the GP record

Just over half (56%) of survey respondents stated that they had seen their own GP record. Within this, the most common method of access was the NHS App (37% of all survey respondents). A sizeable proportion (43%) stated that they had not seen their GP record before.

People believe it is important to be able to view their GP record. A strong majority (81%) of survey respondents felt it was '*Very important*' or '*Somewhat important*' to be able to see their record. Indeed, almost two-thirds (64%) of those who had never seen their GP record thought it was '*Very important*' or '*Somewhat important*' to be able to see their record.

The survey findings aligned with the findings from the qualitative research. When asked about accessing their GP record, workshop and interview participants felt it was important for them to be informed about how they can access it.

Sharing and using GP record data for individual medical care

There was limited awareness of how the data from GP records could be used and shared. Most survey respondents (82%) were aware that GP record data could be used to help provide a person with individual medical care. However, they were less likely to identify other uses of GP record data beyond individual medical care: '*Planning and improving services*' (62%), '*Population health*' (52%), '*Research studies you have explicitly agreed to take part in*' (48%) and '*Research studies you have not explicitly agreed to take part in*' (23%).

For individual medical care, most respondents thought that all GPs (89%) and all nurses (82%) in their GP surgery would have access. This was in line with who they would be comfortable with having access: GPs (89%) and nurses (85%).

They were less likely to be aware that receptionists or administrative staff in their GP practice can access information from the GP record, although a slim majority (54%) did expect them to have access. Less than half (40%) would be comfortable with administrative staff having access.

Outside of the GP practice, most respondents (83%) expected hospitals to be able to access their GP record data to help provide a person with individual medical care. A smaller number of people thought healthcare services, such as pharmacies (30%) and dentists (23%) have access.

This echoes the findings from the workshops and interviews, which demonstrate that people expect medical information from their GP record to be shared with healthcare services across the NHS to support their individual care, but they are not aware what types of data are shared, how data is shared, or who it is shared with.

Sharing and using GP record data for purposes beyond individual medical care

Awareness of how GP record data can be used and shared for purposes beyond individual medical care is limited. Just over half (54%) of survey respondents correctly identified that '*People who work in the NHS to plan and analyse health services*' have access to GP record data. Indeed, more than a third of respondents (37%) did not think that <u>any</u> organisations listed in the survey (such as '*Researchers at medical research charities*' or '*People who work in the NHS to plan and analyse health services*') have access to GP record data for purposes beyond individual care.

These figures are similar when it comes to which organisations respondents were comfortable with having access for purposes beyond individual care. '*People who work in the NHS to plan and analyse health services*' accessing GP records was acceptable to a majority of respondents (59%). A third (33%) of respondents were not comfortable with <u>any</u> of the organisations listed having access.

For most people, there is very limited awareness of how data from GP records can be used for purposes other than their individual care. This was a key area of interest for participants in the workshops and interviews. They were unaware of who had access to the data in their GP record or why, and, due to concerns around misuse of their personal information and data security, they wanted to know more about this.

Finding out more about the topic caused a shift in perceptions amongst participants. Concerns about their personal information being shared and used seemed to abate when it was explained that, in most cases, de-identified data is used for purposes beyond individual medical care. After discussing the purposes that GP record data can be used for, participants were supportive of GP record data being used for purposes which benefit the 'public good' (such as for research or service improvement).

Information preferences and needs

The research suggests that people want more information to be made available about the data held in their GP record. When asked about receiving information about how data from their GP record is used, shared, stored and managed, 45% of survey respondents wanted the option to receive this if they asked, and 31% wanting to receive information without having to ask. Just under a quarter (24%) did not want to receive any more information about their GP record data.

The findings from the workshops and interviews demonstrate that people want more information about topics that can answer their concerns about data security and their data being shared and used for purposes they disagree with, such as selling data to private organisations for profit. In particular, participants wanted to know:

- Who has access to GP record data, both within and outside the NHS
- What level of detail they have access to and why
- How their GP record data is kept safe and secure
- Their choices around opting out of their data being used and shared

This aligns with the survey findings. From a list of topics (see appendix for full survey), respondents were asked what they would like to receive more information about. The top three most-selected options were: *'Who can access my data'* (61%), *'What protections are in place to help keep my data secure'* (54%) and *'How my data is used'* (53%).

Qualitative research participants were also keen to know how to access their GP record, so they can find and check their medical information.

Whilst people feel it is important for this information to be made available to the public, workshop and interview participants were ambivalent about whether they would engage with this information if they received it without having to ask. Whilst some felt it was important for this information to be sent to people without them having to ask, many suggested that they would not engage with information if it was sent to them, due to low levels of pre-existing interest in the topic of GP record data. However, participants did emphasise that information about GP record data should be made available for those who are interested.

Whilst few had actively looked for or passively received any information about the data held in the GP record, workshop and interview participants said that they would look for this information online via an NHS website or by asking their GP surgery if they wanted to find out about the topic.

Participants trusted their GP surgery or another NHS body, above any other organisation, as a source of information. 78% of survey respondents suggested that information about GP record data should come from their GP surgery, with 53% suggesting that it should come from a national health body, such as NHS England.

2. About this report

The data held in a person’s general practitioner’s (GP) patient record, in comparison with a person’s hospital or other health records, is often considered the most extensive source of information about a person's health and is very useful for both individual patient care and secondary purposes. It is used to ensure that a patient’s care team has access to as much information as possible about them to help provide the best care, to pay GPs for the services they provide, and can be used for research and analysis within and outside the NHS.

Each GP surgery in England manages its own patient data, sometimes taking different approaches to decisions about GP data. As a result of this, there has been some debate in recent years about the best way to realise the benefits of analysing GP data whilst retaining public trust in the system. Despite this, there is relatively little evidence regarding public attitudes towards GP data specifically. Prior research has tended to focus on views about specific existing or proposed primary care data initiatives or testing specific models for the use and sharing of GP data. Indeed, we know relatively little about whether people – as is sometimes theorised – perceive GP data as being different in any respects to patient data collected in other settings. This research builds on existing research by focusing on an in-depth exploration of how people feel about primary care data specifically, how their attitudes about it compare to other health data, and what their information needs are regarding GP data.

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

This report will use the term ‘GP record data’ as a shorthand to refer to routinely collected patient data held in GP records in the NHS. Data about a person and their health is collected and entered into their GP record, as part of their normal contact with their GP surgery, or when other parts of the health service share information with the GP practice.

In line with research conducted by Understanding Patient Data on the best words to use when talking about data, the term ‘individual care’, rather than ‘direct care’, will be used to refer to data that is used to prevent, investigate or treat a patient’s health problem. The term ‘data’ will also be used in the singular rather than the plural. Whilst the plural form is more technically accurate, the singular form is more widely used and understood by members of the public.[1]

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[1] Understanding Patient Data. ‘Patient Data: Finding the best set of words to use.’ Understanding Patient Data, March 2017.

3. Introduction and background

The information held in an individual's GP record (henceforth referred to as 'GP record data') is key to providing patients with the best care and treatment and has the potential to contribute significantly to improving healthcare services, population health management, and medical research.[2] Whilst studies have found that large portions of the population are willing to share their data for varying uses within the NHS (contingent on adequate security), concerns remain around data security and secondary uses of data.[3] [4]

Each GP surgery is responsible for storing, managing and making decisions about their patients' data. This means there are over 6,000 data controllers managing GP data in England and approaches to data sharing are fragmented. In the past few years, there have been high profile attempts to bring GP data together, which have been met with pushback from privacy campaigners, parts of the medical profession and some members of the public.[5] More recently, the British Medical Association (BMA) has urged GPs to make certain changes to data sharing functionality as part of collective action surrounding the GP contract.[6]

However, despite the salience of GP record data, existing research has primarily looked at public attitudes towards patient data in a broader sense, or focused on specific policy initiatives such as General Practice Data for Planning and Research (GPDPR). This project addresses the gap in knowledge around public views, expectations, and levels of awareness towards GP record data specifically. Given the pushback from some campaigners and members of the public about centralising GP record data and integrating it with other NHS datasets, it could be theorised that patients and members of the public perceive GP record data as somehow different to other routinely collected data. This research also aims to explore whether it is perceived as somehow different, and if so in what sense.

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[2] Macon-Cooney, Benedict, et al. 'A New National Purpose: Harnessing Data for Health'. Tony Blair Institute for Global Change, May 2024.

[3] Stockdale, Jessica et al. '"Giving something back": A systematic review and ethical enquiry into public views on the use of patient data for research in the United Kingdom and the Republic of Ireland.' Wellcome Open Research 3 (2022) 6: 1-26.

[4] Understanding Patient Data. 'Public attitudes to patient data use: A summary of existing research'. Understanding Patient Data, July 2018.

[5] Crouch, Hannah. 'GPDPR September implementation date is scrapped'. Digital Health, July 20 2021.

[6] British Medical Association. 'Protect your patients, protect your GP practice', accessed 16th December 2024, https://www.bma.org.uk/our-campaigns/gp-campaigns/contracts/gp-contract-202425-changes

As noted, existing literature indicates several common issues regarding public understanding of and support for various uses of GP record data. Public awareness of the ways in which data is collected, stored and used is generally limited. Some studies highlighted misunderstanding around ownership of data, with participants discussing data 'as if it were the property of the individual'.[7]

With current levels of public awareness and understanding about GP record data and how it is controlled and processed seemingly low, this research aims to assess public understanding and awareness of GP record data, measure public attitudes towards GP record data, and to understand information and communication needs regarding GP record data.

Considerations for this research methodology

Low levels of public knowledge and familiarity, and the complexities of an unfamiliar topic, have distinct implications for the approach to this research project.

For example, measures were taken to ensure that the survey was intuitive to use, accessible, and comprehensible. Existing literature indicates that complex terminology is a barrier to public understanding of health data usage.[8] In light of this, the survey includes an explanation at the beginning of sections outlining exactly what certain processes involve, such as the use of data for secondary purposes. For the workshops and digitally disengaged interviews, each topic of discussion was accompanied by visual explainers and, where possible, simple and relatable examples. This helped to ensure that participants have a clear base level of understanding of each topic discussed and thus responses are not solely grounded in assumption. Additionally, where possible, 'data from the GP record' or 'information from the GP record' was used instead of the term 'GP record data', as it offers a clearer picture of exactly what information is being referred to.

The literature also makes clear that there are legitimate concerns from participants around trusting that their data will be kept and shared safely and with good reason. High-profile concerns around data security and broader newsworthy discussions about the running of the NHS have contributed to these anxieties.[9] Thus information around the security of and purposes of data storage and sharing have been included

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[7] Wyatt, David, et al. 'Perceptions of the uses of routine general practice data beyond individual care in England: a qualitative study.' BMJ Open 8 (2018): 1-8.

[8] Research Works Limited. 'NHS Digital GPDPR'. Research Works Limited and NHS Digital. April 2022.

[9] The University of Manchester Centre for Social Ethics and Policy and the Patients Association. 'General Practice Data Trust: Report on Patient Focus Groups.' January 2023. p. 22.

in both the survey and the qualitative materials to ensure that research participants were provided with the appropriate level of information. For example, qualitative moderators were provided with a further information sheet which equipped them to answer further questions from participants as they arose, and ensure that they were not misinformed.

4. Methodology

The research consisted of three stages:

- Stage 1: Quantitative survey with members of the general public
- Stage 2: Qualitative online workshops and telephone depth interviews with members of the general public
- Stage 3: Qualitative co-design online workshops and in-person depth interviews with members of the general public

Project set up & desk research

Stage 1

Online panel survey
1,000 completes

Face-to-face (CAPI) survey
104 completes

Stage 2

Online workshops
6 x workshops (40 participants total)

Telephone interviews
5 x interviews (with digitally disengaged)

Stage 3

Around half of Stage 2 participants recontacted and recruited

Online workshops
3 x workshops (20 participants total)

In-person interviews
3 x depths (with digitally disengaged)

Reporting & final informational resource design

4.1 Project steering group

Each stage of the research was designed with input from a steering group consisting of expert stakeholders from across the NHS, arms' length bodies, and civil society with an interest in GP data. The steering group provided feedback on the project through online meetings, and reviewed research materials offline to ensure they were accurate and achieved the objectives of the research.

Before each stage of the research, steering group members advised on key question topics, and provided feedback on key research materials, such as the survey and the discussion guides.

Following completion of Stage 3, the steering group met to discuss the research findings and the best approach for designing the final version of the informational resource.

4.2 Stage 1: quantitative survey

Sample

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

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

A top-up sample (n=104) of those who would be less likely to complete an online survey was gathered through a CAPI (computer-assisted personal interviewing) survey in England. The top-up sample was intended to ensure the research gathered insights from digitally disengaged groups. Screener questions were added to the survey, and minimum quotas on digitally disengaged respondents included, to ensure we targeted these groups.

Survey question development

Following the preliminary desk research which helped pinpoint knowledge gaps around public awareness and expectations, a series of survey questions were formulated.

The survey covered the following sections:

- About your GP record and how it is stored
- Seeing your own GP record
- Uses of data in your GP record
- Using GP record data for your individual care
- Using GP record data for secondary purposes
- Level of involvement in decision making
- Information about how your GP record data is stored, used and shared
- Comparing the GP record to other health records

The survey took on average 20 minutes to complete.

Sample profile

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

For the online survey, data collection was conducted using an online panel provider Dynata. The survey remained open from 4th October to 16th October 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.

For the top-up CAPI survey, data collection was conducted using Qa’s network of interviewers, who administered the survey face-to-face using our CAPI system. 18 interviewer shifts (2 shifts in each region of England) were conducted from 17th October to 27th October 2024, and a total of 104 surveys were completed through this approach.

Minimum quotas were set based on digital engagement to ensure the survey gathered insights from those who were unlikely to be able to complete the survey online.

Final sample profile

The table below show the final sample for all survey respondents, compared to the population of England as of the 2021 census. The table excludes those who answered '*Don't know*' or '*Prefer not to say*'.

UK Profile	Population	Final Sample	
Gender	*%*	*n*	*%*
Male	48.35%	517	46.83%
Female	51.65%	587	53.17%
Age			
18-34	12.68%	140	12.68%
35-44	19.91%	205	18.57%
45-54	20.27%	221	20.02%
55-64	19.06%	228	20.65%
65+	28.08%	310	28.08%
NHS region			
North East and Yorkshire	14.43%	168	15.22%
North West	13.09%	140	12.68%
Midlands	19.12%	213	19.29%
East of England	11.19%	118	10.69%
London	15.43%	172	15.58%
South East	16.41%	178	16.12%
South West	10.32%	114	10.33%
Ethnicity			
White British or Irish	81.04%	933	84.51%
Any other ethnic group	18.95%	164	14.86%
Social Grade			
ABC1	56.23%	586	53.08%
C2DE	43.77%	505	45.74%
Disability			
Disability	17.30%	205	18.57%
No disability	82.70%	875	79.26%
Total		***1,104***	

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 +/-2.95%.

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, 29 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.

4.3 Stage 2: qualitative workshops and interviews

Sample and recruitment

In total, 40 members of the general public took part over 6 online workshops. 42 participants were recruited (7 per group), allowing for participant drop-out. Participants were recruited through free-find or pre-approved lists.

The 6 groups were split according to life-stage (pre-family, family and post-family). Participants with strong positive or negative views on sharing GP record data for purposes beyond individual medical care were split into separate groups to avoid any workshops being dominated by participants with radically opposing views.

The table overleaf shows the breakdown of the final sample.

UK Profile	**Final Sample**						
Gender	*Group 1 Pre-family*	*Group 2 Pre-family*	*Group 3 Family*	*Group 4 Family*	*Group 5 Post-family*	*Group 6 Post-family*	**Total**
Male	3	3	2	3	3	3	**17**
Female	4	4	4	3	4	4	**23**
Age							
18-34	4	4	1	1	0	0	**10**
35-44	3	3	4	2	0	0	**12**
45-54	0	0	1	3	0	0	**4**
55-64	0	0	0	0	3	4	**7**
65+	0	0	0	0	4	3	**7**
NHS region							
North East and Yorkshire	2	2	1	1	1	1	**8**
North West	1	2	0	0	2	1	**6**
Midlands	2	2	1	1	1	2	**9**
East of England	2	1	1	2	0	0	**6**
London	0	0	2	1	2	1	**6**
South East	0	0	0	0	0	0	**0**
South West	0	0	1	1	1	2	**5**
Ethnicity							
White British or Irish	6	6	5	6	6	6	**35**
Any other ethnic group	1	1	1	0	1	1	**5**
Social Grade							
ABC1	4	4	4	3	4	4	**23**
C2DE	3	3	2	3	3	3	**17**
Total	***7***	***7***	***6***	***6***	***7***	***7***	**40**

Alongside the workshops, 5 digitally disengaged participants were recruited to take part in telephone depth interviews, in order to ensure that the research was accessible to those who would be unable to participate in the workshops online. The table below shows the breakdown of the final sample.

UK Profile	Final Sample
Gender	
Male	2
Female	3
Age	
55-64	1
65+	4
NHS region	
North East and Yorkshire	2
Midlands	2
South West	1
Ethnicity	
White British or Irish	3
Any other ethnic group	2
Social Grade	
ABC1	2
C2DE	3
Total	***5***

Online workshop method

Participants took part 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 £40 incentive for taking part.

Online workshops were selected as the most appropriate and cost-effective method to engage with members of the general public. The accessibility and flexibility provided an opportunity for individuals from diverse regions and demographics to participate over Zoom.

Digitally disengaged interview method

Interviews were also conducted over the telephone with digitally disengaged participants. This meant that the research was accessible to those who would otherwise be unable to take part in the online workshops, and ensured that insights were gathered from this key group.

Digitally disengaged participants were sent a physical copy of the stimulus presentation in the post, allowing the participant to fully engage with the topic.

The interviews lasted 60 minutes, and participants received a £30 incentive for taking part.

Validation

In order to validate the identity of research participants, confirmation calls were carried out ahead of the workshops and interviews, where participant identity and demographic information were checked. Moderators also confirmed participants' identity at the beginning of each session.

Discussion guide and stimulus

A discussion guide with a semi-structured format was created to guide the workshops and interviews. The guide covered the following sections:

- Levels of knowledge about how data in GP record is stored, used, shared and managed
- Information received to date about GP record data
- Information needs
- Discussion of topics of interest and answering questions
- Communication preferences

The discussion guide was supported by stimulus material. Showcards were produced on PowerPoint, and were used in the sessions to support deliberation, providing participants with visual explanations and prompts to inform discussion. A full version of the discussion guide and stimulus can be found in the Appendix.

Analysis

The qualitative team took a thematic approach to the analysis of the data. The first step was to individually create transcripts of the online workshop and interview recordings, identifying common themes and responses. Following this individual analysis, the team came together to share, debate, and finalise the important themes in a collaborative analysis session.

The nature of qualitative research means that it cannot be said to be nationally representative. Rather, it provides further depth in understanding public views and levels of knowledge around GP record data.

4.4 Stage 3: co-design workshops and interviews

Sample and recruitment

Following the Stage 2 workshops and interviews, half of the participants who took part in the previous stage were re-contacted and recruited to take part in Stage 3, which aimed to produce a public-facing resource explaining key facts about GP record data through a co-design process.

Recruiting participants who took part in Stage 2 ensured participants had a base level of knowledge about the topic, which meant that less time could be spent on deliberation, and participants could focus on contributing to the co-design process, drawing on discussions from the previous set of workshops and interviews.

In total, 20 members of the general public took part over 3 online workshops. 21 participants were recruited (7 per group).

At the end of each workshop in Stage 2, moderators noted which participants would be likely to contribute well to the co-design workshops. These participants were prioritised for recruitment to ensure the co-design workshops were productive.

The 3 groups were split according to life-stage (pre-family, family and post-family). As with the Stage 2 workshops, demographic quotas were used to ensure a diverse sample, which reflected a variety of perspectives.

The table overleaf shows the breakdown of the final sample.

UK Profile	**Final Sample**			
Gender	*Group 1* *Pre-family*	*Group 2* *Family*	*Group 3* *Post-family*	**Total**
Male	2	2	3	**7**
Female	5	5	3	**13**
Age				
18-34	4	2	0	**6**
35-44	3	2	0	**5**
45-54	0	3	0	**3**
55-64	0	0	3	**3**
65+	0	0	3	**3**
NHS region				
North East and Yorkshire	1	2	2	**5**
North West	3	0	0	**3**
Midlands	3	2	0	**5**
East of England	0	0	0	**0**
London	0	1	2	**3**
South East	0	0	0	**0**
South West	0	2	2	**4**
Ethnicity				
White British or Irish	6	6	5	**17**
Any other ethnic group	1	1	1	**3**
Social Grade				
ABC1	3	4	3	**10**
C2DE	4	3	3	**10**
Total	***7***	***7***	***6***	**20**

Alongside the workshops, 3 digitally disengaged participants were recruited to take part in in-person depth interviews, in order to ensure that the research was accessible to those who would be unable to participate in the workshops online. The table below shows the breakdown of the final sample.

UK Profile	Final Sample
Gender	
Male	2
Female	1
Age	
55-64	1
65+	2
NHS region	
North East and Yorkshire	2
Midlands	1
Ethnicity	
White British or Irish	1
Any other ethnic group	2
Social Grade	
ABC1	1
C2DE	2
Total	***3***

Online workshop method

Participants took part in an online workshop, guided by a semi-structured discussion guide and visual stimulus. Example visual resources were shown to participants to encourage discussions about what makes an effective public-facing resource.

The workshops lasted 90 minutes, and participants were provided with a £50 incentive for taking part.

Digitally disengaged interview method

For Stage 3, in-person interviews were conducted with digitally disengaged participants in their homes. Conducting the interviews in-person ensured that participants could review the stimulus with the moderator and be actively involved in the co-design process, which would be harder to achieve over the telephone.

The interviews lasted 60 minutes, and participants received a £50 incentive for taking part.

Discussion guide and stimulus

A discussion guide with a semi-structured format was created to guide the workshops and interviews. The guide covered the following sections:

- Reflections on the previous workshop/interview
- Discussion of example public-facing resources
- Structure preferences for the co-designed resource
- Content preferences
- Language preferences
- Preferences around presentation and visual style

The discussion guide was supported by stimulus material. The stimulus included: examples of existing public-facing visual resources, draft structure ideas, and three versions of a draft resource poster about GP record data. This stimulus material was used to support the co-design process, as it enabled participants to critique existing materials, and use them as a platform to voice what the final co-designed resource should include.

A full version of the discussion guide and stimulus can be found in the Appendix document.

Analysis

As with the Stage 2 findings, the qualitative team employed a thematic analysis approach to the data. The first step was to individually create transcripts of the online workshop and interview recordings, identifying key themes and areas of consensus amongst participants. Following this individual analysis, the team came together to share, debate, and finalise their key takeaways in a collaborative analysis session.

Resource production

Following the analysis process, the key takeaways from the co-design workshops and interviews were used to produce a public-facing information resource explaining the key facts that people want to know about GP record data.

This report will set out our key takeaways from the co-design process, which were used to produce the final information resource.

5. Findings: Stages 1 & 2

This section covers the findings from Stages 1 and 2 of the research, which aimed to explore public understanding of, views, and expectations towards GP record data, as well as information needs and preferences. The quantitative and qualitative findings are combined under different overarching topic sections.

Section 1: Contents and storage of GP records

Levels of awareness about the information held in the GP record

Survey respondents were provided with a brief explanation of data held in the GP record:

'*As part of your normal contact with your GP surgery, data is collected about you and your health and entered into your GP record. The data from your GP record can be used for your care, as well as for research and other purposes in the NHS such as helping to plan and evaluate health services'.*

Following this explanation, survey respondents were asked what information they think is available in their GP record.

43% selected *'All of the above',* incorrectly believing that all the information listed is included in the GP record. In the table overleaf, respondents who selected '*All of the above'* have been included in the proportion of respondents who selected each type of information.

The table below also highlights the types of information that are not typically held in a patient's GP record (shown in red), highlighting some gaps in respondents' knowledge about what is typically collected their GP record. It is possible that some additional information e.g. communication or access needs might be noted by some GP surgeries, but not consistently or routinely collected and coded. As GP records also contain free text, information not included below may also be found in free text, which is harder to analyse and compare.

Q1. What information do you think is available in your GP record? Select all that apply	**%**
Illnesses and diagnoses	88%
Medicines	87%
Vaccinations and immunisations	86%
Test results, x-rays and scans	83%
Contact details	83%
Examinations and investigations	82%
Allergies	77%
Operations	76%
Notes from appointments at the surgery	76%
Height and weight	76%
Demographic information (e.g., your name, date of birth, ethnicity)	76%
Notes about appointments in other NHS settings (e.g., hospital appointments)	70%
Letters from other medical staff	64%
Lifestyle information (e.g., smoking, drinking, exercising)	63%
Communication preferences (e.g., not English as first language, visually impaired, needs large font communications)	**60%**
Accessibility requirements (e.g., wheelchair user)	**54%**
Notes from a non-NHS clinical setting (e.g., private GP, non-NHS mental health counselling)	**52%**
None of the above	**3%**
Other (please specify)	<1%
Base: 1104	

Respondents generally assumed that any information directly related to their medical care (such as '*Illnesses and diagnoses*', '*Medicines*', and '*Vaccinations and immunisations*') and their contact details are held in their GP record, with a strong majority selecting these options.

Not all survey respondents selected these options, which could be explained by the framing of the question. Respondents were asked *'What information do you think is available in your GP record?'*, suggesting that the respondents who did not select responses such as *'Illnesses and diagnoses'* may not have thought that this information is held in their personal GP record. Therefore, this does not necessarily mean that these respondents are not aware that this information can be collected and stored in patients' GP records.

Interestingly, respondents were less likely to select the 'incorrect' options (such as '*Communications preferences*'), although a majority of respondents did select each of these options (60%, 54% and 52%) excluding *'None of the above'*.

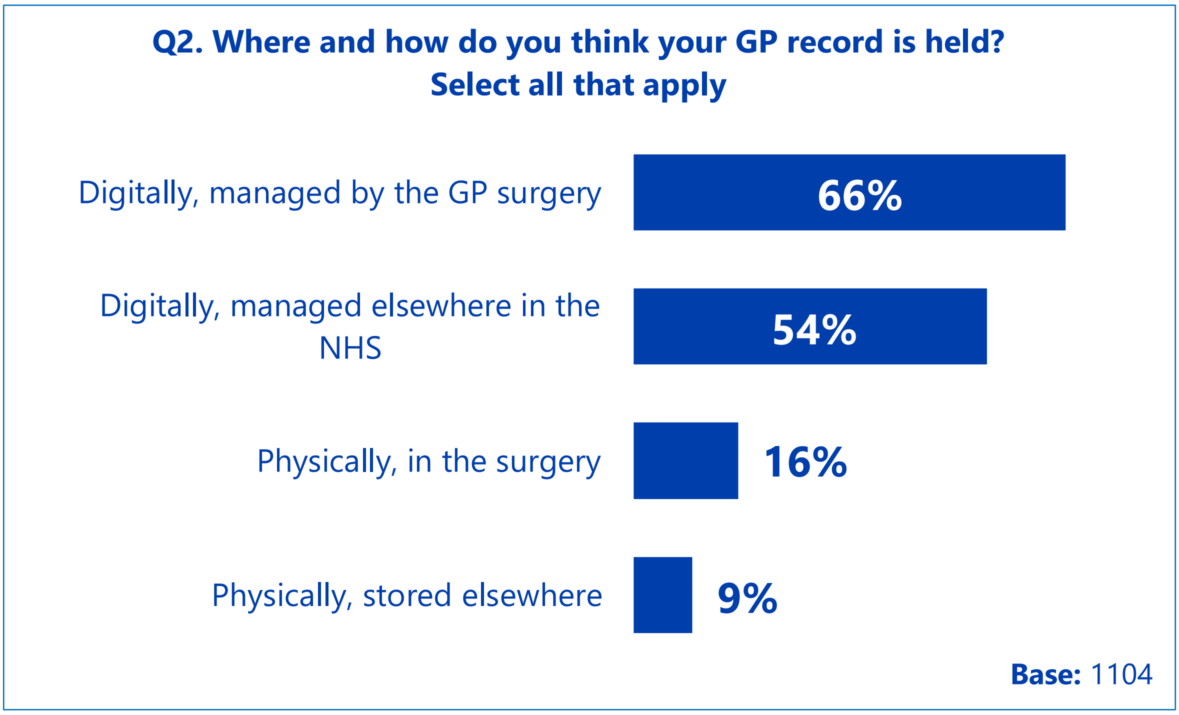
A similar set of findings emerged from the qualitative insight. In the workshops and interviews, participants were shown a list of the different types of information collected and held in the GP record. Whilst they were not always aware of the specific types of information collected, they generally expected information about a patient, their health and their lifestyle to be collected and held in their GP record.

> *"There's nothing there that's a surprise…that's pretty much the information that I thought would be stored" – Group 2, Pre-family*

In almost all cases, the types of information collected matched their pre-existing assumptions. Participants questioned whether other types of information, such as family history, labour/birth records and occupation, could be collected and held in the GP record in a standardised way.

Levels of awareness about how GP records are stored

When asked where and how they think their GP record is held, almost all survey respondents expected their record to be held digitally (95% selected one or both of '*Digitally, managed by the GP surgery*' and '*Digitally, managed elsewhere in the NHS*').

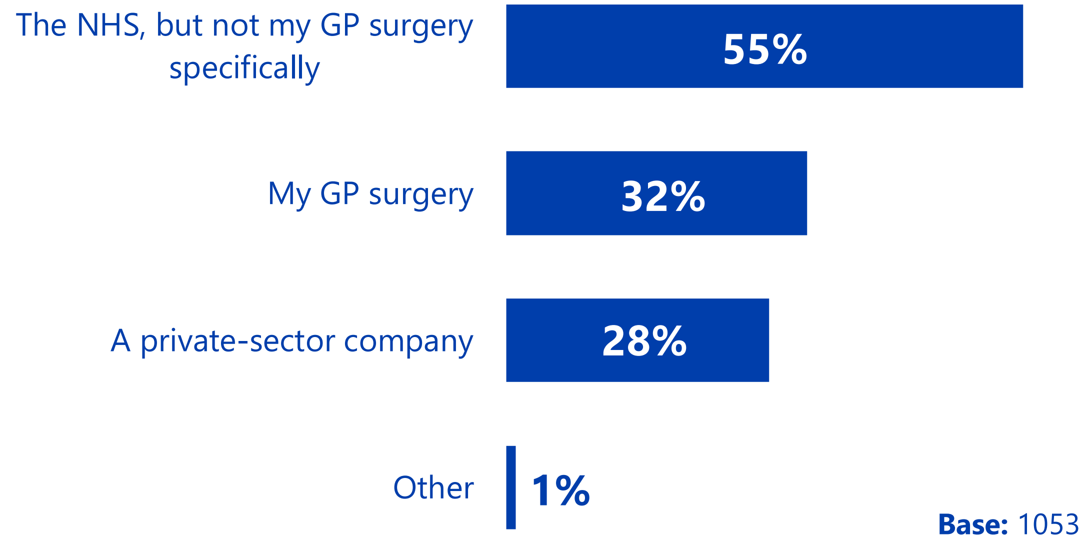


As the chart above shows, there was low awareness of who is responsible for managing GP records. Whilst the most commonly selected option was '*Digitally, managed by the GP surgery*' (66%), over half incorrectly selected '*Digitally, managed elsewhere in the NHS*' (54%).

Most respondents expected their GP record to be held digitally, with 79% only selecting a digital method of storage (one or both of '*Digitally, managed by the GP surgery*' and '*Digitally, managed elsewhere in the NHS*'). A small proportion (5%) only selected a physical method (one or both of '*Physically, in the surgery*' and '*Physically, stored elsewhere*'). Whereas, 17% selected a mixture of digital and physical methods.

Respondents who selected at least one of '*Digitally, managed by the GP surgery*' and '*Digitally, managed elsewhere in the NHS*' (n=1053) were then asked who they think provides the computer systems that GPs use to manage and store patient records, as shown in the chart overleaf.

Q2a. Who do you think provides the computer systems that GPs use to manage and store patient records? Select all that apply

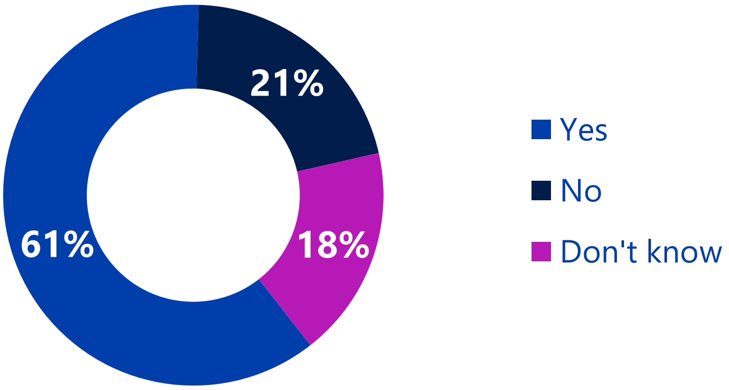


Base: 1053

Just over a quarter (28%) of respondents correctly selected '*A private-sector company*'. This suggests there are low levels of awareness around who is responsible for providing the computer systems that GPs use to store records, with a majority (55%) expecting the NHS to provide these systems. It should be noted that, whilst private-sector companies do provide the computer systems, these systems have to meet NHS requirements and be approved by NHS England, so the NHS do have a level of involvement in this process.

Survey respondents were then asked if they thought that, alongside the GP record, there is a single national healthcare record, containing all the data collected about them by the NHS.

Q3. Alongside the GP record, which contains data collected by your GP, do you think there is a single national healthcare record which contains all the data collected about you by the NHS?



Base: 1104

A majority of respondents (61%) incorrectly believed the NHS held a single national healthcare record containing all the data collected about them. Less than a quarter of respondents (21%) correctly answered '*No*', with a sizeable proportion (18%) selecting '*Don't know*'. This suggests that levels of awareness surrounding the storage and management of patient records are low.

This might reflect situations where respondents have experienced their data being shared across care settings for their medical care, which could be the result of the use of local Shared Care Records or the Summary Care Record.

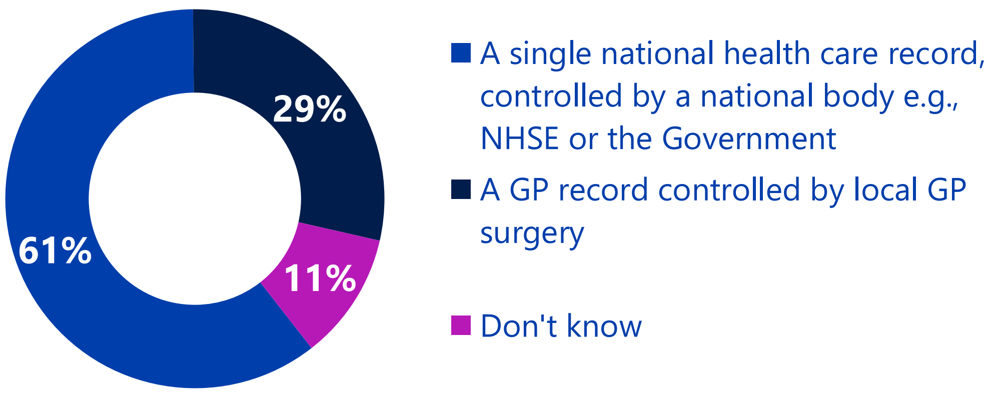
Furthermore, discussions in the workshops uncovered that participants tended to perceive the NHS as a single organisation. This may also help to explain why people expect the NHS to hold a single national healthcare record about them.

The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. Younger people, men, and people from a minority ethnic background were more likely to incorrectly assume there was a single national healthcare record.

Q3: Is there a single national healthcare record?	**Yes**	**No**	**Don't know**
Age			
18-34	**76%**	14%	11%
35-54	**65%**	**21%**	15%
55+	54%	**24%**	**22%**
Gender			
Female	58%	22%	20%
Male	**64%**	20%	16%
Ethnicity			
White ethnic background	60%	21%	**19%**
Minority ethnic background	**68%**	21%	11%
Social grade			
ABC1	62%	**25%**	13%
C2DE	59%	18%	**23%**
Base: 1104			

Respondents were then asked whether they would prefer for the data collected by their GP to be stored in a single national healthcare record controlled by a national body, such as NHS England or the Government, or a GP record controlled by their local GP surgery. Currently, the data collected about a person and their health by their GP surgeries is stored in a GP record controlled by their local GP surgery.

Q4. For the data collected about you by your GP, would you prefer it to be stored in:



Base: 1104

As the chart above shows, respondents were more likely to prefer for the data collected about them by their GP to be stored in a single national healthcare record controlled by a national body (61%) compared to their GP surgery (29%).

The table below shows any statistically significant differences between demographic groups on this preference, highlighted in blue. Male respondents, respondents from social grades ABC1, and those who completed the survey online (and were therefore digitally engaged) were more likely to prefer their data to be stored in a single national healthcare record.

Q4: Where would you prefer data to be stored?	**Single national record**	**GP record**	**Don't know**
Age			
18-34	66%	29%	5%
35-54	63%	27%	**10%**
55+	57%	30%	**13%**
Gender			
Female	57%	31%	21%
Male	**65%**	26%	9%
Social grade			
ABC1	**69%**	24%	8%
C2DE	51%	**34%**	**14%**
Method of participation			
Online	**62%**	28%	11%
CAPI	50%	37%	13%
Base: 1104			

Respondents were then asked to explain their answer to Q4. For those who preferred '*A single national healthcare record, managed by a national body*', the main reasons (shown in descending order of popularity) were:

- Easier access to patient data for different NHS services to provide medical care and treatment
- A central database would keep data safe and secure
- More efficient to store data in one central database, rather than in separate records
- Expectation that this is how their data is currently stored

For those who preferred '*A GP record controlled by your local GP surgery*', their reasons (shown in descending order of popularity) were:

- Safer and more secure than a national healthcare record, with less risk of data leaks or breaches

- Trust in their local GP
- Prefer their data to be stored and accessed at a local level
- Expectation that this is how their data is currently stored
- Enables privacy as the record contains personal information

The qualitative findings echoed the survey results and shed more light on perceptions surrounding the storage of GP record data. In the workshops and interviews, moderators explained that different NHS organisations, such as hospitals or mental health services, hold their own records, which contain data about a person and their health collected when they interact with the organisation. It was explicitly stated that there is no single national healthcare record containing all the information collected by NHS organisations in one place.

Knowledge that there isn’t one single national healthcare record varied widely amongst participants. Some respondents already knew or had assumed that there was not one. However, many had expected that there would be one overarching healthcare record that stretches across the NHS, and many expressed a preference for this method of storage as it seems more efficient.

> *“There should be a centralised record, and then, depending on the needs of that department or provider or whatever, they should be able to access different levels within that record.” Group 3, Family*
>
> *“You would think there would be one system that you could access under one umbrella, because I assume different formats and different systems are used by different sides of the NHS, you would think there'd be just one function that if you did need to access something different, you'd be able to get it without having to request it as such.” Group 1, Pre-family*

Speaking from personal experience interacting with different NHS services, some participants were frustrated about the lack of a centralised healthcare record.

“My dad's got cancer, and we've been around various hospitals…you show up at one, and then you go through a test at somewhere else, and they know nothing about it, so they then have to ring the other hospital to get them to send all the information…I just find it bizarre.” Group 4, Family

For a few groups, there was some unease about separate health records, as it caused concern that different health services wouldn’t have access to the information from their GP record, for example, in an emergency. Although there are summary care records and share records in place for this reason and it was explained that information from the GP record may be accessed by some NHS services for individual care, it is worth bearing in mind for any future information resources. When people hear that their data is stored in separate record, rather than a central database, there is a risk that they assume that this means that different NHS services cannot access any of this data for their individual medical care.

Additionally, it is important to note that this discussion around data storage revealed the common misconception that the NHS is a single entity, rather than a collective of different providers, which contributed to their surprise that the NHS does not hold a single national healthcare record.

Moderators also explained that GP surgeries use digital systems to collect and store information in a patient’s GP record, and that, in some cases, GP records can be stored physically where patient information was historically collected in paper records. Aligning with 95% of survey respondents who expected their GP record to be held digitally, participants expected their GP record to be stored on an online system. They have seen their GP enter their information on a computer during their appointment. Therefore, there was some surprise that GP surgeries may still hold paper records.

“It's crazy that some records are still held on paper. To me, it just seems insane.” Group 3, Family

Some older participants recalled their GP using paper records in the past, but were aware that their information is now collected and held digitally.

For some groups, these discussions about data storage near the start of the session led into conversations about data security, indicating how important this is to participants.

> *"The GP may own our data, but we are the data. And I think that if corporate entities are handing over cash for a part of us, I think we should know who's getting it and for what purposes, and then we can make a decision." Group 6, Post-family*

This conversation about data security was also centred around the digital systems used to store GP records. Participants were surprised to find that the digital systems used by GP surgeries are supplied by private IT companies approved by NHS England. As with the survey respondents (*see Q2a*), most expected the NHS, rather than private companies, to supply the digital systems used to store GP records. There was some trepidation amongst a few participants about private IT companies having access to private information, and some were concerned that this would increase the risk of data misuse or breaches.

> *"I'm just very cynical about private organisations with large amounts of very confidential data." Group 5, Post-family*

Whilst they were informed that NHS England must approve these companies, some participants also felt they should be made aware whether these private companies have access to the information held on the systems they provide, and the security measures in place to protect their data.

> *"But I guess the important thing is that you know how, to what extent they can use that information, presumably not at all, but they're just, you know, processing the data and setting up the systems, I guess maintaining the systems. But I suppose that's the main concern, where that information goes beyond that." Group 2, Pre-family*

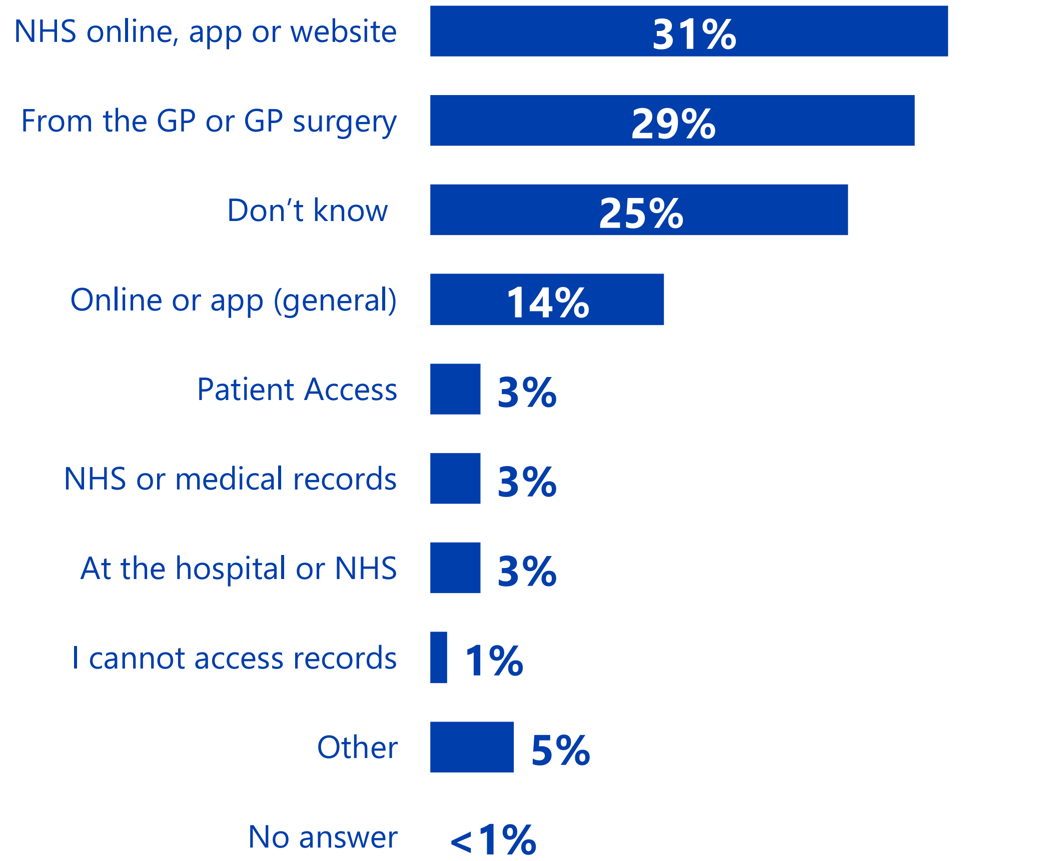
The emphasis placed on data security suggests that it will be an important area for inclusion in any information resources, especially when explaining how GP records are stored. The involvement of private IT companies in providing GP surgeries with online storage systems is an emotive topic and would need to be explained with care, clearly setting out whether this companies can access personal information.

Section 2: Accessing the GP record

Awareness of how to access the GP record

Survey respondents were asked where they think they can find and see their own GP record in an open response question. The verbatim answers given have been coded and grouped together, as shown in the chart below.

Q6. Where do you think you can find and see your own GP record?



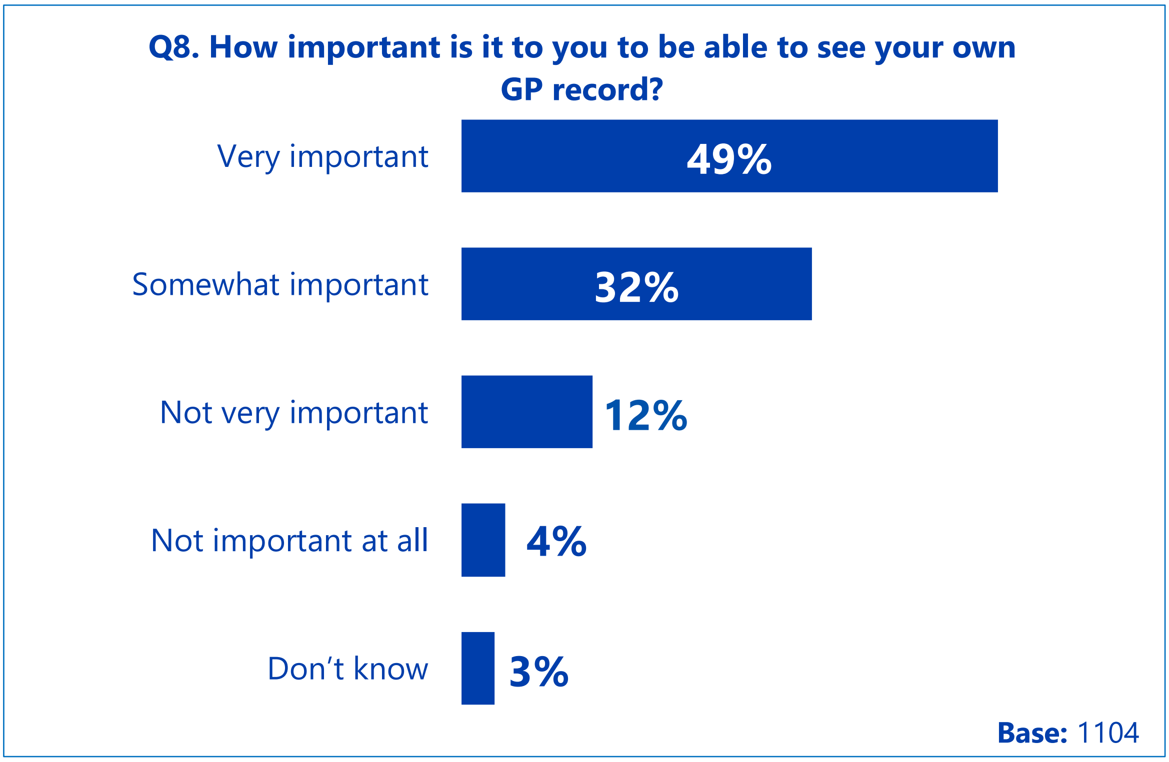
Base: 1104

Respondents were most likely to think that they could access their GP record via '*NHS online, app or website*' (31%) or '*From the GP or GP surgery*' (29%). A quarter of respondents (25%) answered '*Don't know*', suggesting that a sizeable proportion of the population are not aware of how to access their own GP record.

When asked whether they had ever seen their GP record, more than half (56%) of respondents said they had. A large minority (43%) stated that they had never seen their GP record.
Those who had seen their GP record were most likely to have accessed it on the NHS App (37% of respondents selected this option).

Q7. Have you ever seen your GP record?	%
Net - Yes	56%
No	43%
Don't know	1%
Yes, on the NHS App	37%
Yes, on my GP's website	13%
Yes, on the NHS website	10%
Yes, by specifically requesting some or all of my records from my GP surgery	8%
Yes, asked my GP surgery for the information	7%
Yes, on a third party health app e.g., Patient Access, MyGP, Evergreen Life	5%
Base	**1104**

When asked how important it is to be able to see your own GP record, 81% of respondents stated that it was '*Very important*' or '*Somewhat important*' (49% and 32% respectively).



The table below shows any statistically significant differences between demographic groups in whether accessing their GP record was important, these are highlighted in blue. Those from younger age groups, minority ethnic backgrounds, social grades ABC1 and those who completed the survey online (and were therefore digitally engaged) were significantly more likely to state that it is '*Very important*' or '*Somewhat important*' to be able to see their own GP record.

Q8: How important is it to see your GP record?	Net - Important	Net - Not important	Don't know
Age			
18-34	**94%**	6%	1%
35-54	82%	**15%**	3%
55+	77%	**19%**	4%
Ethnicity			
White ethnic background	80%	**17%**	3%
Minority ethnic background	**89%**	8%	3%
Social grade			
ABC1	**85%**	13%	2%
C2DE	76%	**20%**	**4%**
Method of participation			
Online	**83%**	15%	3%
CAPI	64%	**28%**	8%
Base: 1104			

The table below shows the responses to Q8 split by whether respondents said that they had seen their GP record (Q7). Statistically significant differences are highlighted in blue.

Q8 (importance of seeing record) vs Q7 (seen GP record)	Yes - seen GP record	No - not seen GP record	Don't know
Very important	**66%**	30%	21%
Somewhat important	29%	34%	50%
Not very important	4%	**21%**	14%
Not important at all	0%	**10%**	-
Don't know	1%	**6%**	14%
Base: 1104			

As we might expect, those who have seen their GP record are significantly more likely to think it is important to see their record (66% of those who have seen their record stated that it was *'Very important'* compared to 30% of those who had not seen their record). However, it is important to note that almost two-thirds (64%) of those who have not seen their GP record think that it is either '*Very important*' or '*Somewhat important*' to be able to see their GP record (30% and 34% respectively).

Respondents were then asked to explain why viewing their GP record was important or unimportant. For those who stated it was '*Very important*' or '*Somewhat* *important*', the verbatim reasons given covered the following categories (in descending order of popularity):

- Useful to see medical information, e.g. medication or test results
- To ensure their record is accurate and up to date
- It contains personal information
- They have a right to see information collected about them

For those who stated it was *'Not very important'* or *'Not important at all'* to be able to see their own GP record, the verbatim reasons given covered the following categories (in descending order of popularity):

- No reason or need to see their record
- Trust their GP to update and maintain their record accurately
- Already know what information is likely to be held in the record

At the qualitative stage, there was a mixture of participants who had accessed their GP record and those who had not. Many of those who had not accessed their record were simply not aware that they could. Those who had seen their record had either accessed it through the NHS App, a third-party app like Patient Access, or were shown it by healthcare staff in their GP surgery.

Likewise, there was a mixture of participants who felt they knew how to access their GP record and those who did not. There was a consensus, however, that patients should be told how to access their GP record so they can access and check information about their health.

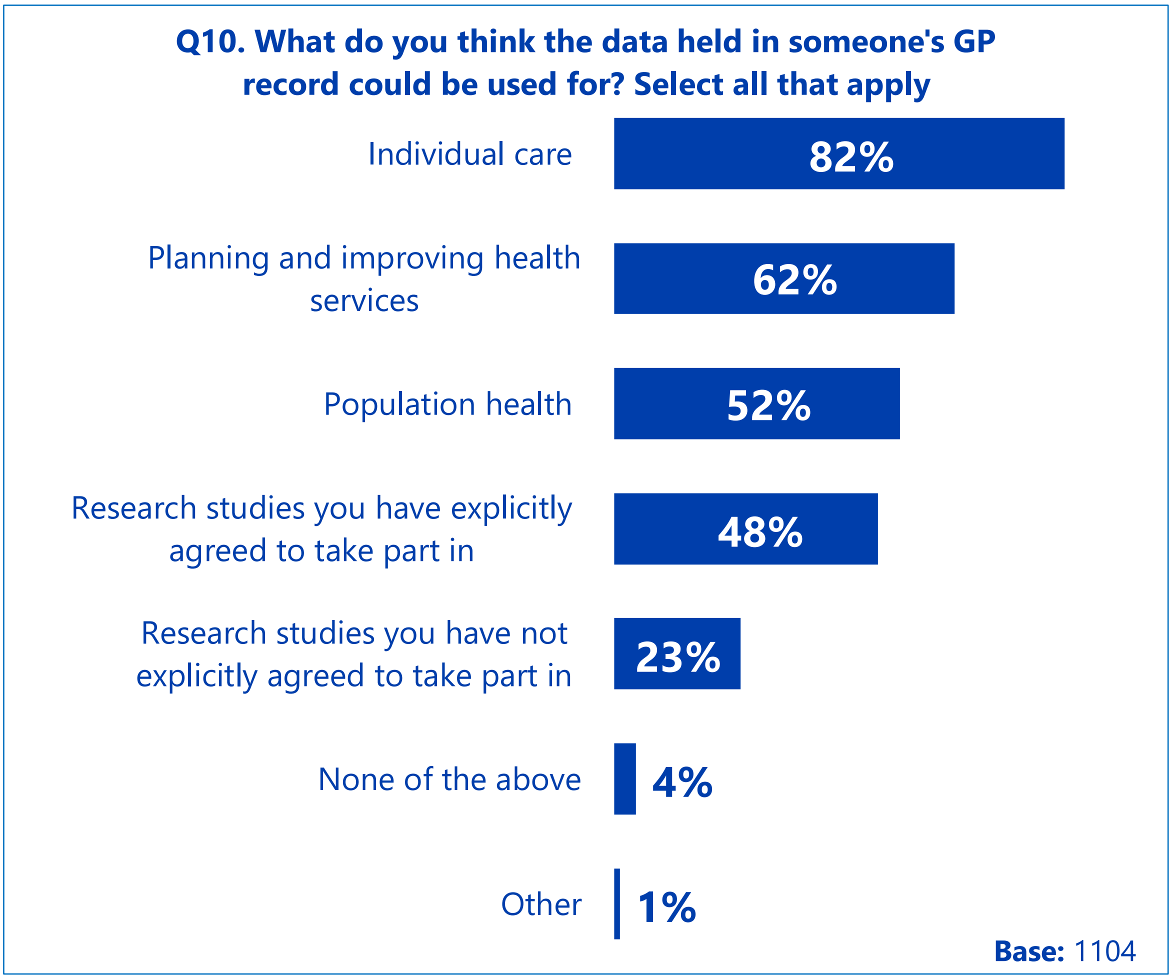
> *"I would [like to know how to find my GP record], yeah. I had no idea you could get so much information…I would like to know a bit more about what they're holding." Group 5, Post-family*
>
> *"It'd be good to check up see and what I've had. You know? I think the vaccinations is a good one, especially going away a lot. It's definitely a handy tool to know." Group 2, Pre-family*

Regardless of whether they had previously accessed their record, the findings from both stages of the research suggest that, in general, members of the public want to know how they can access their GP record. This suggests that it needs to be easy for members of the public to access their own GP record, and that a clear explanation of how to access the GP record needs to be clearly communicated to the general public.

Section 3: Sharing and using GP record data

Awareness of uses of GP record data

Survey respondents were reminded of the types of data that are collected and held in the GP record, and asked what they thought the data held in someone's GP record could be used for. They were provided with a list of different use cases, and each use case was accompanied by a broad example for clarity (e.g. '*Population health – e.g., used to understand the needs of groups of people based on things they have in common like age or ethnicity and target health services to these groups*').



As the chart above shows, awareness of the different use cases for GP record data is mixed. Most respondents (82%) were aware that GP record data could be used to provide a person with individual medical care. Whereas, they were less likely to identify '*Planning and improving services*' (62%), '*Population health*' (52%), '*Research studies you have explicitly agreed to take part in*' (48%) and '*Research studies you have not explicitly agreed to take part in*' (23%).

Responses varied by demographic group:

- **Age:** Older people were more likely to be aware of the different use cases for GP record data:
    - 87% of those aged 55+ selected '*Individual care*', compared to 72% of 18-34 year olds and 80% of 35-54 year olds
    - 59% of those aged 55+ selected '*Population health*', compared to 40% of 18-34 year olds and 48% of 35-54 year olds
    - 54% of those aged 55+ selected '*Research studies you have explicitly agreed to take part in*', compared to 39% of 18-34 year olds and 44% of 35-54 year olds
    - 25% of those aged 55+ selected '*Research studies you have <u>not</u> explicitly agreed to take part in*', compared to 17% of 18-34 year olds
- **Gender**: Male respondents were more likely to be aware of several uses:
    - '*Planning and improving services*' (67% male vs 57% female)
    - '*Research studies you have explicitly agreed to take part in*' (51% male vs 45% female)
    - '*Research studies you have <u>not</u> explicitly agreed to take part in*' (27% male vs 19% female)
- **Ethnicity**: Those from a White ethnic background were more likely to be aware of certain use cases:
    - 84% selected '*Individual care*' compared to 72% of those from a minority ethnic background
    - 54% selected '*Population health*' compared to 43% of those from a minority ethnic background
    - 49% selected '*Research studies you have explicitly agreed to take part in*' compared to 40% of those from a minority ethnic background
- **Social grade:** Those from social grades ABC1 were more likely to be aware of certain use cases:
    - 69% selected '*Planning and improving health services*' compared to 54% of those from social grades C2DE
    - 58% selected '*Population health*' compared to 47% of those from social grades C2DE
    - 53% selected '*Research studies you have explicitly agreed to take part in*' compared to 43% of those from social grades C2DE

In the workshops and interviews, a key area of concern was how the information from their GP record is used for purposes beyond individual medical care. When asked, without prompting, what they would like to know about the topic of GP record data, many participants spontaneously said they wanted to know who has access to data from their record, and for what purposes, due to worries that their data could potentially be shared with non-NHS third parties for profit or for uses that they disagree with.

> *"I would want to know what sort of bodies [can access information from my GP record] and what they're going to be doing with my data" Digitally disengaged interview*

Across the workshops and interviews, it was assumed that information in a person's GP record would be shared with different NHS services to help provide them with better individual medical care. Whereas participants were not aware that information from a person's GP record can be used for other specific purposes beyond individual care, such as population health, planning and improving services or health research.

Whilst levels of awareness around the specific uses for GP record data were low, when participants were shown the different uses, they were generally seen as plausible and acceptable. These uses met their expectations for how their data might be used, even though they were not aware of these specific use cases before the session.

The findings from the workshops and interviews suggest that how GP record data is used, and by whom, is a key area of interest for members of public, and an area where levels of understanding are low.

Accessing GP record data for individual medical care

Survey respondents were informed that information held in their GP record is used for their individual medical care. They were then shown a list of healthcare staff and asked who, within their GP practice, they think has access to their GP record for the purpose of providing individual medical care.

In reality, all of these healthcare staff have some degree of access to patient's GP records dependent on their role. For example, a receptionist will be able to access some information which they need to do their job and help patients get the care they need.

Q11. Who within your GP practice do you think currently has access to your GP record for the purpose of providing you with medical care, diagnosis or treatment?

Base: 1104

As the chart shows, most respondents expect all GPs and nurses in their GP practice to be able to access their GP record for the purposes of providing individual medical care. They are less likely to be aware that receptionists or administrative staff in their GP practice can access some of the information from the GP record, in order to support a person's medical care.

Respondents were then shown the same list of healthcare staff and were asked who they would be comfortable with having access to their GP record for the purpose of providing individual medical care.

Q12. Who within your GP practice would you be comfortable with having access to your GP record for the purpose of providing you with medical care, diagnosis or treatment?

Base: 1104

There was a correlation between who respondents thought already had access and who they were comfortable having access to their GP record for the purposes of individual medical care. Most respondents were comfortable with GPs and nurses in their practice having access to their record, whereas less than half (40%) were comfortable with receptionists or administrative staff having access.

Responses varied by demographic group:

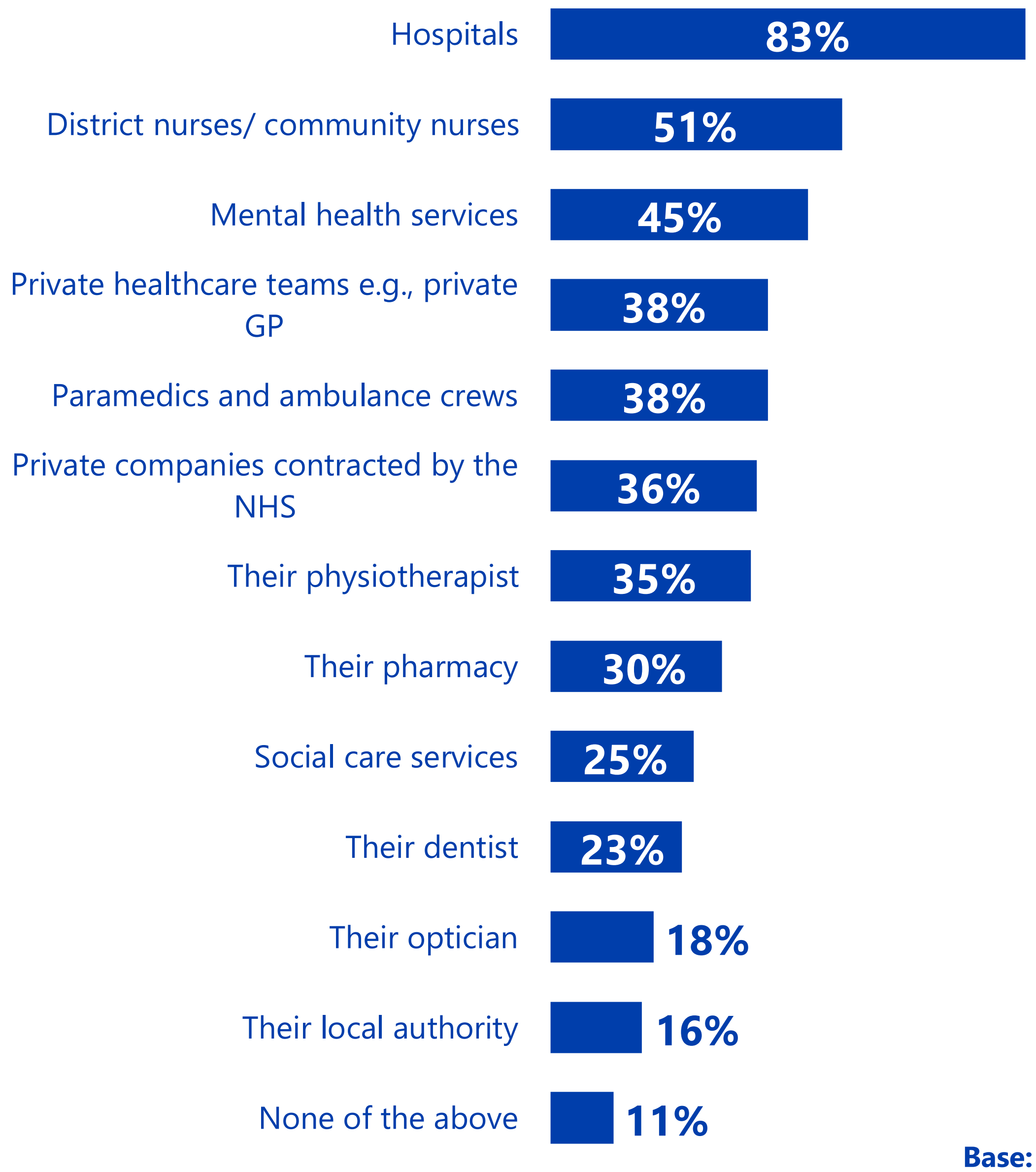
- **Age:** Older people were more likely to be comfortable with different healthcare staff within their GP surgery having access to their GP record for the purpose of providing medical care:

  - 98% of those aged 55+ selected '*My named GP*' compared to 93% of 18-34 year olds
  - 93% of those aged 55+ selected '*Any GP in my surgery*' compared to 83% of 18-34 year olds and 85% of 35-54 year olds
  - 89% of those aged 55+ selected '*Nurses in my surgery*' compared to 79% of 18-34 year olds and 81% of 35-54 year olds
- **Ethnicity**: Those from a White ethnic background were more likely to be comfortable with healthcare staff beyond their named GP having access to their GP record for the purpose of providing medical care:
  - 97% selected '*Any GP treating me*' compared to 88% of those from a minority ethnic background
  - 91% selected '*Any GP in my surgery*' compared to 79% of those from a minority ethnic background
  - 87% selected '*Nurses in my surgery*' compared to 68% of those from a minority ethnic background
  - 76% selected '*Other healthcare staff in my surgery*' compared to 62% of those from a minority ethnic background

Who has access, from outside the GP practice, for individual medical care

Respondents were then asked who, outside their GP practice, they think has access to information from a person's GP record for the purpose of providing them with individual medical care.

Q13. Who outside of the GP practice do you think currently has access to information from a person's GP record for the purpose of providing medical care, diagnosis or treatment?



Base: 1104

Most respondents (83%) expected '*Hospitals*' to have access to information from a person's GP record to help provide them with individual medical care. Around half expected '*District nurses / Community nurses*' (51%) and '*Mental health services*'

(45%) to have access. A smaller number of people thought healthcare services, such as pharmacies (30%) and dentists (23%) have access.

It is also worth noting that 11% of respondents did not think that any of these organisations have access to information from the GP record. The mixed response to this question suggests that there is confusion about which organisations from outside the GP practice can access information from a person's GP record for individual medical care.

In the workshops and interviews, the topic of how organisations access GP records for individual medical care was discussed with participants. Moderators explored interest in the topic, and what, if any details, participants wanted to know about.

In the digitally disengaged interviews, some participants already assumed that GP record data is shared with different health services across the NHS. Therefore, this was not a topic they were particularly interested in finding out more about. Whilst they were not necessarily aware who, from within the NHS, specifically could access their GP record to provide them with better care, they generally trusted their data to be used appropriately for their treatment.

Similarly, in the workshops, most expected that key information from their GP record, such as allergies or prescription information, would be shared with different NHS services to help them provide medical care and treatment. When moderators explained that systems for sharing data (e.g. GP Connect) exist, participants stated that this met their assumptions, and they were reassured by this in the case of an emergency.

> *"I think it's good, especially in terms of the paramedics. If someone's coming to your house…about like being allergic to something like penicillin or something, they'd know straightaway, especially if you weren't at capacity to talk properly." Group 3, Family*
>
> *"I think I assumed that there probably was something that did, that could do that because your doctor will send your prescription across to the pharmacy. I just assumed that there would be a system that linked everything together." Group 1, Pre-family*

A few concerns were raised, however, around the different levels of access that individuals and organisations within the NHS have to the GP record. Few were aware that there are protocols in place to prevent unauthorised access.

> *"You would hope that people that needed to within different parts of the NHS could [access GP record data] when necessary…at the same time, you don't want people accessing your records that don't need access to them." Group 1, Pre-family*
>
> *"I think I'd like to know whoever's needing my data, they can have access to what they need, and not just unlimited [data]…as long as they're getting what they need, and they're able to look at everything to help them make the right choices, then I'm happy with that. But how do I know if that is the case or not?" Group 4, Family*

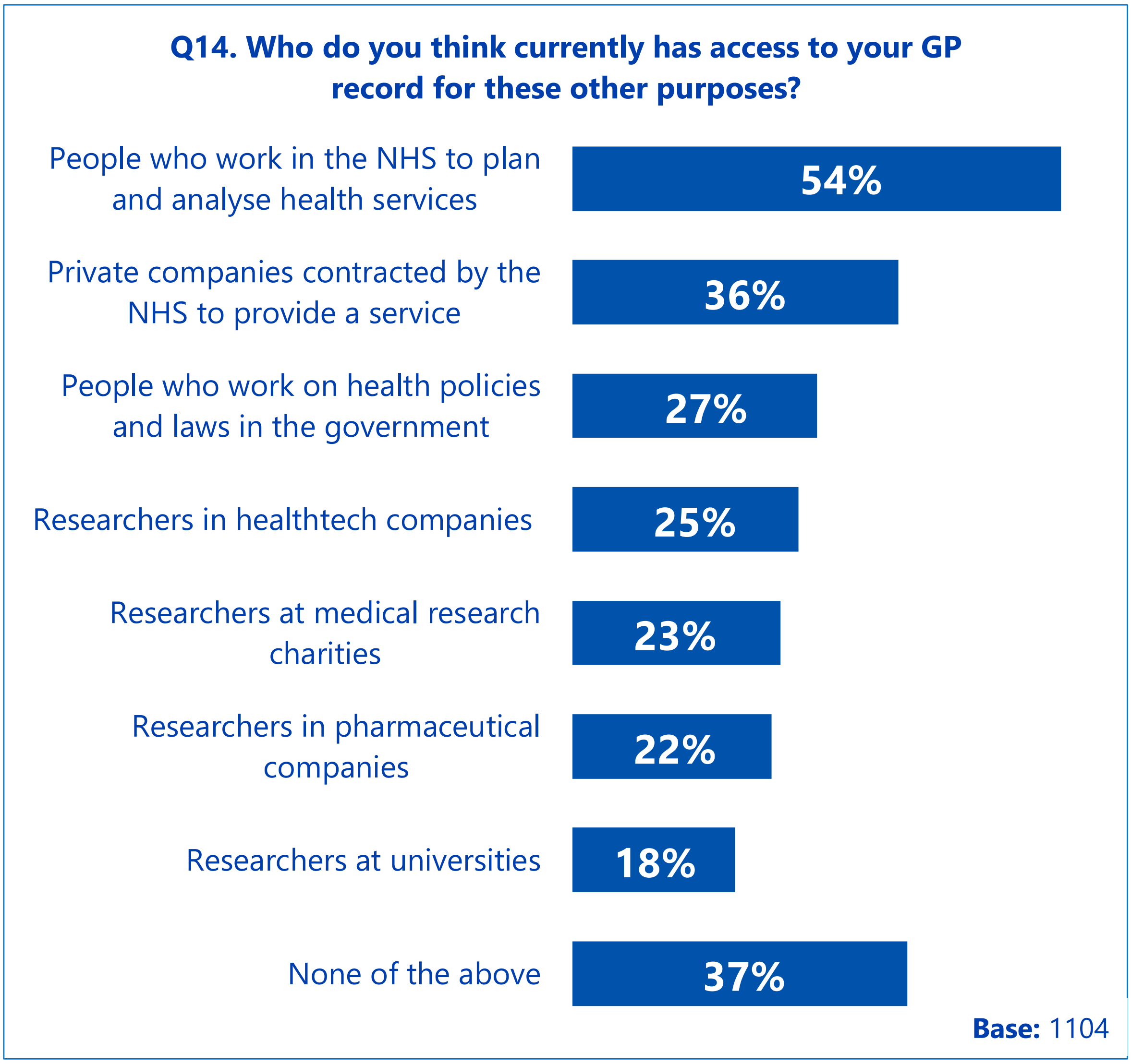
Participants generally did not express a need to be told much about NHS organisations accessing GP record data for individual care. Most expected their health information to be shared across NHS services to support their care, and the information presented to them confirmed their assumptions.

Who has access to GP record data for purposes beyond individual medical care

Survey respondents were informed that the data held in GP records can be used for other purposes beyond individual medical care. It was explained that GP record data can be used to help plan and analyse services, tailor NHS services to different groups of people, and support health research. The survey explained that:

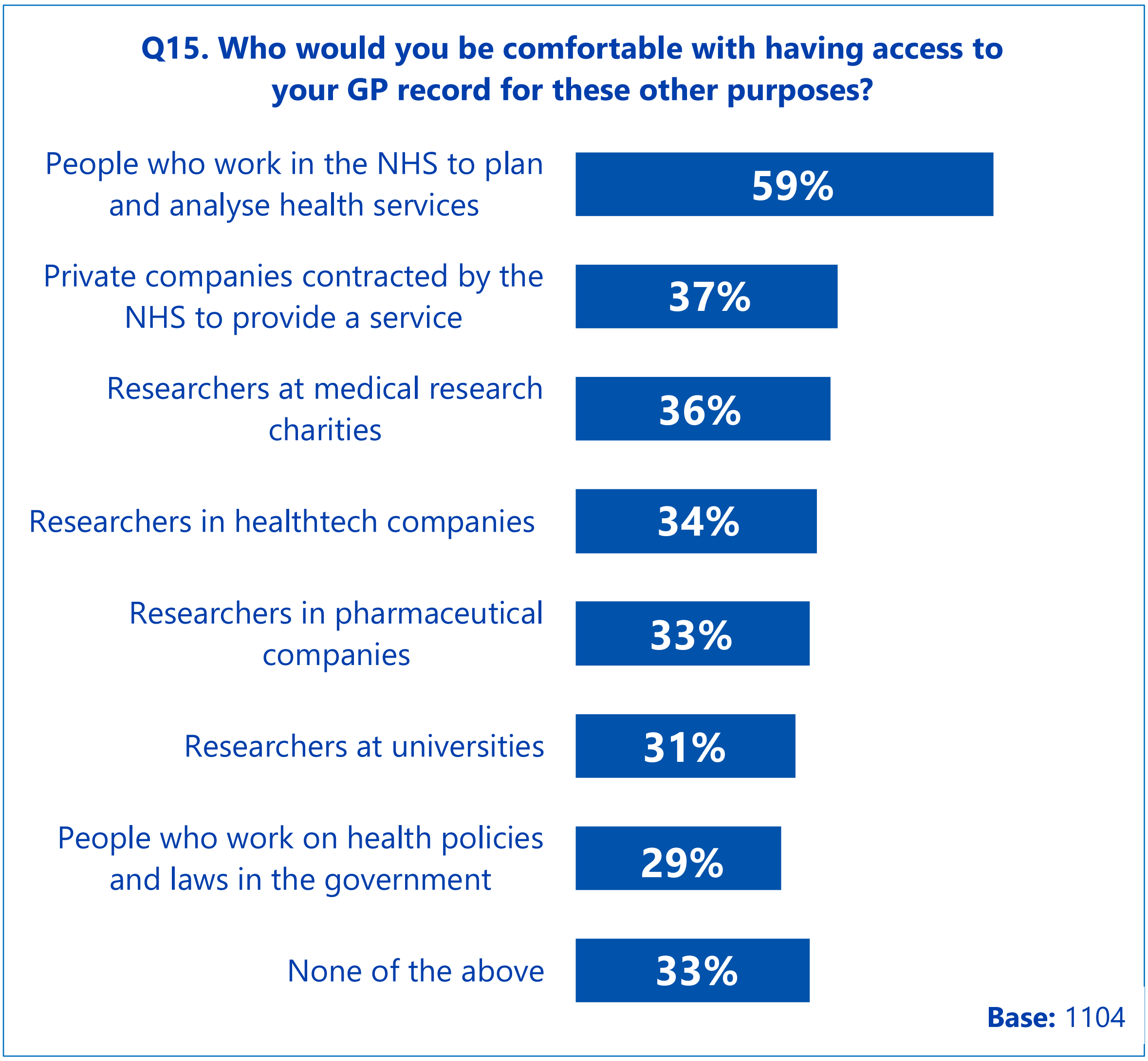
- GP record data is only used in specific circumstances
- Identifying details are removed in most cases
- Only the minimum amount of data needed is shared for these uses

Respondents were then asked who they think currently has access to their GP record for the purposes set out above.



As the chart above shows, awareness levels around who might be able to access GP record data for purposes beyond individual care are low. All of these organisations except *'Private companies contracted by the NHS to provide a service'* are typically able to request access to GP record data for secondary purposes (though it is important to note that those outside the NHS and government will have to request access to data for a defined project, such as for a research study, and this is subject to approval). More than half (54%) correctly identified that '*People who work in the NHS to plan and analyse health services*' can access some data, whereas less than a quarter correctly identified that researchers from a range of different organisations can request access to GP record data for research projects. Additionally, more than a third of respondents (37%) did not think that <u>any</u> of these organisations have access to GP record data for purposes beyond individual care, even after these purposes were explained.

Respondents were then shown the same list of organisations and were asked who they would be comfortable with having access to their GP record for purposes beyond individual medical care.


Q15. Who would you be comfortable with having access to your GP record for these other purposes?

Base: 1104

As the chart above shows, only '*People who work in the NHS to plan and analyse health services*' had a majority of respondents (59%) stating that they were comfortable with them having access for purposes beyond individual medical care. This option was the only one in which it was explicitly stated that they were part of the NHS. Additionally, a third of respondents (33%) were not comfortable with any of these organisations having access to their GP record. This suggests that any future communications will need to approach this topic with care and sensitivity, as people do not seem to be as comfortable with organisations from outside the NHS accessing their GP record data.

Responses varied by demographic group:

- **Age:** Younger respondents were more likely to be comfortable with different organisations having access to their GP record for purposes beyond their individual care:
    - Those aged 18-34 were significantly more likely to select any of these options, apart from '*Researchers at universities*'
    - Those aged 35-54 and 55+ were more likely to select '*None of the above*' (38% and 33% respectively, compared to 18% of 18-34 year olds)
- **Gender:** Those who identified as male were more likely to be comfortable with the following organisations having access:
    - '*People who work in the NHS to plan and analyse health services*' – 63% compared to 56% of respondents who identified as female
    - '*Researchers at medical research charities*' – 40% compared to 33% of respondents who identified as female
    - '*Researchers in pharmaceutical companies*' – 36% compared to 30% of respondents who identified as female
    - Those who identified as female were more likely to select '*None of the above*' (37% compared to 29% of male respondents)
- **Social grade:** Respondents from social grades ABC1 were more likely to be comfortable with different organisations having access:
    - Those from social grades ABC1 were significantly more likely to select any of these options, apart from '*Researchers at universities*' and '*Researchers at pharmaceutical companies*'
    - Those from social grades C2DE were more likely to select '*None of the above*' (39% compared to 28% of social grades ABC1)

Perhaps unsurprisingly, this topic provoked the longest discussion and most diverse reactions amongst workshop and interview participants. Due to concerns about data security and the perception that the GP record contains personal information, participants were keen to find out who has access to the data in their GP record and why. They wanted to know whether their personal information was being used for purposes they didn’t agree with (e.g. for profit), or if it was being shared with external organisations they opposed.

> *“If they were thinking of giving your records, i.e. to somewhere, which I perhaps was uneasy about, I’d probably like to know that” Digitally disengaged interview*
>
> *“It's such sensitive data, isn't it? [It] would be reassuring to know that it's only being shared with people who need it, and when it's necessary, when it's being shared, and why it's being shared, you just don't want your stuff to end up in the wrong hands” Group 2, Pre-family*

Initially, there was a mixture of awareness of how GP record data can be used for purposes beyond individual care, and who has access. Moderators explained that, for example, research organisations must apply for access to data from GP records for specific research projects. Some participants would have assumed that there is a certain level of access.

> *“To some degree I did [expect this], you see bulletins on the news, for example, massive increase in diabetes so they’ve obviously got that from somewhere, but when you outline it, it’s a bit, not shocking, but I didn’t sort of realise. At the same time, I obviously understand they get this information from somewhere, somehow.” Group 4, Family*

One theme that emerged was a clear hierarchy of purposes for sharing data with parties outside of the NHS. For example, any use that was seen to be ‘for the greater good’, such as planning and improving NHS services and treatments, was generally seen as acceptable.

> *“I think it was just good to know who’s accessing it. I guess it’s good to know that they’re using it for a good reason for their like, particularly Cancer Research, obviously, to help their research, or…for the greater good.” Group 2, Pre-family*

However, the distinction between medical research and third-party or commercial interests became of great importance again, with an example on a showcard about Cancer Research UK using data from GP records for medical research acting as a springboard into these concerns for one group.

> *"They're selling it, showing all the nice examples, you want to see underneath, what actually they're not sharing, without a doubt."*
> *Group 6, Post-family*

Another concern was around privatisation and companies with commercial interests having access or selling data. Whilst there was recognition that 'private' doesn't always equate to bad intentions, the idea of money changing hands caused concern, particularly if this was at a disadvantage to taxpayers and the NHS. That meant some participants wanted to know if GP patient data was sold, and if so, what happened to the money. Whilst this is not something that they would expect to see on a resource such as a poster or pamphlet, some participants thought that a publicly available list of companies with access would be useful.

Distinctions around worthy uses of data were present in the digitally disengaged interviews too.

> *"It just seems there's a lot of organisations and things that can access your [information] without your consent but if it's all for research, very good, that's fine…As long as it's safe, that's the thing, isn't it?" Digitally disengaged interview*

Several participants felt that they should have to give their explicit consent for their data to be used for purposes beyond their individual care.

> *"I do think, like other companies, they should have to ask us whether we're happy for that information to be shared for these purposes." Group 1, Pre-family*

The idea of ‘public good’ persisted in these workshops and interviews, as did concerns around third parties. Explaining these different use cases (planning, population health and research) often caused a major shift in perceptions. Many participants felt reassured by this top-level detail. They were content with knowing that their GP record data was only used for purposes which benefit patients (i.e. for the ‘public good’), rather than being sold or used for purposes they disagree with. This group would not necessarily need to know how their data is used, and by whom, in any greater level of detail than this.

“Speaking to you…I [now] know how my data is being used, which probably, I wouldn’t have any objection to them using it if it’s going to help somebody” Digitally disengaged interview

As mentioned, workshop participants were particularly interested in how data is kept secure. The information held in the GP record is perceived to be personal and private, which causes concern about who may have access to it and what level of information they have access to. With regards to other uses, there were some initial concerns about how data transferred outside of the NHS would be kept safe.

“Who are they sending it to? Which organisations? [I’d want to know] a bit more about what they’re using it for, and potentially how it’s stored, because all the things you see now on TV, there’s a lot of hacking, and there’s a lot of data being sent somewhere by accident” Group 1, Pre-family

Finding out about de-identified data also caused a major shift in perceptions across the workshops and interviews. The moderators explained that, in most cases, de-identified data is used for purposes beyond individual care, meaning that identifying details about a patient, such as their name or address, have been removed or disguised.

Learning that de-identified data is used in most cases was highly reassuring for many participants. In fact, for some participants who were originally concerned about who accessed their GP record, after finding out that this rarely includes personally identifiable information, were no longer concerned about this or felt they needed to know who their data was being shared with. For the majority of the participants, there was a perception that de-identified data removed the risk of their personal information being misused, leaked or lost, as long as appropriate safeguards remain in place.

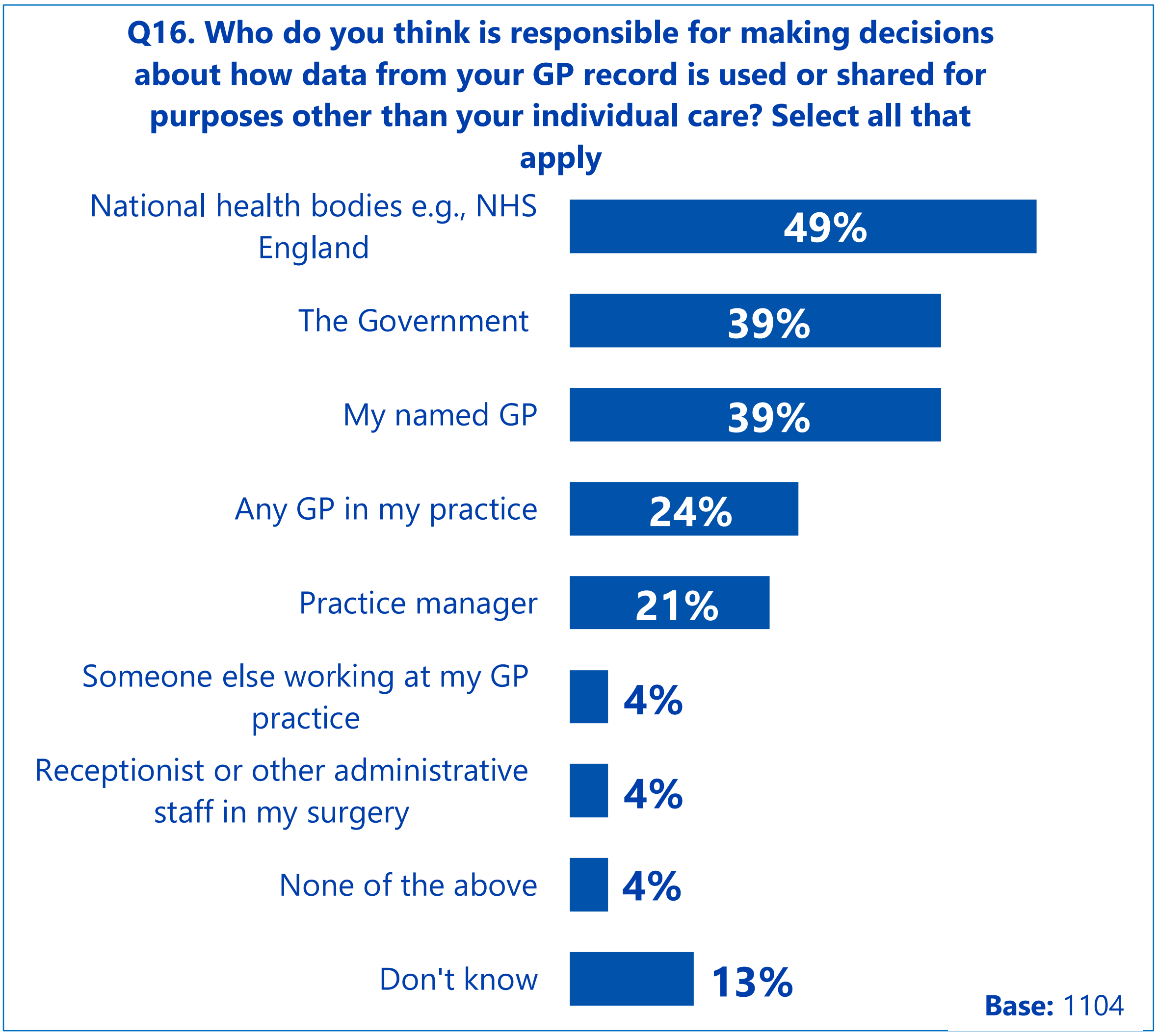
> *"If the data is de-identified I'm not really interested, I'll be honest…provided that there is a control there, and obviously a record is kept." Group 6, Post-family*
>
> *"It seems like people will benefit from having that information, and also it's de-identifiable anyway, so it's not really necessarily that something would come back with my name on it." Group 2, Pre-family*

When explaining the key facts about GP record data, the fact that de-identified data is used in most cases should be communicated very clearly to the public, as it provides a key piece of context, which answers people's concerns about how their personal information is used and shared. The perception that using de-identified data removes all risk may need to be countered. There is still an element of risk when de-identified data is used, and any communications would need to be accurate on this point to avoid engendering a false sense of security.

Despite the reassurance offered by de-identified data, though, the term is complex and not necessarily accessible. Some suggested using the term 'anonymous', but this will pose a distinct challenge for any future public-facing information resources, as 'anonymous' and 'de-identified' are not synonyms. There is a risk that the term 'de-identified' could be misconstrued or not fully understood. Indeed, it required a fair amount of explanation from the moderator before this concept was fully grasped, therefore any explanatory materials should take particular care explaining 'de-identification' in a simple way.

Who makes decisions about how GP record data is used

Survey respondents were asked to select any organisations from the list shown in the chart below which they think are responsible for making decisions about how data from their GP record is used or shared for purposes beyond their individual medical care.



As data controllers, GP surgeries are generally responsible for making decisions about how GP record data is used or shared for purposes beyond individual medical care. However, there are instances where national bodies mandate data sharing for certain purposes, such as to enable GP surgeries to get paid for the care they provide or during the COVID-19 pandemic to help coordinate the response.

Respondents were most likely to think that *'National health bodies'* (49%), *'The Government'* (39%), and/or *'My named GP'* (39%) are responsible for making decisions about how GP record data is used or shared for purposes beyond individual medical care. This suggests that people expect that a national executive body, such as NHS England or the Government, or their GP is responsible for making decisions about their data.

Respondents were then asked who they trust to make decisions about how their GP record data is used or shared for purposes beyond their individual medical care.

Whilst people expect national bodies, such as the Government or NHS England, to make decisions about how data from their GP record is used or shared for purposes beyond their individual medical care, they are most likely to <u>trust</u> their GP to make these decisions. A majority of respondents (58%) trust their named GP to make these decisions about their GP record data. Just over a third stated that they would trust '*Any GP treating me*' (35%) or '*Any GP in my practice*' (35%). Whilst 39% of respondents expected the Government to be responsible for making decisions

(*Q16*), a lower proportion (21%) stated that they trusted the Government to make decisions about how data from their GP record is used or shared for purposes beyond individual medical care.

In the workshops and interviews, questions around decision-making were not particularly significant for participants. When prompted, participants were not interested in finding out who makes decisions about GP records, suggesting this is not a particularly salient topic for members of the public.

As noted, trust in the NHS is generally high, and this may go some way to explaining why this wasn't a major concern.

> *"I think we leave it in their [the NHS's] capable hands…They know what they're doing, so we leave it to them really." Digitally disengaged interview*

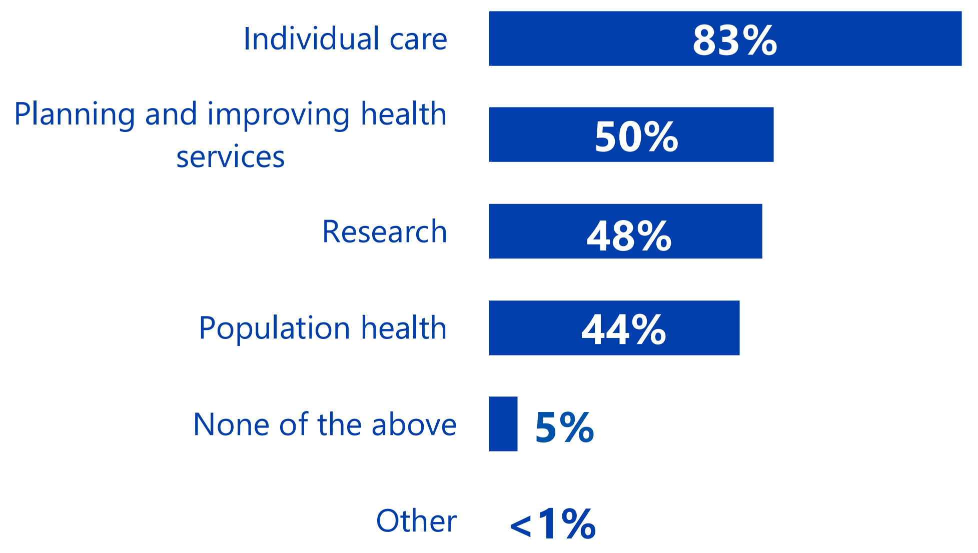
Aligning with the survey findings, there was a level of assumption that either GP surgeries or the NHS as a whole make decisions about how the data held in GP records is used and shared.

Support for sharing data from the GP record

Survey respondents were asked to identify for which purposes they were happy for data from their GP record to be shared. They were provided with a list of different use cases, and each use case was accompanied by a broad example for clarity (e.g. '*Population health – e.g., used to understand the needs of groups of people based on things they have in common like age or ethnicity and target health services to these groups*')

Less than a third (29%) selected *'All of the above'*. In the chart below, respondents who selected '*All of the above'* have been included in the proportion of respondents who selected each use case.

Q19. For what purposes are you happy for data from your GP record to be shared? Select all that apply



Base: 1104

As the chart shows, respondents were supportive of sharing their GP record data for their individual care (83% selected this option). They were less supportive of sharing their GP record data for purposes beyond their individual care. Half, or less than half, of respondents were happy for their GP record data to be shared for purposes beyond their individual care (50% selected '*Planning and improving services*', 48% selected '*Research*', and 44% selected '*Population health*').

This suggests there are mixed levels of support amongst the general public for data from their GP record being shared for purposes other than their individual medical care.

The table below shows any statistically significant differences between demographic groups highlighted in blue. For example, those aged 55+ were significantly more likely than those aged 18-34 or 35-54 to be happy to share their GP record data for *'Individual care'* (87% compared to 75% of those aged 18-34 and 82% of those aged 35-54).

Q19. For what purposes are you happy for data from your GP record to be shared?	**Individual care**	**Pharmacy**	**Planning**	**Research**	**Population health**	**None of the above**
Age						
18-34	75%	59%	51%	44%	46%	4%
35-54	82%	57%	47%	42%	40%	4%
55+	**87%**	**65%**	51%	**54%**	**47%**	5%
Gender						
Female	84%	63%	46%	45%	41%	4%
Male	82%	58%	**53%**	50%	**48%**	5%
Ethnicity						
White ethnic background	**85%**	61%	51%	**49%**	45%	5%
Minority ethnic background	77%	60%	44%	38%	41%	5%
Social grade						
ABC1	84%	60%	**57%**	**52%**	**51%**	3%
C2DE	83%	62%	42%	43%	37%	**7%**
Base: 1104						

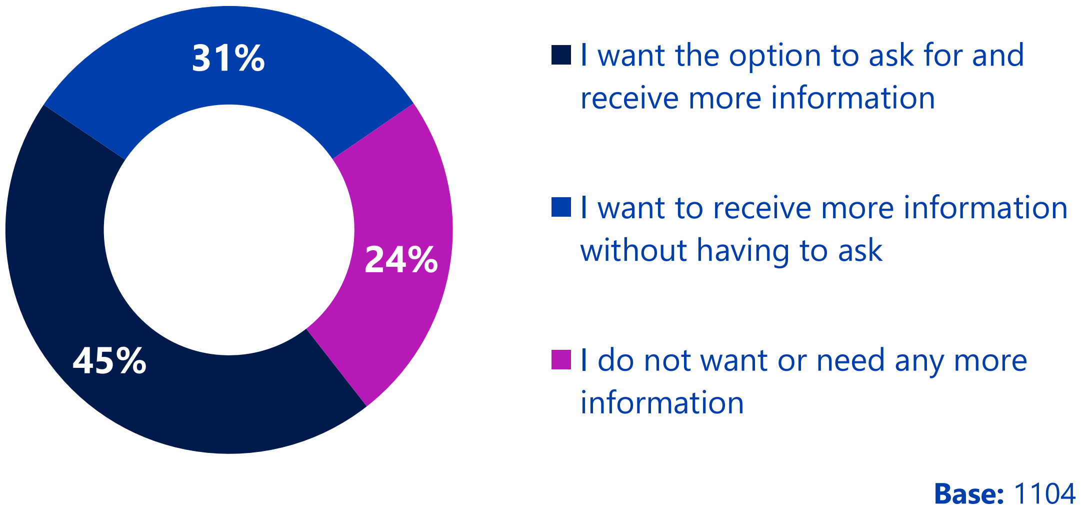
Section 4: Information preferences and needs

Receiving information

All stages of the research explored information preferences and needs, in order to understand what people want to know about GP record data, and how they want that information to be communicated. This section covers the findings from Stages 1 and 2 of the research.

As the chart below shows, survey respondents were asked to select which statement most applies to them, when it comes to information about how data from their GP record is used, shared, stored or managed.

Q20. When it comes to information about how data from your GP record is used, shared, stored or managed, which of the following statements most applies to you:



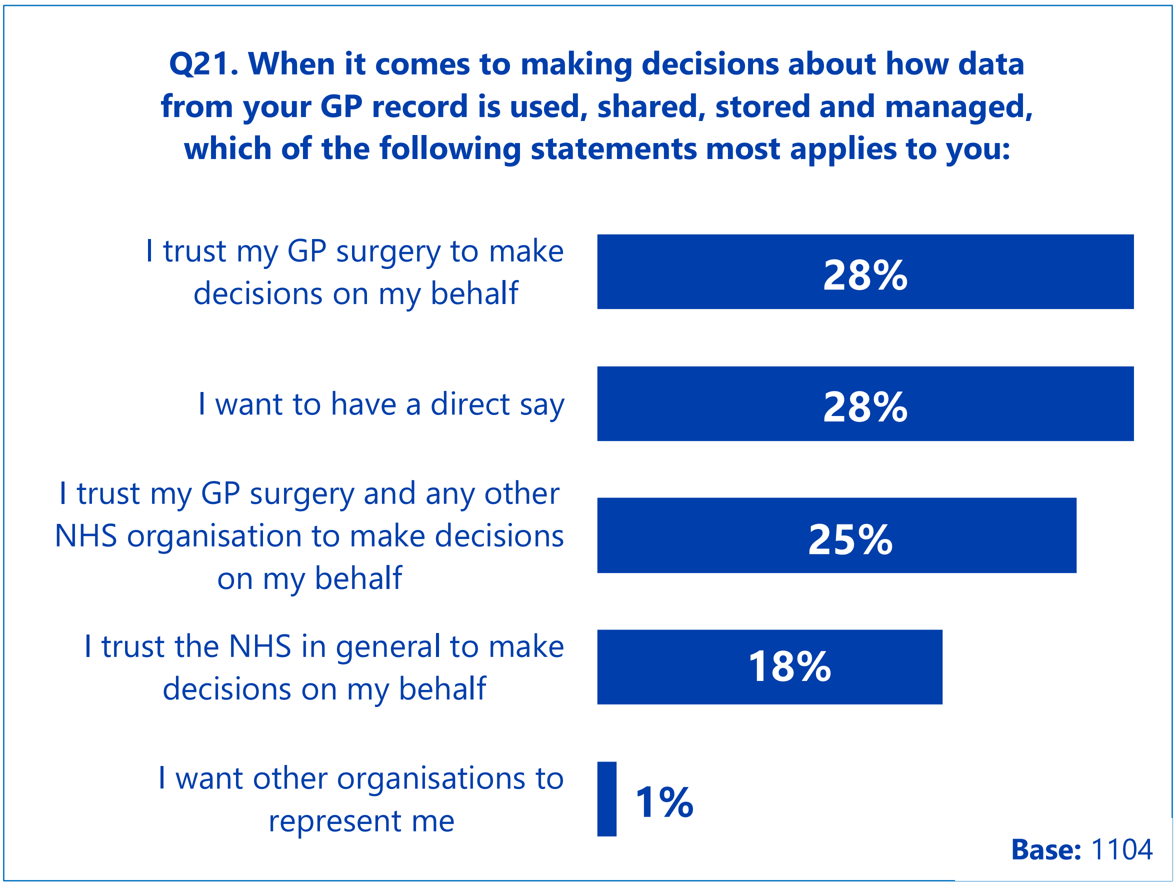
The chart highlights the mixed response. There was no clear preference for any option. However, it does suggest that, in general, most people want more information about their GP record data to be made available, with 45% stating '*I want the option to ask for and receive more information*' and 31% stating '*I want to receive more information without having to ask*'.

The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. Older respondents, those from a White ethnic background, those from social grades C2DE, and those who completed the survey face-to-face (and were therefore likely to be digitally disengaged) were more likely to state '*I do not want or need any more information*'.

Q20: Which statement applies to you?	**Option**	**Receive**	**None**
Age			
18-34	**52%**	36%	11%
35-54	47%	28%	**25%**
55+	41%	32%	**27%**
Ethnicity			
White ethnic background	44%	30%	**25%**
Minority ethnic background	47%	35%	18%
Social grade			
ABC1	47%	33%	20%
C2DE	42%	29%	**30%**
Method of participation			
Online	45%	**32%**	23%
CAPI	42%	23%	**35%**
Base: 1104			

Level of involvement in decision making

As the chart below shows, survey respondents were then asked to select which statement most applies to them, when it comes to making decisions about how data from their GP record is used, shared, stored and managed.



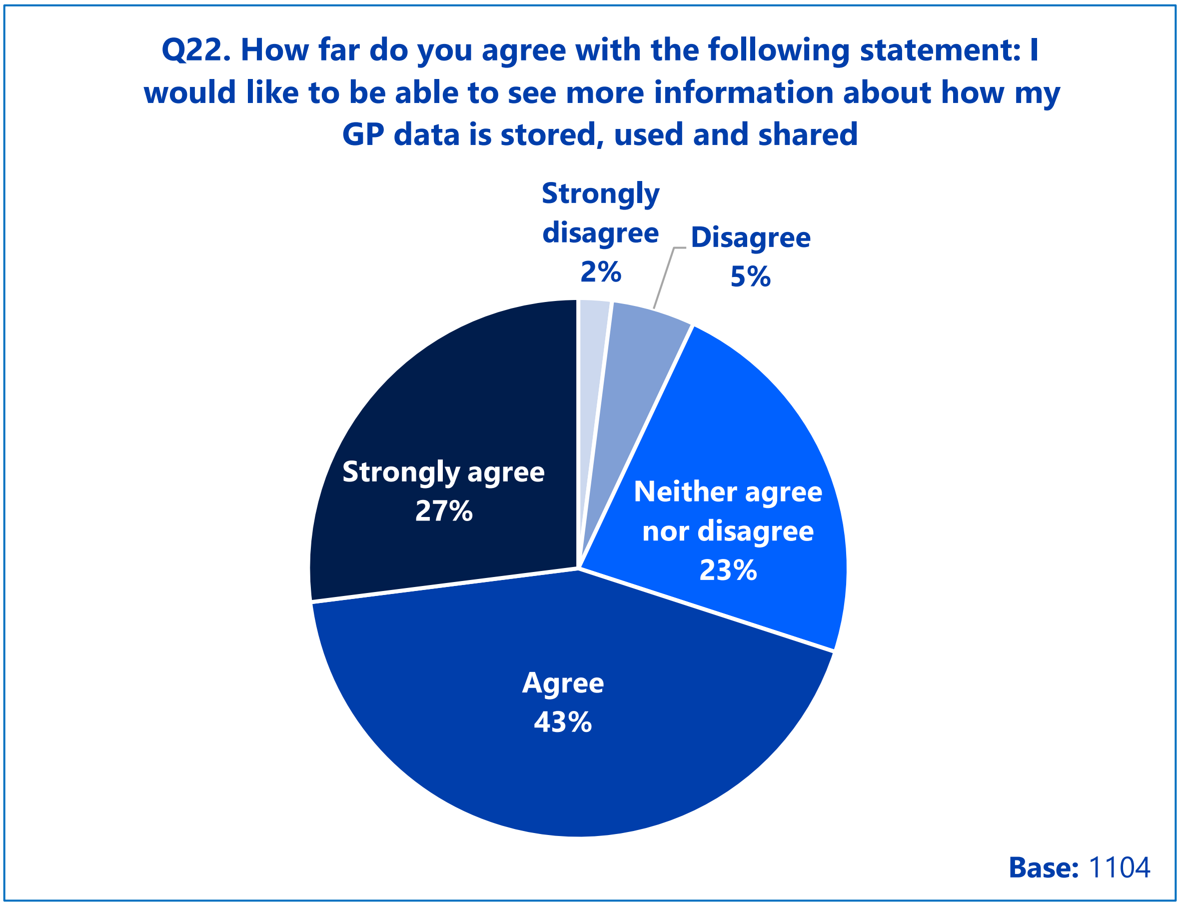
Whilst *'I want to have a direct say'* was selected by over a quarter of respondents (28%), most respondents trust their GP surgery or an NHS organisation to make decisions about their GP record data on their behalf (71% selected '*I trust my GP surgery to make decisions on my behalf* ', '*I trust my GP surgery and any other NHS organisation to make decisions on my behalf*', or '*I trust the NHS in general to make decisions on my behalf*').

It also suggests that GP surgeries are, in general, trusted to make decisions about data from people's GP records (53% selected '*I trust my GP surgery to make decisions on my behalf* ' or '*I trust my GP surgery and any other NHS organisation to make decisions on my behalf*').

The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. For example, female respondents (32%) were significantly more likely to want a direct say than male respondents (24%).

Q21: Which statement applies to you?	**Direct say**	**GP**	**GP and NHS**	**NHS**	**Other**
Age					
18-34	24%	32%	21%	21%	3%
35-54	30%	28%	19%	**21%**	1%
55+	28%	27%	**30%**	14%	1%
Gender					
Female	**32%**	28%	23%	16%	1%
Male	24%	28%	26%	**20%**	1%
Ethnicity					
White ethnic background	27%	**29%**	25%	17%	1%
Minority ethnic background	**31%**	23%	24%	20%	2%
Social grade					
ABC1	30%	24%	25%	20%	2%
C2DE	26%	**33%**	25%	16%	1%
Disability					
No disability	29%	26%	25%	**19%**	1%
Disability	24%	**40%**	23%	11%	2%
Base: 1104					

When asked how far they agreed with the statement '*I would like to be able to see more information about how my GP data is stored, used and shared'*, 69% of respondents selected '*Agree*' or '*Strongly Agree*'.



Q22. How far do you agree with the following statement: I would like to be able to see more information about how my GP data is stored, used and shared

Base: 1104

This suggests that, in general, there is a desire for more information to be made available about how GP record data is stored, used and shared. Furthermore, a sizeable proportion of people (27% who selected *'Strongly agree'*) feel strongly that they should be able to see more information, reinforcing the need for more information about GP record data to be made available to the public.

The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. Younger respondents, respondents from a minority ethnic background, respondents from social grades ABC1, and those who completed the survey online (and were therefore digitally engaged) were more likely to agree or strongly agree that they would like to be able to see more information about how their GP record data is stored, used and shared.

Q22: How far do you agree?	Net - Agree	Net - Disagree	Neither
Age			
18-34	**89%**	2%	9%
35-54	**72%**	**6%**	**22%**
55+	62%	**11%**	**28%**
Ethnicity			
White ethnic background	68%	8%	**24%**
Minority ethnic background	**77%**	5%	18%
Social grade			
ABC1	**76%**	5%	19%
C2DE	61%	**10%**	**29%**
Method of participation			
Online	**71%**	6%	23%
CAPI	51%	**24%**	25%
Base: 1104			

Reflecting the survey findings, most qualitative participants were interested in having more information about GP record data made available. Workshop and interview participants were given a task in which they were given a series of topics they may like to receive more information on. They were asked if they'd want to know more about the topics, and if so, to group them into information they'd like to receive automatically (e.g. via email or text) and information where it should be available if needed (e.g. available online) (*see Appendix, p.34*).

Throughout the workshops, most thought that information on each topic should at least be made available for people to access if they want to find out more. Most participants had not thought about their GP record data and how it is used, shared and stored prior to the session, and as such had not attempted to look for any information before. When discussing what information should be made available, participants did not feel outraged or frustrated that they had not received this information before, suggesting that this is not an area of high priority.

One workshop participant went as far as to state that, as they had not thought about the topic before, they would not want to receive any information about it in future.

> *"Before this, I wouldn't have even thought about it to be a big issue. I've obviously thought about kind of where things would be, but I wouldn't go out of my way to make a Google search or go directly to my doctors and be like, where's this information going? Because I just don't think I put that much importance on it." Group 2, Pre-family*

However, this was an extreme viewpoint and most wanted some form of information to be made available. However, across the groups, it was ambivalent whether they wanted to receive this information automatically without having to ask, or whether they wanted this information available to access if they were interested. Information that was most commonly suggested to be sent automatically included:

- How to find and see the GP record
- Who has access to data from their GP record, what level of information they have access to and why
- Choices around opting out of their data being used and shared
- How GP record data is kept safe and secure

Where participants did request more information about these topics, these were generally about more personal aspects of their GP record, for example how to access the GP record to see the information collected about them or to check that their data was not being misused, leaked or insufficiently protected. This reflected concerns about data security, privatisation and third-party access.

> *"I think that should be provided without needing to ask, so that you can see straightaway who can access your GP records. You shouldn't have to wait for that sort of information to know who's seen that information about yourself." Group 1, Pre-family*
>
> *"I also would just like to be able to access and see who could access my record without having to then phone up and ask my GP for it." Group 2, Pre-family*

Whilst most participants thought that other topics of information should be available if you are interested, a few pointed out that it all should be provided without needing to ask, in order to give people a choice as to whether they want to engage with it.

“I was just thinking, to be honest, I would want all of this provided to me, and it’s my choice whether I’ll sit and read through it…because unless you know you can opt out, you wouldn’t go looking for this.” Group 3, Family

One group in particular struggled to determine what they thought should automatically be told and what should be available if they wanted to find out more. Whilst they wanted to receive some information automatically, they also considered the cost of and reaction to such communications, with one participant suggesting it could lead to a mass opt-out. Another participant in a different group questioned whether they would actually engage with any information about this topic if they received it without asking.

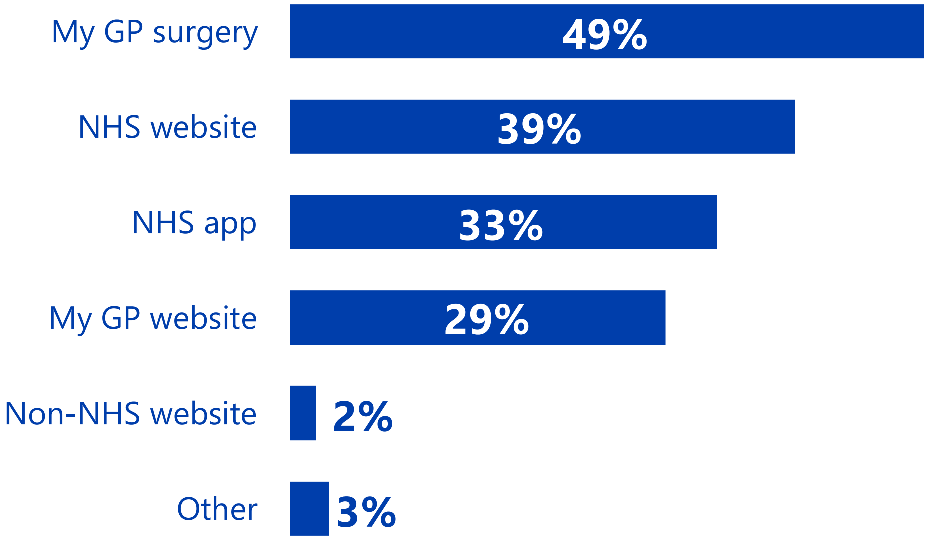
“I think if I've received an email like that [i.e. without having to ask], I'd probably glance at it and delete it. I wouldn't particularly go into it. So I think it's more, if you want to know, just ask”
Group 2, Pre-family

Finding information

When asked where they would go to find information about how data from their GP record is stored, used and shared, respondents were most likely to suggest that they would go to their GP surgery (49% selected this option).

A sizeable proportion also stated that they would go to the '*NHS website*' (39%), '*NHS app*' (33%), '*My GP website*' (29%). This suggests that there are a range of sources of information where people would go if they wanted to find out more, which would need to be considered when making information about GP record data available.

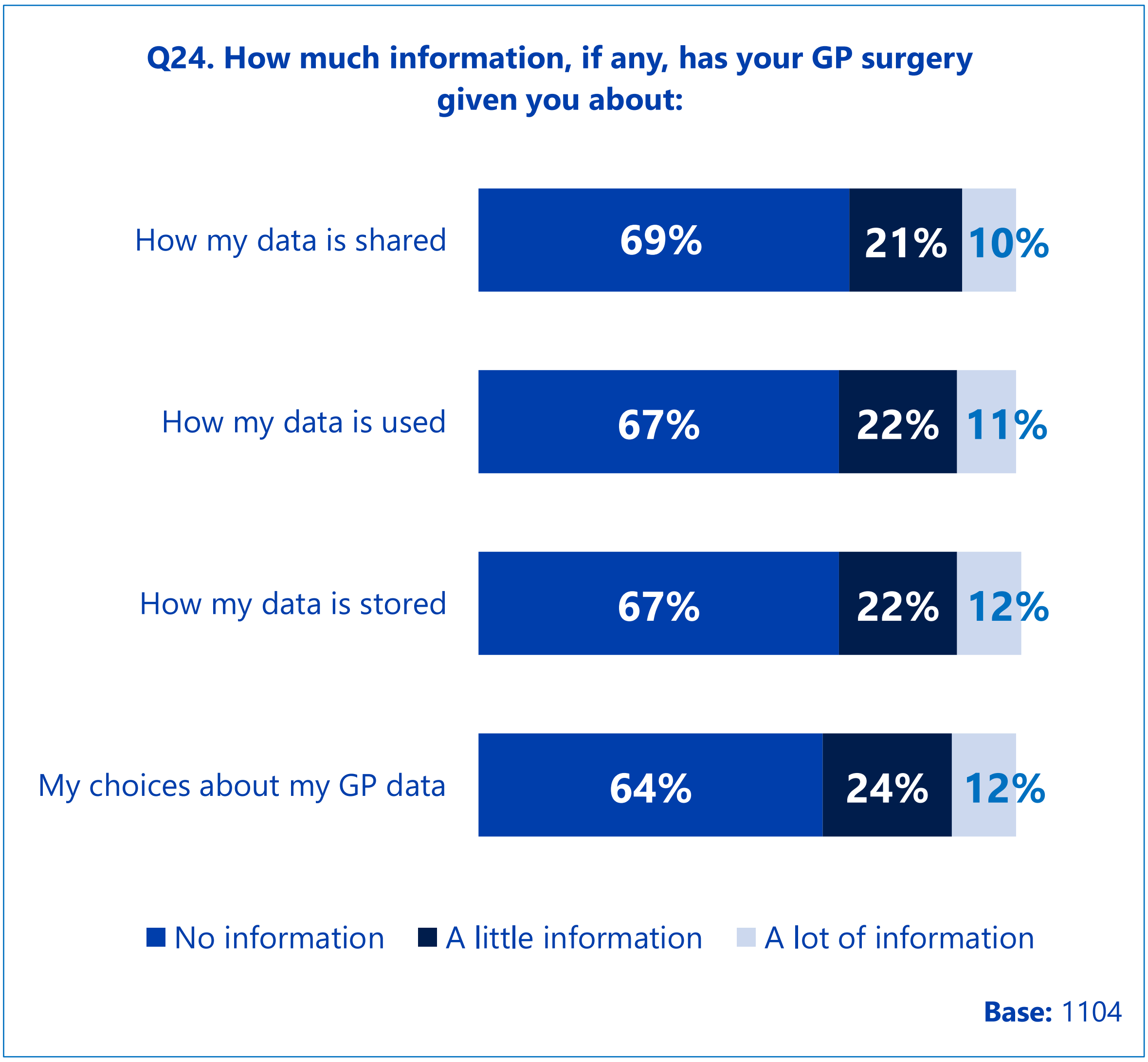
Q23. Where would you go to find information about how your GP data is stored, used and shared? Select all that apply



Base: 1104

Prior information received

Respondents were asked if their GP surgery has shared any information about how their data is shared, used, and stored, and the choices available to them. For each option, a broad example was provided for clarity (e.g. '*How my data is stored e.g., what protections are in place to make sure my data is held securely*').



As the chart above shows, people are unlikely to remember receiving information about their GP record data from their GP surgery. Around two-thirds of respondents (64%-69%) stated that they had received no information for each option. A majority of respondents (57%) stated that they had received no information for any of these options. This could suggest that people are unlikely to have received information from their GP surgery, or simply do not remember it.

Certain demographic groups were more likely to suggest that they had not received any information from their GP surgery.

- **Age:** Those aged 35-54 and 55+ were more likely to state that they had received no information across Q24 (54% and 68% respectively, compared to 26% of 18-34 year olds)
- **Ethnicity:** Those from a White ethnic background were more likely to state that they had received no information across Q24 (60% compared to 43% of those from a minority ethnic background)
- **Social grade:** Those from social grades C2DE were more likely to state that they had received no information across Q24 (65% compared to 51% of those from social grades ABC1)

Respondents who stated that they had received any information at Q24 (n=473) were asked what information they received. The verbatim answers given have been coded and grouped together, as shown in the table below.

Q24a. You said that your GP surgery provided you with a little or a lot of information about [e.g. How my data is stored]. What information did you receive?	**%**
Information about data protection	25%
Via text, online, email	20%
Information about medical conditions or records	15%
Via leaflets or letters	7%
General information	5%
Information about or from the GP	5%
About appointments, opening times	3%
Information about personal details	2%
The right amount of information for me	2%
Other	17%
Do not know or can not remember	12%
Prefer not to say	2%
Base	**473**

As the table shows, the responses given tended to be non-specific, or about the method of communication itself, rather than about the content, which suggests that respondents may have struggled to recall what the information they received was about.

When respondents did recall what the information was about, they were likely to state that they received '*Information about data protection*' (25%) or '*Information about medical conditions or records*' (15%).

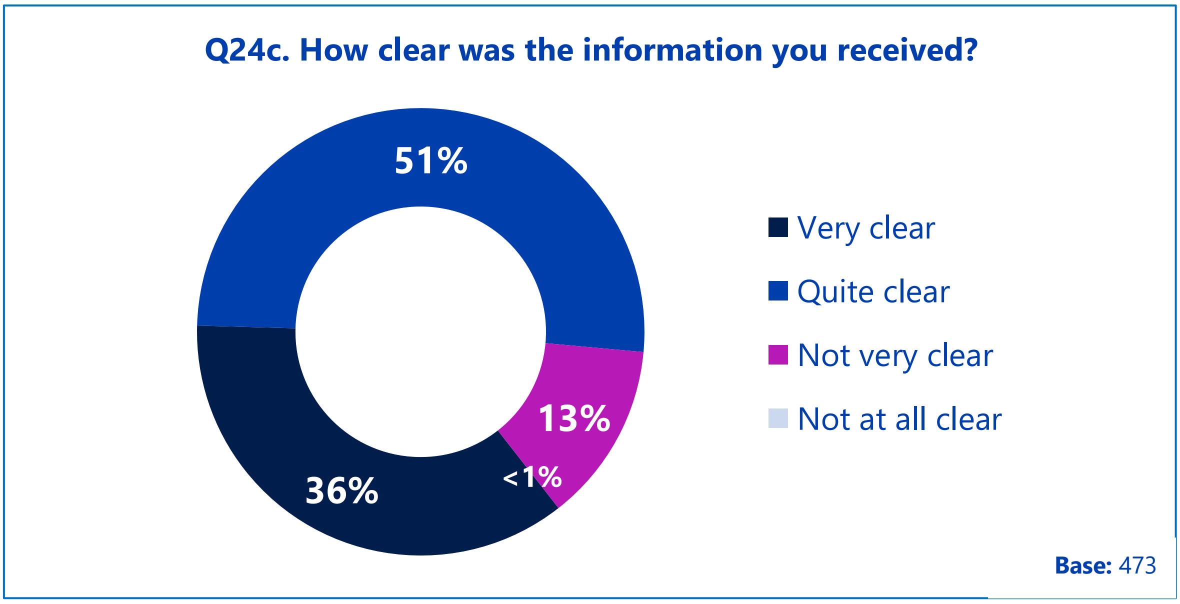
Respondents who stated that they had received any information were then asked how they received that information.

Q24b. How did you receive that information? Select all that apply	%
Online – GP website	37%
Email	29%
NHS App	28%
Available in practice – GP staff	23%
Letter	15%
Text message	13%
Available in practice – posters or information	12%
Other	4%
Base	**473**

Respondents received information from a range of different sources. They were most likely to have received information online via their GP practice's website (37%). More than a quarter of respondents received information via email or the NHS App (29% and 28% respectively), with just under a quarter (23%) receiving information from GP practice staff.

A small proportion selected *'Other'* (4%) and, when asked to specify, either stated that they received the information via a phone call or that they couldn't recall how they had received the information.

Respondents were then asked how clear the information they received was, as shown in the chart below.



Most respondents (87%) stated that the information they received was either '*Quite clear*' or '*Very clear*'. Whilst it could be concluded that information about GP record data is typically clear, the responses to Q24a suggest that respondents struggle to recall much about the information they received, so it could be difficult for them to judge whether this information was clear.

Respondents who answered '*Not very clear*' or '*Not at all clear*' (n=63) were then asked how the information they received could be made clearer. The verbatim answers covered:

- Using simple, plain language, avoiding medical or data jargon
- Providing shorter, more concise information
- Explaining specifically how data is shared, with whom and for what purposes
- Different method of communication preferred e.g. letter, leaflet or through the NHS App

In the workshops and interviews, no participants had actively looked for information about the data collected or held in their GP record. Additionally, very few recalled receiving any information when prompted, either from their GP surgery or from another source. However, caution should be taken here as it is not possible to know what has been sent and not picked up. People may have received information about the data held in their GP record and not recall it.

> *"I don't recall anything. This probably sounds really bad. If I did, I probably didn't even pay any attention to it … there has occasionally been a few letters that have come through the post from the GP, and if they're not something of importance, I probably haven't even read them." Group 3, Family*

One participant remembered consenting for the information collected by their GP surgery to be shared with other organisations involved in providing care. However, they did not receive any additional information about this beyond a consent form. Another participant claimed to have received a letter, and one person had opted out of data sharing after receiving a text from the GP. They looked further into the issue and decided they did not want the data shared with third parties. However, these examples were anomalies; most participants had not heard anything.

Participants were also asked where they would go to find out more information about the data held in their GP record. As they hadn't considered the topic in much detail before, they were unsure where information would be available, and could only suggest where they would go. However, this does provide an indication of possible behaviour, highlighting where people would go if they wanted to find out more, and who they would trust to provide accurate information.

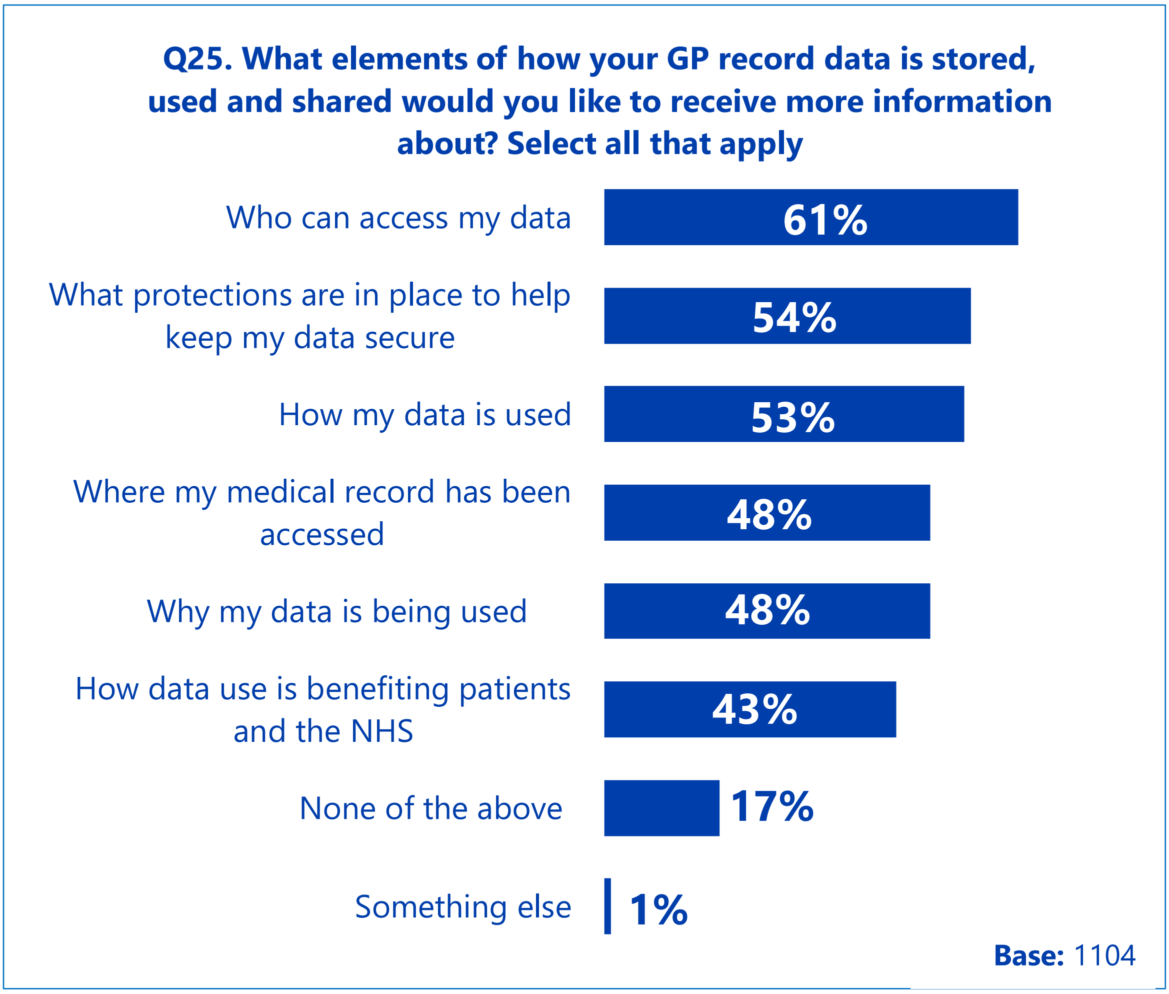
Most suggested that they would either search for information online, prioritising trusted sources such as NHS websites, or they would ask their GP or a member of staff in their GP surgery for more information.

> *"If I was particularly bothered about it, it'd probably ring up or go down and speak to the receptionist, and then someone you think would know something... or they'd get someone relevant to contact you." Group 1, Pre-family*

As participants made it clear that GP record data is not a topic that is at the forefront of their minds, it seemed unlikely that they would actively seek out this information on their own. This does not necessarily mean that public-facing information about GP record data is not required. As mentioned, participants wanted to know about several key topics once they had the opportunity to think about it in the workshops and interviews. Furthermore, even though they hadn't looked for information themselves, participants felt it was important that the NHS is transparent about this topic and that information should be made publicly available online for those who need it.

Information topic preferences

Survey respondents were asked which elements of how their GP record data is stored, used and shared they would like to receive more information about, as shown in the chart below.



Q25. What elements of how your GP record data is stored, used and shared would you like to receive more information about? Select all that apply

Base: 1104

From the list of topics provided, respondents were most likely to be interested in receiving more information about *'Who can access my data'* (61% selected this option). Additionally, more than half would like to receive more information about *'What protections are in place to help keep my data secure'* and *'How my data is used'* (54% and 53% respectively).

The discussions in the workshops and interviews did not differ significantly from the survey findings. Qualitative participants mainly wanted to know more information about: who has access to GP record data, what level of detail they have access to and why; how GP record data is kept safe and secure; and their choices around opting out of their data being used and shared. As previously covered, participants also wanted to be informed about how they can access their own GP record.

The digitally disengaged interviews tended to be interested in fewer topics, on the whole, as they were more likely to state that they trust the NHS to use and share their data appropriately. However, as with the workshop participants, they were most interested in finding out about how their data is used for purposes beyond their individual care, and how their data is kept safe and secure.

> *"[I'd like to know] what they're sharing your data with. That's the only one I'm concerned with. Research could be a good thing, but, yeah, that's the scary one sometimes: who they could share all your data with?" Digitally disengaged interview*

Generally, there was more interest in purposes beyond individual medical care or outside of the NHS, due to concerns about private third-party organisations accessing and using personal information held in the GP record. However, questions around who can access GP records for individual medical care were still present.

> *"I think it'd be interesting to know about how they share the information, especially across like, say, different trusts, if you're going to move, things like that, how that information is shared if you move to a GP practice in a different area." Group 1, Pre-family*

As with the survey, there seemed to be definite boundaries around different medical or medical-adjacent staff and how comfortable they would be with them having access. They wanted to know whether their personal information was being shared with staff beyond their GP, and, if so, what level of detail, they can access.

> *"You'd want to know if a receptionist is able to access your GP record and how much they can look at." Group 2, Pre-family*

Perhaps understandably, it was the sharing of data outside of the NHS that was of most interest. Participants wanted to know both how GP record data can be used and who can access it for purposes beyond their own individual medical care. As mentioned earlier, concerns around access and interest in the topic lessened when participants learned it was mostly de-identified data that is used. However, for initial responses to this, there were concerns around their personally identifiable information being used without their permission. Even though data ownership is more complex, some participants sensed that if it is their personal information, they are the owners, and they should have to give their consent for their data to be used.

> *"I just think whenever health records are involved, I think it's important to know when and where it's being used, how it's being used, and you should have the say in whether that's right or wrong…whether that be for research, service improvement…you should always be asked first." Group 2, Pre-family*

Some participants also wanted to know what types of organisations have access. Discussion about using GP record data for research and service improvement often led into questions about private companies, whether they have access and why.

> *"I've always wondered whether they share it with insurance companies, you know, right? You know, like for life insurance and things like that." Group 3, Family*

At one extreme, one participant wanted to be provided with a full list of all the non-NHS organisations who currently have access to their data so they could check that their personal information was not being used for purposes they disagreed with.

There was a clear difference among participants between purposes perceived to be 'for the greater good' and purposes that may prioritise private enterprise and profit. Whilst levels of trust in the NHS are high, one group in particular were keen to hear about what protective measures are in place to stop patient data being used for 'nefarious' purposes.

> *"I don't have any problem with records being held within the NHS. When it's offered to third parties, or it becomes available for sale to private drug companies, then money is going to start changing hands, and that's the controls that are needed, and it's just a bit vague so far." Group 6, Post-family*

More broadly, participants wanted to know how their GP record data, which is perceived to be personal and private, is being kept safe and secure. Concerns were raised about data breaches, leaks, hacking and misuse of data.

> *"I think you hear a lot about data breaching…So if, if that sort of information is all leaked, then what's to say that this can't be leaked and someone hack into the system and whatnot and leak all your information and your details?…it's very personal." Group 2, Pre-family*

Participants wanted to know what procedures and safeguards are in place to keep the data in their GP record secure. When it came to the topic of how GP records are stored, participants were solely interested in how the systems used to store their data are kept secure.

This information is important, but it does not need to be detailed. Participants mainly wanted to know that as much as possible is being done to protect their data from breaches, rather than knowing what specific systems are used to store GP records for example.

> *"As long as I know my records are secure, I think that's the most important thing of all" Digitally disengaged interview*

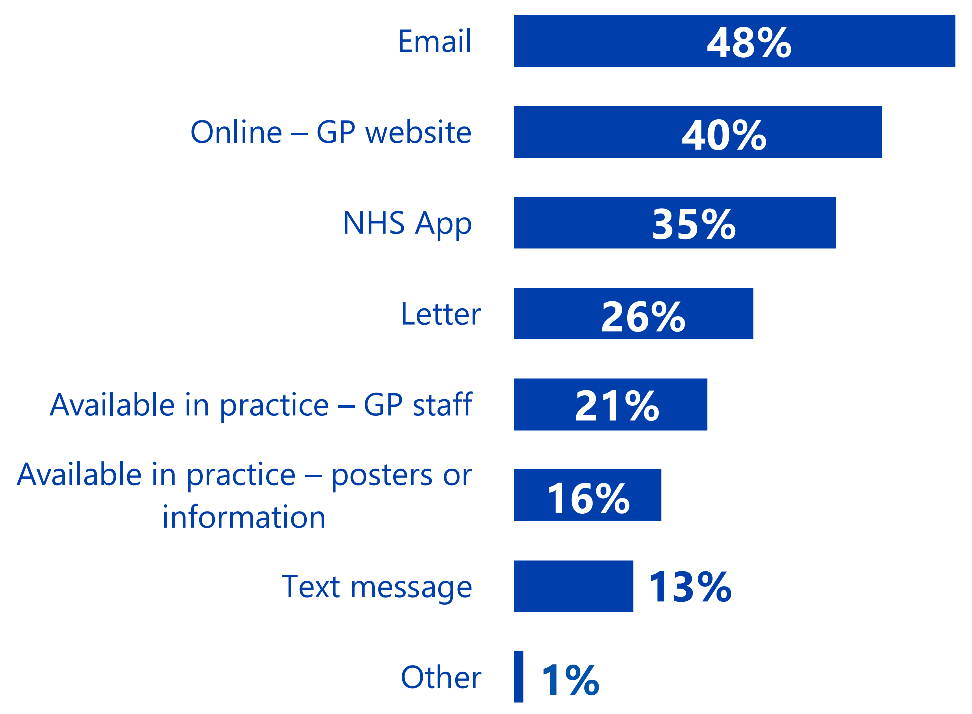
As some groups were concerned about permission, and with at least one participant having already opted out, information about opting out was also considered essential by some, who felt that they needed to be made aware that this is a choice available to them.

Participants were also prompted on other topics related to GP record data. They were less interested in topics which did not relate to their concerns about their personal information or data security, such as *‘How using this data can benefit you, NHS services and other patients*'.

Information method and format preferences

When asked how they would like receive information about their GP record data, respondents were most likely to select an online method of communication, such as via *'Email'* (48%), *'Online – GP website'* (40%), or *'NHS App'* (35%).

Q26. How would you like to receive information about your GP record data? Select all that apply



Base: 1104

Whilst they wanted to receive information via an online format, respondents were less likely to want information about GP record data to be made available in their GP practice, either via GP staff (21%) or posters or information (16%).

The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. Older people, those from social grades C2DE, and those who completed the survey face-to-face were more likely to want to receive information about GP record data via a non-digital method, such as a letter or from staff in their GP practice. Younger people, those from social grades ABC1, and those who completed the survey online were more likely to want to receive information via a digital method, such as email or on the NHS App.

Q26: How would you like to receive information?	**Email**	**GP website**	**NHS App**	**Letter**	**Practice: GP staff**	**Practice: posters**	**Text**	**Other**
Age								
18-34	**61%**	42%	**46%**	19%	27%	16%	**22%**	0%
35-54	**53%**	43%	36%	26%	21%	17%	**16%**	<1%
55+	40%	38%	31%	**29%**	20%	14%	8%	**2%**
Social grade								
ABC1	**53%**	43%	**39%**	20%	19%	14%	13%	1%
C2DE	41%	38%	29%	**33%**	**24%**	17%	12%	1%
Method of participation								
Online	**50%**	**43%**	**37%**	23%	20%	14%	12%	1%
CAPI	21%	16%	10%	**57%**	**34%**	**29%**	18%	4%
Base: 1104								

Across the workshops and interviews, communication preferences were mixed. Format preference varied widely between and throughout groups, and each communication method comes with advantages and disadvantages.

For information that participants felt should be available for people to find when they need it, most preferred this information to be made available online via the website of a trusted organisation, such as NHS England, or in some cases through the NHS App. Understandably, digitally disengaged participants and some of those from the post-family groups preferred information to be made available offline, either through written information (e.g. a leaflet) or verbal information (e.g. a conversation with their GP) provided by their GP surgery.

For the information that people felt needed to be provided automatically without needing to ask (e.g. how to access the GP record), there was not a clear consensus over how this should be communicated. Preferred methods of communication included: letters, text messages, emails, and posters/leaflets in the GP surgery.

Advantages of postal communications include their accessibility for the digitally disengaged. Some respondents also indicated that letters might seem more important than text or email. However, letters are also more likely to be considered junk or to get lost.

Another accessible option is posters and leaflets in the GP surgery. Some participants felt this was an appropriate location for information about the GP record and they would trust information in their GP surgery to be accurate and reliable.

> *"Maybe have that kind of thing on the, you know, the screen that they have in the doctor's, like, while you're waiting, because you often sit there for a long time don't you?" Group 3, Family*

However, one post-family group pointed out that not everyone visits their GP regularly, and so other formats would need to be made available.

Digital communications also have a series of benefits and drawbacks. Text messages were a popular choice, particularly as they are less likely to go into a junk folder as with email, but recent media attention on text message scams has made some participants more wary of this format.

Across these communications formats, it was unclear whether participants would actually engage with information they had received without asking for, or whether it was an important enough topic for them to consider engaging with without prior thought, if, for example, they received a letter containing information about their GP record.

From the discussions across Stage 2, it is evident that there are limited levels of knowledge around how to go about finding information about GP record data. Rather than actively sending out information, as a few participants reflected, it may be more effective to signpost to information resources for those who want to know more about GP record data. For example, having a poster in a GP surgery which signposts to a webpage for those who want to know more, providing a deeper layer of information for those that need it.

Additionally, equitable and consistent access to information was emphasised.

> *"I think whatever is provided should be provided for everybody. Regardless of who your GP is or where you live, it should all be the same, and each trust should have to do the same thing for everybody." Group 1, Pre-family*

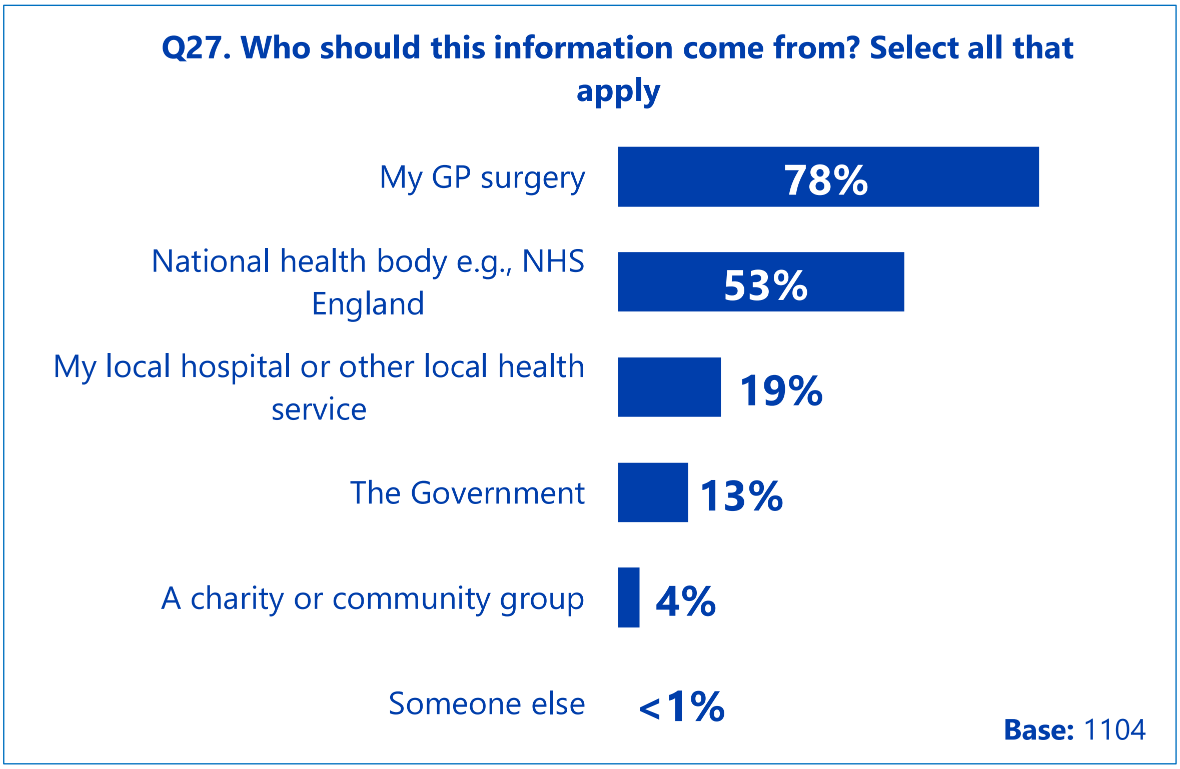
In terms of format, whilst there were several varying preferences across the qualitative participants, the key message was to communicate the information as simply as possible. Ensuring that any information is *"short, brief and easy to read"* is paramount. Bullet points and imagery to break up the text and engage the reader were suggestions that had broad support. Ultimately, participants did not want too much detail, they wanted the key facts to be laid out simply in an accessible format which allowed them to easily find the answers to any questions they have.

A few participants suggested that it would be useful to set out any information in a question-and-answer format, similar to a FAQs page, which would allow people to find out what they want to know more easily.

> *"A question-and-answer [format] would be quite good. Giving that question, and then answering, is going to be appropriate, or, you know, this is going to be what you want to know about" – Digitally disengaged interview*

Information source preferences

Survey respondents were asked who information about GP record data should come from, as shown in the chart below.



The findings suggest that people expect information to come from their GP surgery or a national health body. A strong majority (78%) thought that this information should come from their GP surgery, whilst just over half (53%) thought that this information should come from a national health body, such as NHS England.

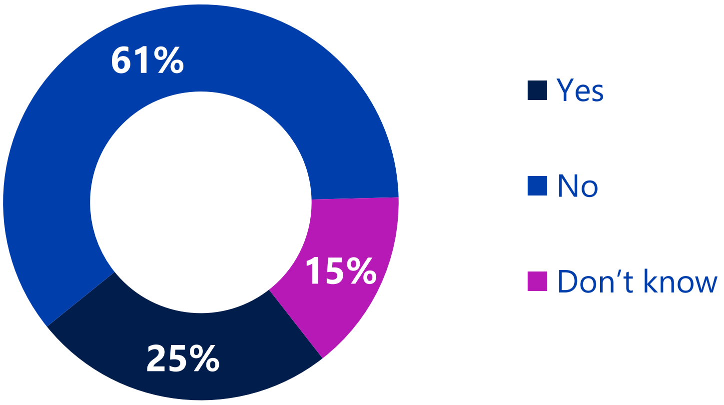
Unlike the discussions around format, there was a broad consensus across the workshops and interviews on preferred sources of information. As with the survey findings, GPs ranked highly, often because of the personal relationship involved and the high levels of trust in GP surgeries This was closely followed any other NHS organisations, such as NHS England. Trust in the NHS is high on the whole, and NHS organisations also seemed like the 'right' source for such information, rather than this information being provided by a charity or the Government, who were perceived to be less related to the topic.

Although GP surgeries were the most trusted source of information, qualitative participants felt that national health bodies would be better situated to provide uniform, accurate information due to their resources and reach, when compared to individual GP surgeries.

Whilst many would use a search engine as a first port of call to look for information, some pointed out that it can be difficult to know which websites to trust, and that NHS organisations, such as NHS England, seem most likely to have accurate information.

Section 5: Comparing the GP record to other health records

Survey respondents were reminded of some of the types of data contained in the GP record, and how it is collected. It was then explained that other health records contain data about a person, collected when they interact with other health services. When asked if they felt differently about their GP record when compared to these other health records, a clear majority (61%) stated that they did not feel differently.



Q28. Do you feel differently about your GP record compared to other health records (e.g. hospital records, dentist records, records held by specialist clinics)?

Base: 1104

The table below shows any statistically significant differences between demographic groups. These are highlighted in blue. Respondents from younger age groups, male respondents, and those from social grades ABC1 were significantly more likely to feel differently about their GP record.

Q28: Do you feel differently?	Yes	No	Don't know
Age			
18-34	**38%**	50%	12%
35-54	**26%**	56%	**18%**
55+	20%	**67%**	13%
Gender			
Female	22%	61%	16%
Male	**27%**	60%	13%
Ethnicity			
White ethnic background	24%	**62%**	14%
Minority ethnic background	30%	52%	17%
Social grade			
ABC1	**28%**	63%	9%
C2DE	21%	59%	**20%**
Base: 1104			

Respondents were asked to explain their answer to Q28. The verbatim answers given have been coded and grouped together. The tables below show the top five answers given in response to each answer at Q28 in rank order.

When asked to explain their answer, those who did not feel differently about their GP record compared to other health records (n=270) either simply restated that they did not feel differently or explained that they felt that all health data is the same, should be treated the same, or that all records should be equally accessible to those who need to use them. These results are shown in the table below.

Q29a. If no at Q28, please explain your answer to the previous question.	**%**
I do not feel differently; happy with records	14%
All data is equally important or all the same	13%
All data should be treated the same or with the same confidentiality	10%
All relevant people should have access to the records e.g. for emergencies or collaboration	10%
It is all professional, personal or about healthcare	10%
Base	**670**

Many respondents who felt differently about their GP record (n=273) thought that the information in the GP record is more personal or sensitive than the information held in other health records. Others felt differently because they thought that GP practices require different levels of information to other health services, or because they trust GP practices or GP staff more than other health services. These results are shown in the table below.

Q29b. If yes at Q28, please explain your answer to the previous question.	**%**
It has more personal, specific or sensitive information	37%
The different bodies need different levels or kinds of information	11%
To maintain privacy, safety and confidentiality	10%
More comfortable with these bodies; they are more trustworthy or professional	8%
I access this record more and understand what is in it	8%
Base	**273**

In the workshops and interviews, when asked if they felt differently about the GP record, there was a mixed reaction. Participants' reasons given for and against broadly align with those given by survey respondents.

For example, those who did not feel differently felt that each record held important medical information.

Others felt strongly that GP records contain more personal information than other records, and are therefore more sensitive and private.

> *"I think your GP records are very personal to you…there's a lot of private information on there compared to your dental records. I can't imagine many people being upset if their dental records got into the wrong hands or shared with the wrong people, whereas your GP records, I think that everyone would be upset with that just because there is a lot of personal information in there." Group 2, Pre-family*

For some participants, they did not necessarily perceive a difference between GP records and all other patient records. Instead, they distinguished between GP and hospital records, and other patient records from other health and care services such as dentists. GP and hospital records were seen as more personal than other patient records.

> *"I'm probably more precious about my GP [record]. I mean, it's difficult because I think hospital records, I probably feel the same about hospital records and GP records, but dental records, I'm not really too fussed about." Group 2, Pre-family*

Communicating with members of the general public about GP record data: key takeaways from Stages 1 and 2

- There is a common misconception that there is one single national healthcare record and that the NHS is one entity
- People are unlikely to have received, or recall receiving, any information on this topic from their GP surgery
- Many have not accessed their GP record, but they want to know how to do so
- Overall, participants felt that information should be made available about their GP record data to access in case they want to find out more
- Participants were primarily concerned about data security, misuse, and access, and were particularly interested in information about: how their data is used for purposes beyond their individual care, who has access and what level of detail they have access to, and how their data is kept safe and secure
- Levels of interest are higher in topics that are perceived to be relevant to people's own records, e.g. people want to know how they can access their GP record to view their medical information
- Most people do not need great levels of detail about these topics. For example, people mainly want to know that steps are being taken to keep their data secure, but they don't need to know the specifics about each of these steps
- People are less likely to want information around topics they have an assumed level of knowledge about, such as the types of data collected in the GP record, and how it is used for individual care
- Whilst people want information to be made available online or in their GP surgery, they are ambivalent about whether information should be sent out automatically
- Many suggested that they may not engage with information if it was sent to them, due to low levels of awareness or pre-existing interest in the topic
- With uses of data beyond individual care, it is important to be as transparent as possible about who has access and why, whilst also providing assurances around security and data being shared for a 'legitimate' reason
- It is important to emphasise that, in most cases, de-identified data is used for purposes beyond individual care, as this was perceived to address participants' concerns about data security and access. However, de-identification was perceived as a complex idea which needs defining when providing information
- People trust information from NHS organisations over others when it comes to GP record data, and would expect information to come from these sources

6. Findings: Stage 3

This section covers the findings from Stage 3 of the research which involved co-design workshops and interviews.

These key takeaways were used to produce an information resource explaining what people want to know about the data in their GP record and how it is used and shared in a clear, engaging and easy-to-understand format.

Findings may also be useful to consider when designing any future public-facing information resource about GP record data.

Discussion of example posters

The discussions started by reviewing three different example infographics *(see Appendix, p50-52)* for different aspects such as language, structure and visual style. These resources were not about GP record data, and participants were asked to focus on how information was presented, rather than the content. This was used to get participants to think about what makes an effective visual resource, and to consider what style the GP record data resource could use.

The key takeaways from this discussion, that need to be considered when designing a public-facing resource, are:

- **Use a range of colour:** most participants found a monochrome colour scheme on one of the visual resources dull and difficult-to-read. A range of colours caught their attention and kept their interest. It was mentioned that this could help it stand out if it was disseminated in a healthcare setting, such as a GP surgery.
- **Avoid being too serious**: one group found the serious tone of one of the example resources off-putting and suggested it deterred them from wanting to read the information provided. They felt it was important for the content to be serious, whilst balancing it out with a 'lighter' visual style. As such, it was suggested to **use cartoon-like imagery** to make a resource more engaging
- **Steer clear of specialist language**: such as medical or data jargon, where possible – participants found some medical and technological terminology difficult to understand and suggested replacing it with simpler language, or adding relatable examples
- **Vary the layout of text:** long paragraphs of text were hard-to-read and off-putting. Several participants suggested using bullet points, icons and imagery to cut down the amount of text and keep it engaging

- **Any text needs to be minimal and straight to the point** so the reader can find the information they need. Several participants suggested *"information overload"* would prevent them from fully engaging with any resource
- **Think about the flow of information**: each section of the poster needs to be laid out in a logical order that is easy to follow. Sections need to be ordered from the top of the page to the bottom, rather than flowing from left to right.
- **Make use of QR codes as a tool for signposting to further information**: QR codes are a popular, useful inclusion as they can signpost to further information for those who are interested. This also has the added effect of ensuring that the resource only needs to include key information. They did make the point that QR codes may not be accessible for older readers, and should perhaps be accompanied by a weblink.

Structure and layout

Participants were then presented with two prototype resources about GP record data *(see Appendix, p53-54)* – one question-and-answer style and one structured around an example person and the 'journey' their data takes. Participants were asked which they preferred, or if they would prefer a different structure entirely.

The key findings were:

- **The question-and-answer structure was somewhat preferred:** whilst there was no clear consensus, this structure was somewhat preferred on balance. Those who found preferred this option found it easy to follow and they felt that the question headers would help them pick out the information they want to know more about.
- **People have different questions about GP record data,** and are not interested in every aspect. As such, a question-and-answer structure could enable readers to find the information they need.
- **The data journey structure felt more personal for some:** some participants preferred this structure as it would enable the information to be explained in more relatable terms, making use of examples so people could understand how GP record data is collected, used and shared in context. This made the information feel more *"real"* for some
- **Number each section:** numbering each section of a resource helps the reader to read each point at their own pace.
- **The layout of sections should be varied** to keep the reader engaged. It was suggested that a question-and-answer structure could become repetitive or constrained. The layout of sections could be varied to mitigate this, using a range of bullet points, icons and text box sizes to increase visual interest

> *"I find the first one, the question-and-answer, just a lot simpler. To be honest with you, I don't know if I'd want to go on a journey, you know, I just want the answer to a question. And that's it, just simple." – Group 2, Family*
>
> *"That's what people want [the question-and-answer structure], don't they? Straightforward answers." – Digitally disengaged interview*
>
> *"I like the [journey structure] because it's kind of personalised…it helped to explain and put it into a human context" – Group 3, Post-family*

Content

Participants were shown a mocked-up visual resource explaining key facts about the data collected in the GP record *(see Appendix, p55)*. This resource was used to give participants an idea of what the final co-designed resource could look like, providing them with a point of reference which they could use to inform their input.

This mocked-up resource was designed to cover the key topics that people wanted to know more about in Stages 1 & 2 of the research. The resource covered:
- What information is collected and held in the GP record
- How to access the GP record
- How is GP record data used and why
- Who has access to GP record data for purposes beyond individual medical care
- How GP record data is kept safe and secure
- Choices around opt-out

Participants were asked what information should be included in the content of the visual resource, and what information the resource does not need to include.

The key takeaways are:

- **The most important topics for the resource to cover are: how to access the GP record, how GP record data is used for purposes beyond individual care, who has access and why, and the measures in place to**

keep GP record data safe and secure. Aligning with the findings from Stages 1 and 2, these were the topics that were prioritised by participants in the Stage 3 workshops and interviews

- **The least important topics covered by the resource were: what information is collected and held in the GP record, and how GP record data is used for individual care.** Participants were less concerned with these information topics which they felt they broadly knew about already
- **There was no strong consensus that the resource needed to cover any additional topics**. Whilst no one felt strongly that any information was missing, a few participants suggested that the resource could cover:
    - Where GP record data is stored - whether it's stored on a cloud-based system or on servers located in this or a different country (although it is worth noting that in the Stage 2 workshops and interviews, most participants did not feel this needed to be covered)
    - How, if at all, parents can access their children's records
    - The potential risks of using and sharing GP record data

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"You just want to know how to access it, should you need it"
Group 2, Family

"How data in the GP record is kept safe and secure. This is what people want to know really" Digitally disengaged interview

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- **Tell the reader what they need to know**, without overloading them with information: most people do not need anything more than top-level detail to answer their questions about GP record data. For example, for the question 'Can I opt out of my data being used?', participants expected to see a simple 'Yes' answer with signposting to further information on what this means and how to opt-out for those who are interested.
- **Signposting via QR codes** can be used to direct to more detailed information for the small proportion of people who are likely to want more information
- **Avoid crowding the resource with examples**: it's sufficient to have a point without an example in this type of resource aimed at the general public, as long as the point is easy for the reader to understand and avoids jargon (e.g. Conduct health research). Most participants only want to know information about how their GP record data is used, shared and accessed at a top level,

and in the minority of cases where they want to find out more, they can be signposted to further information with more specific examples.

- **Emphasise that, in most cases, de-identified data is used for purposes beyond individual medical care.** Across Stages 2 and 3, it was made clear that people are concerned about their personal information being used. People are not aware that de-identified data is generally used and they felt that they needed to be informed that steps are taken to remove their personally identifying details before their data is shared and used.
- **Consider avoiding overly reassuring examples**: a few felt that any examples used in the resource needed to be transparent. The mocked-up poster used Cancer Research UK as an example of an organisation accessing GP record data for purposes beyond individual medical care. Rather than using an example of a medical research charity accessing data, which could be perceived as overly reassuring and hiding the truth, it may be better to use an example of how a private organisation accesses and uses data, which could seem more honest and transparent and directly addresses concerns.

> *"It's in my best interest to know that it's secure, but as long as I know it's secure, then that's fine. Do I need to know all the technical details about it?" Group 2, Family*
>
> *"Examples are good, but if it's just on a poster, it could probably be too much for the everyday person" Digitally disengaged interview*
>
> *"[Cancer Research UK] They're big names and everybody's really happy that they might be using our information to help. But I believe there are other organisations who are of a more commercial nature who also apply for that information…so the example given, I think, was a bit of a sort of soft glove" Group 3, Family*

Language

The key takeaways around language are:

- **Keep language simple, avoiding jargon wherever possible**: participants were satisfied with the language used on the mocked-up visual resource, which they found easy to understand.

- **When specific terms are required for accuracy, ensure that they are explained in simple, relatable terms**: some participants struggled with the term 'de-identified data' in isolation. They found the explanation of the term used on mocked-up visual resource helpful (*'Generally this is done using de-identified data from a lot of records, meaning personal details that could identify you – such as your name or date of birth – have been removed or disguised')*. It was even suggested that this explanation should be emphasised by bolding the text.
- **Use personal language, such as 'your' or 'my', throughout (e.g. your GP record) to engage the reader:** as people interacting with the resource will be looking for information about data that they perceive to be personal and private, the poster should avoid using abstract, impersonal language (such as '*a person's GP record*').
- **Ensure language choices are accessible:** participants were asked if they preferred the term 'information' or 'data' to be used (e.g. *'information/data from your GP record'*). Whilst some felt that 'data' was more specific and appropriate for the topic, 'information' is more accessible for older and digitally disengaged audiences, who may not understand or be put off by the term.
- **Be consistent with language choices:** there was no clear consensus around whether the resource should use the term 'individual medical care', 'individual care' or 'medical care and treatment'. Participants understood, and were happy with, any of these options so long as it remained consistent throughout.

Visual style and presentation

Participants were shown another version of the mocked-up visual resource as a point of comparison about the visual style, level of detail and imagery. It replaced the colourful imagery with icons, and removed information from some of the sections. A second identical version was also shown using a different colour scheme (red) to the original *(see Appendix, p56-57)*.

The key takeaways from discussions around visual style and presentation are:

- **Use a range of colourful cartoon imagery**: this makes the poster more engaging than using monochrome icons. Icons can still be used alongside the text to provide a visual explanation of the information, but they should not be used in isolation
- **Use icons to assist with a visual explanation of the text**: although they should not be used in isolation, icons can be helpful in making information

easier to read and understand e.g. using icons alongside bullet points as a visual explainer

- **'Less is more'**: from discussions with participants, it was clear that members of the public are more likely to engage with a resource that, at first glance, looks short and succinct
- **Make the title active, short, and engaging**: suggestions included *"Understanding your GP record"* or *"Information about your GP record"*
- **A blue colour scheme makes the resource seem more trustworthy and reliable**: participants agreed that the resource should use a blue colour scheme to visually link it to the NHS, who they trust as a source of information
- **Consider using an NHS logo or have information about GP record data endorsed by a recognisable NHS organisation** (e.g. NHS England), ensuring people trust that the information provided is accurate and reliable

> *"Every time I see NHS, I sort of trust it in a way. So I look at all the NHS type of things, especially after COVID as well." Group 2, Family*

Method of communication

The discussion guide did not focus on how this resource would be disseminated. However, some interesting points emerged naturally out of wider discussions about the resource, which are worth taking into consideration:

- **Consider layering information**. As interest in the topic of GP record data is mixed, it may be effective to use layers of information, with each layer providing more detail about GP record data, so people can find out what they need to know, either at a top-level or by accessing more detail if they want to know more. Participants emphasised that any information about GP record data not included in the resource should be signposted for those who want a more detailed level of information
- **Use QR codes to assist with layering information**: participants identified this as an effective way to signpost to further information for those who want to know more detail. They expected the QR codes to direct to a webpage, providing more detail about each of the topics on the resource.
- **Make the resource easy to edit**: one group suggested that the resource should be translated for non-native speakers. Whilst it would depend where the resource was disseminated, the resource should be made easy for others to edit to make these feasible. Additionally, this could help with the

suggestion of NHS endorsement, as it could allow different NHS organisations to add their logos to the resource if desired.

7. Conclusions

- Public understanding and awareness around GP record data is generally low. Workshops and interviews indicated that participants in this research were unlikely to have considered the topic in any level of detail prior to taking part.

- Whilst levels of knowledge about GP records were low across the board, the types of data that are collected and held in the GP record matched expectations. People expected information about them, their health and their lifestyle to be collected, and subsequently stored in their record, when they interact with their GP surgery.

- However, there were a number of incorrect assumptions made about GP record data. The research showed that people tend to assume that the NHS is a single entity, rather than a collection of different healthcare services. This likely informed, in part, the expectation held by most that the data collected about them would be stored in a single national healthcare record controlled by a national body, such as NHS England or the Government, rather than, as is currently the case, in a GP record managed by their local GP surgery. Furthermore, the fact that private IT companies approved by NHS England supply the digital systems used to store GP records did not meet expectations, with most assuming that these systems would be provided by the NHS.

- The research findings demonstrated that, whilst respondents are conscious that GP record data can be used for a person’s individual care, there was limited awareness that the data collected by GP surgeries could be used for purposes beyond this, for planning, population health management, and medical research. Further, there are even lower levels of awareness regarding which organisations have access to GP record data for these purposes, which, in some cases, led to concerns about data access and misuse by organisations outside the NHS. This was reflected in lower levels of support for using GP record data for these other purposes compared to using it to provide individual medical care.

- There was an assumption that medical information, such as allergies or prescription information, from a person’s GP record can be shared with different NHS healthcare services to help provide them with medical care and treatment. However, there is confusion around which services specifically, aside from hospitals, have access to this information, or what level of information they have access to.

- Whilst there is an expectation that national bodies, such as the Government or NHS England, make decisions about how GP record data is used or shared for secondary purposes, people are most likely to trust their GP to make decisions about their data. Findings demonstrate that the NHS is trusted in general, with GP surgeries trusted in particular.
- Interest in the topic of GP record data as a whole is mixed. When considering what they want to know more about when it comes to GP record data, people tend to be interested in topics that they perceive to be more personal. Across the research, it appears that is important for members of the public to be informed about how to find and see their GP record, so they can view and check their personal medical information.
- Participants were interested in certain topics due to concerns about the security of their personal information, or their information being used for purposes they disagree with, such as for profit. People wanted more information to be made available about how their data is used for purposes beyond their individual care, who has access to their data and at what level of detail, as well as how their data is kept safe and secure.
- Findings suggest that most participants would only need top-level detail about these topics in order to answer their questions. For example, when it comes to how GP record data is used for secondary purposes, most needed to know the broad categories of use cases, and that de-identified data is used in most cases, to ensure that their personally identifiable information was not being shared or used for ‘nefarious’ purposes.
- When it comes to receiving information around GP record data, people are unlikely to have received, or recall receiving any information, either from their GP surgery or another source.
- Whilst some suggested that information should be sent out to people without them needing to ask (e.g. via a letter or text message), the lack of pre-existing interest in the topic and some participants stating that they would not engage with information if they received it in this manner, suggests that members of the public may be unlikely to engage with information if it was sent to them without them requesting it.
- Instead, as participants emphasised, the most important thing is making information available in case people want it, either online via an NHS website or in their GP surgery. Even those who said they would not seek

this information out themselves generally said that it was important to have the information available, should they want it.

- Most participants who stated they would seek out information about GP record data would look online for this information if they wanted it, or ask staff in their GP surgery, depending on their level of digital engagement, suggesting that these would be the most appropriate sources of information. This information could be signposted in healthcare settings, to ensure that those who want this information are aware of where to find it.

- Overall, as the key takeaways from Stages 2 and 3 show, any information made available to the public would need to be straightforward and simple, so that people who have little existing knowledge about GP record data can easily find details which tell them what they need to know about the topic at a top-level. Any information could also be layered, making use of signposting to further information for the small proportion of people who are likely to need it.

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