JUNE 2025

NHS England | National engagement on data

Cohort 2 Report

1. Executive summary

Please see publication on the NHS Transformation Directorate webpage.

2. Background and methodology

2.1 Background to the work

The DHSC and NHSE set out plans in 2022 to harness the potential of data in health and social care while maintaining high standards of privacy and ethics. A central aim of the strategy was to build confidence for the public in how their data is handled and used to inform care, following previous admitted failings.

As part of this, DHSC committed to building public trust through meaningful engagement on data policy and services. The need for a large-scale engagement programme was identified, to explore complex and high priority topics set out in the Data Saves Lives strategy.

This work is led by the Digital Policy Unit, a joint unit between NHS England (NHSE) and the Department for Health and Social Care (DHSC). Thinks Insight & Strategy have been commissioned to deliver the series of large-scale public deliberations.

This programme of work aims to influence the development of certain data policy and data programmes, ensuring they build on public views and attitudes, by informing members of the public and giving them space to weigh up trade-offs. It also aims to build public trust and confidence in data use and access by generating opportunities for the public to meaningfully and visibly influence policy and services.

Specifically, this large-scale public engagement aims to:

- Understand the public’s attitudes towards health and social care data use.
- Influence policy and services.
- Meaningfully engage with the public to help build trust and confidence.

2.2 Structure of the programme

The programme is split into three different cohorts of work across 2024/5. At inception, the three cohorts aimed to focus on different aspects of the use of health and social care data and privacy.

Cohort 1 covered principles of data use and access, including the exploration of public perceptions of the value of health and care data, views on data access and governance of Secure Data Environments (SDEs), and the creation of a Data Pact. Conversations throughout also explored the creation of a transparency hub.

Cohort 2 covered the linking of primary and secondary care data, with a focus on a single patient record and secondary uses (i.e. planning and research) of data in the GP record.

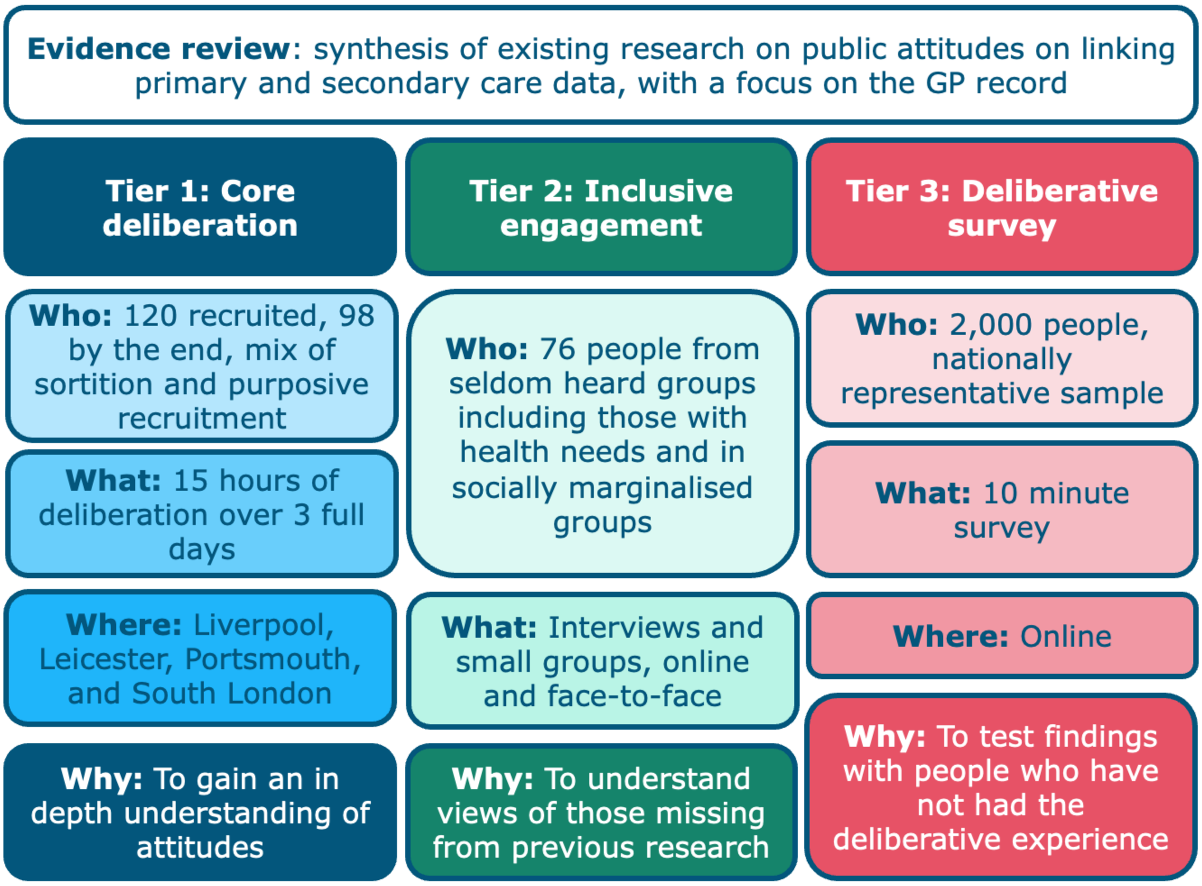
This report explores discussions and findings from Cohort 2. It is split into two main sections:

- Part A outlines the findings relating to a single patient record.
- Part B covers the secondary uses of GP patient record data.

In October 2024, the Department of Health and Social Care formally announced plans to introduce a single patient record. This record will gather together patient data from across all NHS trusts and GP practices. It will be a single electronic record of all health and social care information about a given patient.

Within each cohort, the deliberation includes three Tiers of engagement, as well as a review of existing evidence. By taking a mixed method approach, we aim to provide rich insight into the views of the public, including those often excluded from policy engagement, and understand where views of those taking part in the deliberation change and therefore differ from the wider public. This allows this programme to provide evidence both about what policy is acceptable to citizens and how it needs to be communicated.

This structure was designed to mitigate some of the limitations of deliberative engagement: the inclusive strand (Tier 2) to ensure diverse voices that might otherwise be excluded; and reaching a wider audience who did not have the benefit of 15 hours of information sharing and deliberation (Tier 3). It is important to recognise that this was a national level approach (in England), and so did not address issues specific to each locality.



Evidence review: synthesis of existing research on public attitudes on linking primary and secondary care data, with a focus on the GP record

Tier 1: Core deliberation	**Tier 2: Inclusive engagement**	**Tier 3: Deliberative survey**
Who: 120 recruited, 98 by the end, mix of sortition and purposive recruitment	**Who:** 76 people from seldom heard groups including those with health needs and in socially marginalised groups	**Who:** 2,000 people, nationally representative sample
What: 15 hours of deliberation over 3 full days		**What:** 10 minute survey
Where: Liverpool, Leicester, Portsmouth, and South London	**What:** Interviews and small groups, online and face-to-face	**Where:** Online
Why: To gain an in depth understanding of attitudes	**Why:** To understand views of those missing from previous research	**Why:** To test findings with people who have not had the deliberative experience

***Figure 3**: The Tier structure for cohort 2*

- Tier 1 consists of immersive deliberative engagement. For cohorts 1 and 2, it includes a series of three day-long workshops with 120 people, amounting to 15 hours of deliberation overall. Workshops were held in-person in four different locations, with location varying across each cohort to ensure coverage across England and across the eleven regional SDEs throughout the programme of work. There was a relatively high attrition rate across the week we engaged this tier, with 98 joining the final workshop, due to last minute dropouts and participants experiencing illness or medical issues.
- Tier 2 amplified lesser heard voices in a more inclusive and adapted environment, and to meet accessibility needs that were unavailable via the Tier 1 engagement. This includes groups such as those living with health conditions, and those from cultural or religious minorities. In each cohort, these audiences are engaged on the same topics as in Tier 1 through workshops and one-to-one interviews. In total, 76 people took part in Tier 2 for the second cohort.
- Tier 3 aims to validate findings from Tiers 1 and 2 with a wider public audience. This is done through a deliberative survey, providing participants with some information alongside asking questions, with a nationally representative sample of 2,000 people. This sample was then split in half, with 1,000 respondents answering questions about as single

patient record and the other 1,000 responding to questions about secondary uses of GP patient record data.

Each section of the report – Part A, a single patient record and Part B, the secondary uses of GP patient record data – ends with a set of policy recommendations. Combining the data from each Tier, we identified recurring themes, points of consensus, and areas of divergent opinion. Synthesising these themes with the policy objectives, we have developed into actionable proposals, ensuring these honestly reflect participant opinion.

More detail on the approach to research, as well as sampling and recruitment can be found in the appendix.

2.3 Aims and objectives for cohort 2

In the context of the wider programme of work, cohort 2 aimed address two broad questions framed this round of deliberation:

1. How should a single patient record be designed in a way that maximises the potential benefits and is trusted by the public?
2. What is the best way of ensuring that data in the GP health record is used for planning and research, in a way that the public trust?

Within these two questions, participants deliberated on the following issues:

- **A single patient record**: Initial feelings about and expectations around a single patient record; the conditions that the public ask to be met in order to feel trust and confidence in a single patient record; expectations for access to a single patient record, for health and care professionals and for patients.
- **Secondary uses of GP patient record data**: Initial reactions to GP patient record data being used for planning and research; how the public feels GP patient record data compares to other health and care data; controllership of GP patient record data.

2.4 Fieldwork for cohort 2

Workshops were held on the 2nd, 3rd, and 9th November 2024 in four locations, which were linked together through online video conferencing for plenary presentations and to feed back discussions in each location. The four locations for cohort 2 were:

- Liverpool
- Leicester
- Portsmouth
- South London

Workshops comprised a mix of plenary and breakout discussions run by Thinks facilitators. Note takers were present at each breakout group to ensure conversation was captured for analysis.

Participants learned about data use and access through presentations from specialists, case studies and group deliberation. A breakdown of the materials can be found in the appendix.

Tier 2 comprised a series of small-scale online workshops and one-on-one interviews. These engaged 76 participants in total from November 2024 to January 2025.

The Tier 3 deliberative survey was in field from the 18th to 24th December 2024.

2.5 Data collection and presenting the findings

The findings presented in this report reflect a summary of what participants told us directly during fieldwork plus thematic analysis of the collected data. Analysis was done by the Thinks research team to draw out the common points of agreement and disagreement across locations and audiences.

By the close of Tier 1 deliberations, participants had told us directly:

- The conditions under which the benefits of a single patient record outweigh the risks.
- The rules that should apply to health and care professionals accessing a single patient record, including which staff should have access and when.
- Whether they would want access to their whole single patient record.
- Whether the information in GP health records should be treated differently from other types of health and care data.
- Who should make decisions about how data in their GP health record is used.
- What they would want to see from any new model of decision making about GP patient record data for secondary uses (which could have implications for models of controllership).

Tier 2 participants were asked to deliver similar recommendations, abbreviated in line with the reduced time spent scrutinising the issues and trade-offs. Tier 3 respondents answered a specific set of questions (a full list of which can be found in the appendix).

The collective raw data from Tiers 1 and 2 was captured via note takers (Tier 1). This coding allowed the Thinks research team to compare responses across locations and identify key themes. Syntheses of participant recommendations across all locations were then formed.

During this analysis phase, further thought was given to the implications of these findings for national and regional policy makers, as well as for future health and care data engagement. These recommendations for both policymakers and future engagement represent the final stage of presenting the findings.

2.6 The evidence review

Fieldwork was preceded by a review of the available evidence in publication from 2016 onwards on public perceptions of primary care data and its use and linkage within the context of England’s public health and care system. Exclusion criteria included any research published outside of this timeframe or outside the UK, as well as research which relied on soft evidence or lacked a clear research process to produce credible findings. The list of sources consulted was weighted towards those published in the last 5 years.

The aim of this evidence review was to synthesise any relevant published and grey literature on primary care data and its uses within the context of England’s public health and social care system.

Insights identified in the review informed the design of the study. Best practice and learnings from previous research informed choices around approach, sample structure, materials, discussion topics, and hypotheses for testing.

The evidence review is updated ahead of each subsequent cohort, focusing on the relevant topics each time.

Key findings from the cohort 2 evidence review

The headline findings for the cohort 2 evidence review were:

- **Evidence suggests that most of the public believes that their health and social care data should be used to improve health and care beyond their individual care. But a lack of previous clear and transparent communication on this has led to some mistrust among the public as to how it is enacted.** However, research into this hasn’t allowed for deliberation and exploration of trade-offs sufficiently to confidently inform current policy making and so has not established much beyond agreement in principle. Cohort 2 will dive deeper into trade-offs and build richer insights with deliberation.
- **There is a lack of definitive evidence that the public is comfortable (or uncomfortable) with their GP patient record data being used for purposes other than their individual care.** There is support for this data being used for patient benefit, but limited insight on free text data specifically.
- **The patient-GP relationship is unique, and trust is a crucial part of that relationship.** There are arguments that GPs’ role as data controller for the information held in their records is important to this relationship, but further research is needed to test this thinking with the public.
- **There is a lack of understanding of the opt-out landscape among the public.** The choice to opt out tends to be driven by concerns that data will get into the wrong hands. Clearer communication is needed around the choices that patients have.

- **There’s a range of proposed principles and models for how patient data should be handled and used within the health and social care system.** These are a useful starting point, but we believe that more nuanced and specific guidance is needed.

Part A:

A single patient record

3. Introducing a single patient record

3.1 Context

In his speech to the RCGP (Royal College of General Practitioners) on 4th October 2024, the Secretary of State for Health and Social Care announced the intention to create a single patient record:

> *"We need to work together to create a single patient record, owned by the patient, shared across the system so that every part of the NHS has a full picture of the patient. This applies as much to research as to care."*

This record will gather together patient data from across all NHS services and GP practices and would allow all providers of care to access (to relevant depth) a comprehensive patient record for the individual in their care.

At the stage of commencing fieldwork for this cohort, exactly what a single patient record may look like in practice had not been set out in detail. Cohort 2 of our national engagement on data presented a timely opportunity for the public to shape the design and implementation of this national policy from the ground up. We explored patient views on a single patient record and the issues inherent in introducing it. We spoke to the public on the topic across each of the three Tiers of cohort 2.

3.2 What we explored with participants

Tier 1 (core deliberation) and Tier 2 (inclusive engagement) explored:

- How a single patient record can be designed in a way that maximises its potential benefits and is trusted by patients.

To help answer this, we asked:

- What participants' initial views on a single patient record were.
- The conditions that participants felt they needed to be comfortable with a single patient record.
- What rules should apply to health and care professionals accessing a single patient record.
- Views on being able to see their own single patient record.
- The ways that data would be accessed were not covered in detail with participants.

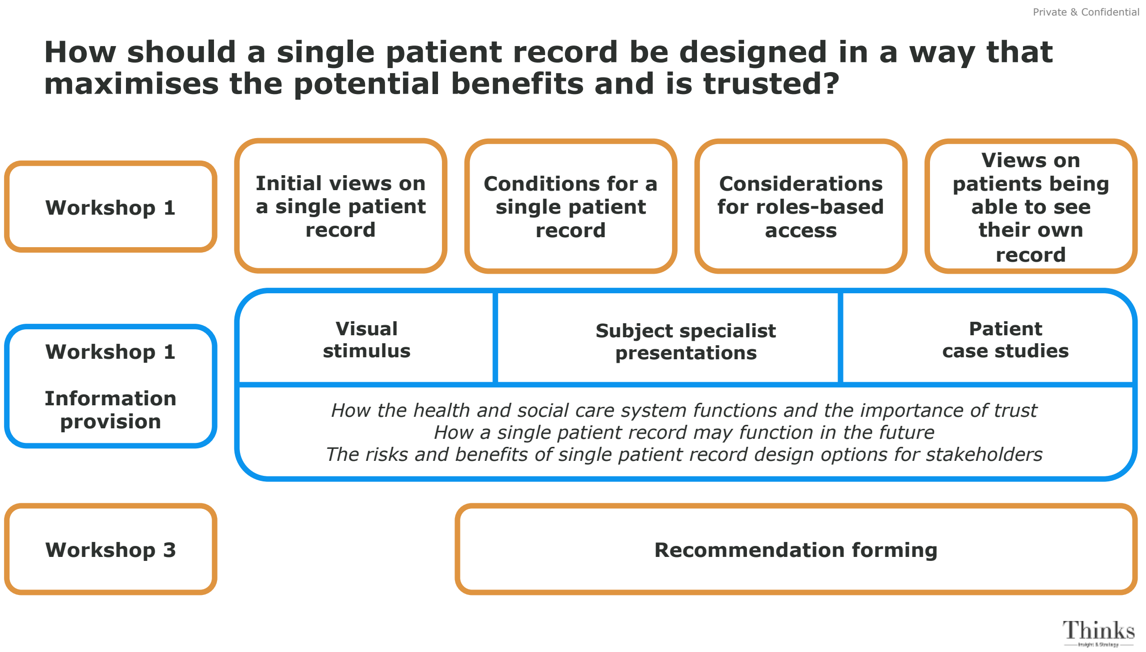


Figure 4: *Flow of core deliberation workshops and information provided to participants*

In the Tier 3 deliberative survey we tested:

- Spontaneous attitudes and support for a single patient record.
- Attitudes and support for a single patient record after information provision.
- The factors most important in building confidence in a single patient record.
- Attitudes towards access to a single patient record (professional levels of access, principles of access, and desired transparency measures).

3.3 Information provided to participants

The full set of stimulus material can be found in the appendix shared alongside this report and is summarised below.

Tier 1

In the core deliberations, we presented participants with a range of information. This comprised visual stimulus and presentations by topic specialists. Case studies were introduced to get at the heart of the various trade-offs inherent in the move to a single patient record.

This information included prospective risks and benefits of a single patient record, both from the perspective of health and care professionals and from patients.

Subject specialist and expert presentations provided information on:

- How the health and care system currently works and the importance of patient trust.

- Various ideas about how a single patient record may function in the future.
- The risks and benefits of a single patient record from the perspective of different stakeholders involved.

We presented two direct care case studies to explore trade-offs:

- A case study concerning a patient with multiple long-term health conditions who interacts with different health and care providers concurrently. We introduced further 'what if' scenarios to add complexity, such as a close friend of the patient working at the local pharmacy and potentially having access to their mental health records.
- A case study addressing the linking of health data with adult social care data, with similar additional 'what if' scenarios introduced as deliberations progressed.

Tier 2

In the Tier 2 inclusive engagement, we showed participants a truncated version of the above information to fit into the time spent with participants in the different settings (2-3 hour workshops and 1 hour depth interviews).

Tier 3

In the Tier 3 deliberative survey, we provided simple information about a single patient record and the benefits and risks it carries. Additionally, we tested ideas generated in the core deliberations.

4. Initial views on a single patient record

Key findings

Spontaneous views revealed that the concept of a single patient record was met with relief and enthusiasm. Participants immediately identified benefits to a single patient record (especially more frequent users of healthcare): better experiences using healthcare systems; improved efficiency of care; and; ultimately, better health outcomes.

They swiftly identified a single patient record as being a potential solution to a common frustration: having to frequently repeat your health history when interacting with different aspects of the health and care system.

Initial reactions also included spontaneous concerns: data accuracy and how this would be maintained; privacy; and security (e.g. a single centralised record might increase the risk, and potential impacts, of cyber-attacks).

Yet the broad consensus across cohort 2 was that the benefits of a single patient record would outweigh these risks as long as high levels of security, patient choice, accuracy of data, and transparency were addressed.

This chapter begins with participants' first reactions towards the concept of a single patient record and then covers participants' views on the potential benefits and risks of having a single patient record. The benefits and risks were explored through participants' own situations and two potential scenarios – someone with multiple and chronic health conditions and someone spending time in a care home after receiving emergency treatment. This chapter ends with a brief summary of the conditions and caveats that were discussed as being initially important for a single patient record.

4.1 Tier 1's initial reactions to a single patient record

Overall, Tier 1 participants were supportive of a single patient record. This was widely felt to be a long overdue and necessary step towards better care.

> *"You have an organisation stuffed with people who can take you apart and put you back together, and yet you cannot share information between GP practices. In the 21st century, you have digital expectations. It's jaw-dropping how much of a b***** mess it is!"*
>
> *Liverpool, male, Workshop 1*

While there were initial misgivings and concerns raised at the start, participants generally felt the benefits outweighed the risks. In particular, those with – or caring for someone with – multiple health conditions could readily identify benefits than those with less healthcare exposure. Participants imagined a record that they could access and potentially edit to ensure the record was up to date. However, there were concerns and questions raised about whether this was a good idea and who would be accountable for the record.

Wider access and security generated lots of discussion and questions around who would have access, whether consent should be obtained to share the record (through the patient and / or GP), privacy (particularly of information considered sensitive), and the accuracy and management of the record.

Benefits of a single patient record

In discussing the benefits that a single patient record may bring, four elements stood out.

It was generally agreed that the main advantage of having a single patient record would be **efficiency**, thus leading to **improved care and better health outcomes**. Much relief was felt at the idea that a single patient record could end the need for **patients to repeat their health information** multiple times across different health and care settings. Participants also suggested that the introduction of a single patient record could lead to **improved quality and accuracy of data.**

Improved efficiency

There was hope that a single patient record would allow healthcare professionals to focus more on providing care. It was expected that less time would be spent on managing data, repeating tests, and having to extract information from patients. In turn, it was assumed that this could create either shorter appointments or more time spent diagnosing and / or creating a more tailored treatment plan.

Participants hoped this improvement could reduce waiting times and save the NHS time, resources, and money. If healthcare professionals' jobs were simplified by having a single patient record, then patients could benefit from this.

> *"It's unfair to expect clinicians to treat you in the best way if they do not have the holistic information."*
>
> *Liverpool, female, Workshop 1*

Improved care, improved outcomes

With full information more readily available, participants believed that healthcare professionals would be able to more quickly and accurately identify a patient's needs and formulate diagnosis and treatment plans.

The ability to see a patients' conditions and needs holistically was identified as a clear outcome for better and more tailored care, potentially resulting in a smoother transition between different health services (e.g. between hospital and care home).

Participants could also see the value if they needed urgent treatment while away from home – they felt confident that having a single patient record would enhance patient safety.

> *"The benefit is, especially if you have a complex condition, you have that information in one place, especially in emergency situations."*
>
> *London, female, Workshop 1*

Less reliance on patients to repeat information

Participants lamented the current system of having to repeat long, complex and detailed information to different healthcare professionals. This was something that many struggled to do. Especially when talking about complex health conditions, recalling specific treatments and medications, and experiences that may have happened decades ago. This was also a challenge for those who cared for loved ones.

Participants described situations in which needing to repeat this information made them feel anxious (that they were being relied on to recall certain information), unheard (that professionals had not listened the first time) and in some cases, retraumatised.

Participants expected that a single patient record would mean they would not be solely responsible to provide this information. And that they would be able to provide a much briefer overview when receiving care.

> *"If you have to re-explain whole situation again and again, you feel deflated."*
>
> *Leicester, female, Workshop 1*

Improved quality of information

A clear advantage in having such a record, participants suggested, was to avoid information being missed or forgotten. Especially if patients are granted access to the record.

Participants imagined that information would be collected in a consistent way across settings. If a patient was lacking mental capacity (unconscious or suffering from dementia for example), then the healthcare professional could refer to the record to administer the right care or treatment.

Concerns about a single patient record

Participants spontaneously raised several concerns – mostly in relation to how the record would work in practice. There was unease about 'sensitive' data being shared more widely and how patients' privacy would be protected. There were fears about the potential effects from cyber-attacks and data breaches. Participants also queried the accuracy of the record especially if the record was used to replace the patient's own voice. Finally, the question of how the NHS could afford to undertake such a complex and costly venture was asked.

Sharing 'sensitive' data

It was considered that people might not want certain details of their health history shared with healthcare professionals beyond their GP. Participants worried about this information being shared with professionals they trusted less and that they felt did not need to know extensive information about them. This generally included administrative staff, as well as professionals who provide more specialised care (i.e. pharmacists, opticians, radiologists). More detail on participants' wishes for staff access is explored in chapter 6.

This more sensitive information included details about previous or current mental health, sexual health, conditions relating to being in the military, gynaecological notes, and domestic violence.

> *"I think I'm now a bit concerned, I've not used the NHS in a long time, but I was in the military for a longtime, and I was in a specific unit, and I was injured in Afghanistan…and I wouldn't want that going out of just the GP."*
>
> *London, male, Workshop 1*

There was concern about being treated differently due to bias and judgement, as staff may find out information about patients that could lead them to treat them differently. This concern often surrounded past mental health issues, and professionals using these to dismiss health issues that patients might be experiencing.

Fears about 'sensitive' information being shared intensified when participants imagined this data being accessed by organisations outside of the NHS – e.g. the Department for Work and Pensions using it to make assessments about eligibility for benefits.

Privacy concerns with more staff being able to access data

For many participants, there were worries about NHS staff not involved in their care being able to access their medical information. There was also some discomfort in people they knew on a personal level working in the NHS being able to access their record.

> *"It's the people I don't trust, not the system."*
>
> *Portsmouth, female, Workshop 1*

Concerns around data breaches, cyberattacks

As participants were not presented with a specific model, they often assumed that all single patient records would be stored in one singular database. Participants viewed this as more enticing for hackers, compared to a database being held in multiple places. There were fears about this causing:

- A risk to other data such as financial information (health data being 'a stepping stone').

- The potential for blackmail.
- Data getting lost temporarily or permanently.
- Negative outcomes for their health due to longer wait times[1].

Errors in the data

There were also concerns about the potential for more errors to be made as more members of staff would have access and be able to amend a patients' record. They felt this could be caused by members of staff who knew them less well editing their record and accidentally adding in errors. Separately, participants also worried that errors in their single patient record could lead to these errors being shared widely across a range of settings and potentially affecting their care.

There was also concern about an overreliance on digital notes which could include errors or incorrectly inputted data, without patients being able to check for accuracy.

> *"If someone's not saying something themselves and then they're relying on the computer how do you know they've not been hacked or how do they know it's been recorded properly."*
>
> *Liverpool, female, Workshop 1*

Cost and complexity

Questions were asked about whether the NHS had the resources to undertake such a large project.

There were further questions raised about the NHS having the capability of undertaking such a project successfully – especially given its seeming complexity. Participants were particularly worried about the skill and investment needed to ensure the highest level of security.

4.2 Tier 2 initial reactions to a single patient record

Tier 2 audiences were also largely supportive of the move to a single patient record and echoed the same benefits.

Those who frequently interact with health services (i.e. those with long-term and/or mental health conditions) spontaneously thought that the single patient record could improve the continuity of their care. They talked about how frustrating it was to have to remember their medical history, repeat themselves across settings, and have important healthcare information fall through the

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[1] Some participants in London had experienced having to wait for a blood test due to a cyberattack at Synnovis, a pathology laboratory which processes blood tests on behalf of a number of NHS organisations https://www.england.nhs.uk/london/synnovis-ransomware-cyber-attack/

cracks. They could also see how processes would be improved – leading to more proactive, streamlined, timely, and personalised care.

> *"I had to do it this week. I went to my GP to get a prescription from them, and then I had to spend about 10 minutes telling them about this other prescription that I'm on because there were interactions. There wasn't even like a footnote on my records or anything."*
>
> *Long-term health condition, in-depth interview*

Unpaid carers were also positive about the single patient record, feeling that improved processes and streamlining could help reduce workloads, alleviating some of the burden of care and minimise delays.

Tier 2's concerns were the same as Tier 1 but their fears around data privacy and security were more pronounced. Sex workers, members of the LGBQ+ community, those with mental health conditions, and those with prior justice system involvement described their data as especially sensitive. They worried about their data being 'leaked' or misused. They were anxious about friends and family working in the NHS seeing their data, and effectively revealing this information. They also worried about misuse by authorised actors working for the NHS or for private, for-profit companies.

> *"My dad's a GP, and I remember when went to university and kind of left that GP practice I thought I can be a bit more transparent and open. I never really went to that GP practice because my dad was there. It's just that feeling that he could go back to seeing everything [about me]."*
>
> *LGBQ+, workshop*

With lower levels of trust in public institutions like the NHS, sex workers, and migrant audiences were more concerned about data sharing between multiple actors, organisations, or people. Transgender people were especially concerned that a single patient record could enable harm in healthcare settings, as almost all described experiencing discrimination from healthcare practitioners previously.

4.3 Tier 3 reactions to a single patient record

Support from Tier 1 and 2 for a move to a single patient record was further evidenced by Tier 3 respondents. They were asked, unprompted, how much they supported or opposed a single patient record. The majority (80%) were in support of a single patient record, with only 4% opposed.

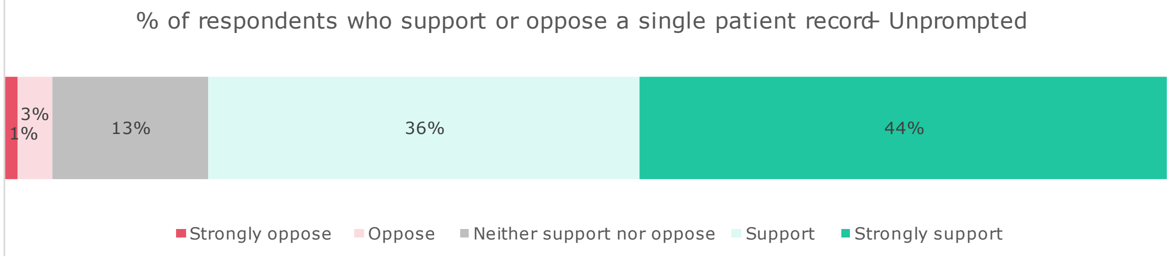


__Figure 5:__ Q1. To what extent would you support or oppose your health and care data being connected through a single patient record? Base: n=1004

When provided with some more information about what a move to a single patient record would look like, Tier 3 respondents were slightly less positive, although still overwhelmingly in favour. Over three quarters (76%) supported a move to a single patient record, while 9% were opposed.

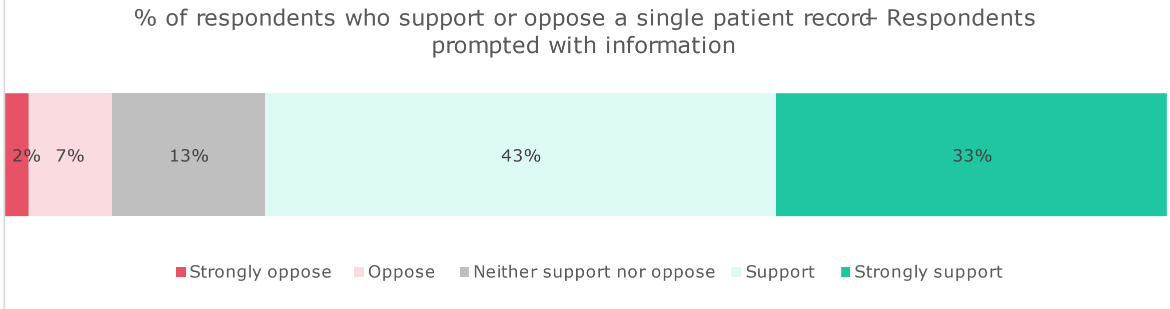


__Figure 6:__ Q3. To what extent would you support or oppose your health and care data being connected through a single patient record? Base: n=1004

4.4 Conditions and caveats

In deliberating the benefits and risks of a single patient record, a number of conditions and caveats were raised. These can be grouped into four overarching themes:

- **Security**: a high level of security, including staff training.
- **Choice**: taking patient preferences into account.
- **Accuracy**: consistency in the updating and synchronisation of data.
- **Transparency**: providing information to the public about the move to a single patient record and the implications - including clarity on who would have access to the patient record.

The next chapter of the report provides more detail on what participants needed to be in place to feel comfortable with a single patient record.

5. Conditions for a single patient record

Key findings

Participants discussed what would make a single patient record system trustworthy to them. Four broad themes were suggested:

- ***Security**: a high level of security, including staff training as well as technical measures.*
- ***Transparency**: in the design and working of the record; providing information to the public about the move to a single patient record and the implications, including clarity on who would have access to the patient record.*
- ***Accountability**: stakeholder involvement over how data is managed and used, including processes for when things go wrong.*
- ***Patient choice**: ensuring that patients are informed and have a say on how some data that is considered sensitive is shared.*

Tiered and roles-based access for staff was also discussed across all four of these key themes. This is covered in detail in the following chapter.

In this chapter, we detail the trade-offs that participants made in deliberating the benefits and risks of a single patient record and what conditions would help them to feel more confident. The chapter continues with a summary of what participants told us were the most important conditions. The final part of the chapter considers the public's information needs around the roll out of a single patient record.

5.1 Tier 1 priorities and trade-offs

A number of issues were discussed amongst Tier 1 participants, and the following priorities were discussed at length:

- Providing security and avoiding data loss.
- Maintaining privacy by restricting access (tiered access for staff).
- Upholding accuracy of the record.
- Allowing for patient access.
- Ensuring that the public are consulted and have choice.

Participants deliberated over which conditions were important in helping to build trust in a single patient record. The following themes were identified as the four priority conditions:

- Security
- Transparency
- Accountability
- Patient choice

Security

To participants, this meant ensuring records are kept as safely as possible, especially while they are accessible to more members of staff than before. This felt like a "hygiene factor" – i.e. something that, through its absence, could cause discontent.

Participants wanted the NHS to learn from other industries such as banking and ensure that systems would be robust enough to protect against cyberattacks and the risk of data getting lost / deleted. They talked about 'back up systems' to ensure duplicate information was held elsewhere.

> *"If things got deleted and they couldn't access anything. If it disappeared for any reason, what would be in place to make sure he still has some records."*
>
> *London, male, Workshop 1*

It was reasoned that a single patient record could allow for greater investment for protection – one set of security systems as opposed to the current approach where there may be differences across services and settings.

> *"To my mind, the more places your data is the more risk there is to that data, so I don't know whether it's weird, I would feel much more comfortable if my data was in one legislated place than spread between many different systems, of different quality."*
>
> *Portsmouth, female, Workshop 1*

Suggestions were made for there to be two-factor authentication for those accessing the data and restrictions on device type.

Transparency

It is important to note that participants kept returning to the notion of transparency and that this applies across communication, security, and accountability. In terms of the system itself, how much access participants wanted varied from individual to individual.

Ultimately, they wanted to ensure that the record would be designed in such a way as to be simple for patients to use and understand, with clarity around who would have access to what aspects.

> *"Transparency is the most important thing…people should know who is looking at their information, what it is used for and who is responsible for handling the data."*
>
> *Leicester, male, Workshop 3*

Accountability

Many of the ideas that participants generated around how they could feel more comfortable relate to the theme of accountability i.e. being able to track staff access, being given a justification for access.

Participants wanted there to be formal oversight. This should also be easy to access for patients to raise concerns regarding a security breach or privacy issues.

> *"I need to know what the actual body is that is keeping central data in order to be reassured."*
>
> *London, female, Workshop 1*

This oversight function should be responsible for audits and holding staff to account for breaches. Some of this need stems from perceptions that the NHS workforce are predominantly clinicians, as opposed to data experts – i.e. that the required expertise to manage a single patient record might be lacking.

An audit system would also provide reassurance about who was accessing their record. Participants needed reassurance that an oversight function would check that only those with a need would access their record. It was important that privacy is taken seriously and that staff without a reason to access their record would be reprimanded.

> *"I think it's quite interesting about tracking breaches, what happens when they occur? Who is held responsible? Come down on people who have breached it, ensure there are consequences."*
>
> *London, male, Workshop 1*

Patient choice

Participants used the words like choice, opt-out, and consent interchangeably. It is also worth noting that when talking about consent, patients were not referring to specific medico-legal definitions. Instead, they had a broader view that they should be able to have choice and express preferences.

Participants felt that patients could be reassured, and feel more in control, by having access to clear information about who their patient record is shared with or could be shared with. To some extent, they felt it would be helpful if patients could flag specific pieces of data they don't want to see shared.

Data accuracy

Participants wanted to allow for data to be corrected if needed, while also ensuring that the wrong information is not added by staff who were less involved in their care or less knowledgeable about them.

Questions were asked about how the record would be updated and reassurance sought about consistency and standardisation. There was unease over who (and how many people) would be adding data and the risk of mistakes being made.

> *"Take my previous example of marriage and moving. I update the GP that I see regularly, but what about other systems? What happens in a centralised system when there is conflicting information?"*
>
> *Liverpool, male, Workshop 1*

Participants did not bottom out whether there needs to be someone responsible for the accuracy (and privacy / access rights / filtering and flagging) of their record and if that should be their GP or themselves or as joint guardians.

Patient access to the single patient record

The ability to access one's own record was important. Participants liked the idea of being able to take some ownership over their health information. Furthermore, some could also see how this would be useful to access if abroad and needing treatment.

Participants thought patient access could extend to the ability to add in information themselves. They thought it could be helpful when it came to information such as allergies and to express preferences about care such as, gender of health care professional, DNR, or transplant wishes.

However, participants raised concerns that seeing new information about diagnoses, or recent test results could cause anxiety or distress if shown to patients without explanation. Furthermore, if notes were complicated with lots of medical jargon, then this could lead to confusion and anxiety.

It was suggested that a summary version should be available alongside lengthy detailed notes.

Staff access

Participants also wanted to see some of the data on their record treated as more sensitive than other types of health and care data. They expected all their data to be stored securely. But there were also suggestions for additional restrictions on access to data they considered sensitive, including mental health or sexual health histories, which some suggested could potentially be flagged by GPs. They felt there were more implications for patients if this data was breached. In particular, they wanted the system to limit who has access to this data (as discussed more in section 6: Tiered access).

When it came to staff behaviour, participants expected a code of conduct and regular ongoing training. This, they felt, would ensure ethical conduct from all staff with access to a single patient record.

> *"Like the food hygiene ratings, you don't need to know [staff training] but it's good to know it's there if you wanted to see it."*
>
> *Leicester, female, Workshop 1*

Participants wanted to maintain privacy, by showing staff and healthcare professionals the relevant aspects of patients' records. However, they recognised that this needed to be balanced with allowing staff to see the wider context of a patients' health needs. This is explored in detail in the next chapter.

5.2 Tier 1 – views on communication and roll out of a single patient record

Much of what participants said would help build trust in the single patient record related to communication and how the record would be introduced to the general public. Many questions were asked about how the record could work, and this gives a useful steer on information needs.

Transparency in communicating the launch of a single patient record

Fundamental to helping participants feel comfortable with a move to a single patient record is transparency: about the record and how it will work, the systems that will be in place, how data is used, and the rules and safeguards to protect their data.

Information needs included:

- Explaining why this is being done now and not previously.
- Making clear whether alternatives have been considered and why the single patient record is the best solution.
- Being clear about the benefits of going ahead with a single patient record, especially the impact it will have on quality of care and improved health outcomes.
- Being transparent about any third parties which might be involved in the single patient record and how they might benefit from this (particularly financially). Participants felt this could help address cynicism around pharmaceutical companies or other private companies being behind the initiative.
- Providing reassurance about data security, privacy, and access rights.
- Establishing clear lines of accountability that patients can use if they have a privacy concern over their record.
- Clear information about the opt-out process, if there will be one – explaining that there is a choice to opt-out, as well as the risks (to patient safety) and implications of opting out (clinicians refusing to treat patients who have opted out because of concerns around safety).

> *"The transparency is what gives you the trust… clear information about why it's going to be implemented is going to help the trust, there will be a lot of questions if a new system goes out."*
>
> *Leicester, male, Workshop 1*

Having a trial run / trial period

A number of participants suggested conducting a trial with a sample of the population. This would:

- Explore any teething problems and see if it works.
- Promote the benefits of the trial as evidence in communicating the value of making the change to a single patient record.

> *“I think…trialling the single patient record with a smaller sample… is something that would probably increase the level of public confidence.”*
>
> *London, female, Workshop 3*

If the trial was deemed not to work, then there would be the opportunity to ‘back out’ and look for an alternative system.

5.3 Tier 2 conditions for a single patient record

For the most part, Tier 2 audiences cited the same conditions for a single patient record as Tier 1. Transparency was felt to be crucial to fostering trust. This includes transparency over who has access to their record and why, an access audit trail, and clear communications with the public about the rules in place which keep their data safe.

Similarly to Tier 1 participants, sex workers, LGBQ+ people, and those with long-term health conditions wanted to see certain parts of their health record restricted – for example, their mental health history – and treated as more sensitive than other types of data which is stored about them. In practice, they felt this should mean roles-based or tiered access to the data, on a strictly ‘need to know’ basis. This reflects the appetite for roles-based access which emerges from Tier 1.

> *“I know mental health is a big thing that a lot of people are quite discreet about, and I can see people wanting to get help for that, but not have it interfere with other services that they're using."*
>
> *Sex worker, in-depth interview*

Among transgender people, sex workers, care experienced adults, carers, domestic abuse survivors, and those with neurodiversity and/or mental health issues, there was a strong preference for patient autonomy and choice to be respected. Some wanted to see a customisable access system, where individuals could choose who gets to see their ‘most sensitive’ information, approving or denying requests, allowing for greater control over personal data.

> *"For anybody who needs access to our records, we should be asked our permission, and we should be given the ability to say yes or no and also given an explanation as to why they need our information."*
>
> *Domestic abuse survivor, in-depth interview*

As with Tier 1, Tier 2 participants emphasise the importance of having stringent legal protections in place, and consequences when these are not adhered to. This is most pronounced among the sex worker and migrant audiences, who expressed significant concern over unauthorised use of their data.

5.4 Tier 3 conditions for a single patient record

Tier 3 respondents rated the importance of a number of different factors regarding the development of the single patient record. This audience prioritised similar factors to Tier 1 participants, with data security being identified as the top factor, closely followed by accountability and transparency. This aligns closely with the findings from cohort 1, where data security was a primary concern for participants and central to data use and access being trusted.

Educating staff was also considered highly important, which aligns with the wider Tier 1 views on staff access, discussed in more detail in chapter 6.

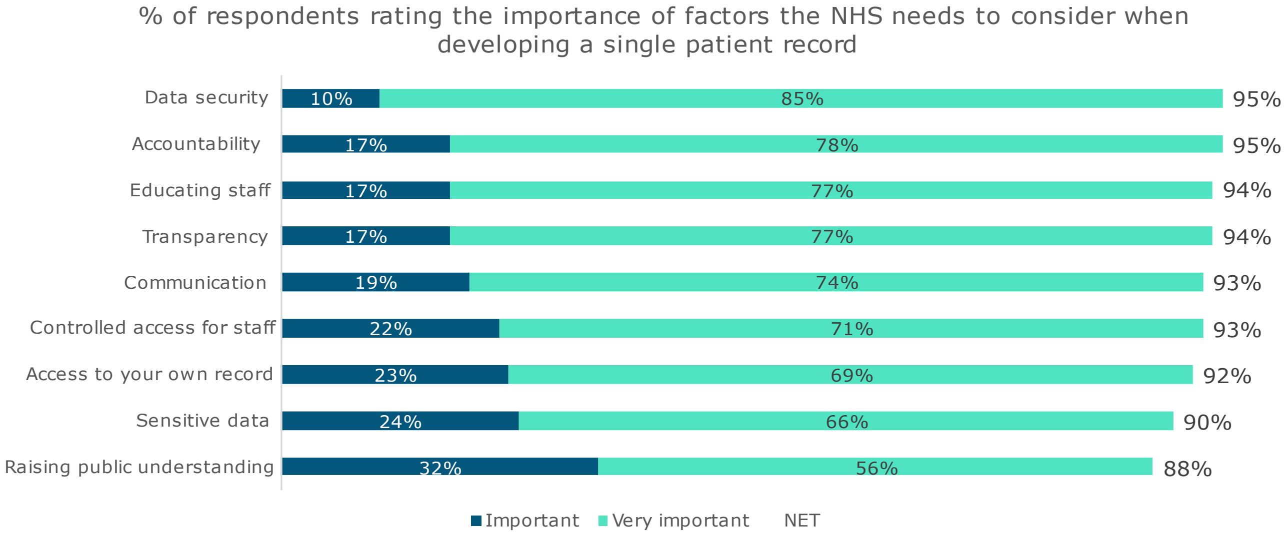


Figure 7: *Q5. How important, if at all, would you say each of these ideas are for the NHS to consider when developing single patient records. Base: n=1004*

6. Tiered access to a single patient record

Key findings

Participants rejected the idea that all health and care professionals should have access to a single patient record. Instead, they favoured a tiered system of access, based primarily on urgency and breadth of care responsibilities.

Decisions should not be binary, with either complete access or no access. Instead, participants wanted access to be restricted to relevant elements of a single patient record.

An audit trail was seen as an essential part of a record system. This would bolster accountability and transparency.

This was particularly emphasised by the seldom heard audiences as an important safeguard. They hoped this will limit instances of misuse by healthcare professionals and provide patients with more confidence in a single patient record.

Thorough vetting and training of professionals on data access protocols and appropriate time limits on access were also viewed as important safeguards to incorporate.

These considerations were felt to ensure that access would be both sufficiently justified and constrained. These desires were rooted in concerns about data misuse, breaches, and patient privacy – especially for the most sensitive patient information contained in a single patient record.

In this chapter, we look at how participant concerns around data security and privacy led them to rejecting a system of open access for all health and care professionals, and how a tiered system of access is important to achieving public trust. We examine the desire for access to be justified and constrained, ordered by responsibilities and relevance.

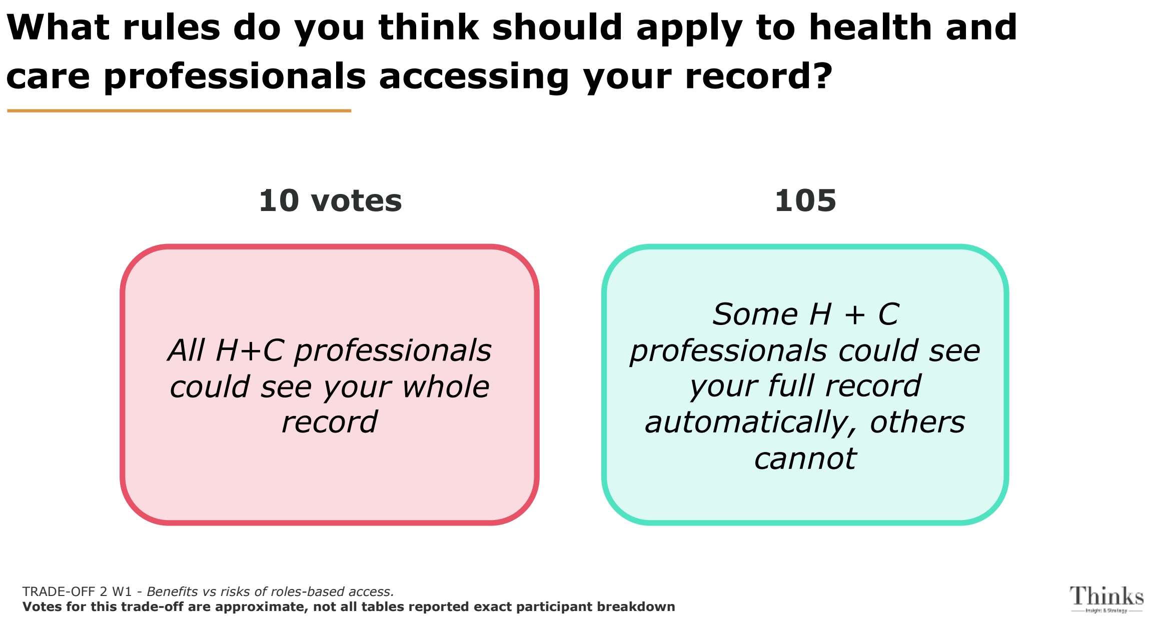
We then look at other important considerations for designing a system that participants are comfortable with. These include a focus on accountability and transparency including an audit trail, ethical standards in vetting and training of professionals, and time limits on access. Finally, we look at the importance of patient choice and consent.

6.1 Restricted access is important

Tier 1 participants clearly saw the potential benefits of health and care professionals having access to their single patient record. However, the notion of all professionals having access to the whole record was not acceptable. In Workshop 1 we presented participants with three options for rules for access:

1. That all professionals could see the whole record automatically.

2. That some professionals could see the record automatically, but others would have to request access.
3. That some professionals, and support staff such as receptionists, could only see part of the record.



What rules do you think should apply to health and care professionals accessing your record?

10 votes

All H+C professionals could see your whole record

105

Some H + C professionals could see your full record automatically, others cannot

TRADE-OFF 2 W1 - *Benefits vs risks of roles-based access.*
Votes for this trade-off are approximate, not all tables reported exact participant breakdown

Figure 8: *The result of the roles-based access voting exercise among Tier 1 participants.*

A tiered system of access was widely regarded as both highly logical and important to have in place. This would see different levels of access granted to different health and care professionals depending on their role in a patient's care and the urgency of need to see the data.

> *"Anyone who is directly involved in the decision-making about your health should have full access. For the others, once the healthcare decisions and treatment plans have been made, they don't need full access.".*
>
> *Liverpool, Male, Workshop 3*

There was also an understanding that the data requirements of professionals would vary depending on the specific patient in question and the complexity of their care needs.

6.2 Access driven by need – urgency and breadth of care

Tier 1 participants felt that access to a single patient record should be least restricted when care is either urgent (e.g. for emergency services) or where there is a breadth of care to be considered (i.e. GPs).

The urgency of care was a key factor in whether access should be available. It was felt that those with a role in emergency services would need to see a single patient record quickly, without time for any request process to take place. Participants reasoned they should be subject to the least constraints in order for them to access the information they deem necessary in situ.

Alongside emergency services, hospital consultants were felt to be the most appropriate for an access 'tier' with the least restrictions on access. Again, this was driven by a belief that this is likely to be in urgent circumstances.

Tier 1 felt that GPs should also be subject to fewest constraints on access to a single patient record. Their role as the main patient point of contact for care and their broad range of care responsibilities for patients meant that they should have the access when they need it. In particular, participants saw the clear benefit of a single patient record in terms of a smooth process of secondary care referral and discharge back to the care of their GP.

> *"They (GPs) should know everything if they need to refer you to everything."*
>
> *Leicester, Male, Workshop 3*

6.3 Less urgent, more specialised care should have more restricted access

Beyond urgent or wide need, Tier 1 participants felt that access to and the range of access within a single patient record should be subject to request.

Those in more specialised clinical roles (such as opticians or dentists) as well as administrative support staff were seen to have less need to see a single patient record in its entirety.

> *"The idea of the dentist having access to your whole record is crazy."*
>
> *Liverpool, female, Workshop 1*

Participants felt most cautious about non-clinical staff (particularly private sector care home staff) having access to their record either without prior approval or extending beyond certain basic information. In settings such as a pharmacy, a distinction was made between the named and registered lead pharmacist and other roles. This was due to the level of qualification required and the view that more junior staff would have higher turnover. Non-permanent members of staff and staff without qualifications in any setting should have further restrictions placed on what they can access and how they obtain access.

The Tier 3 survey indicated that only two thirds (66%) of patients trust the NHS to make decisions on which type of professionals have more or less access to a single patient record.

6.4 How decisions should be made

Participants discussed the conditions they want in place around how access is granted.

Accountability and transparency including an audit trail

Participants expected there to be an audit trail, helping restrict access in an accountable and transparent way. An audit trail would involve professionals making a record of specific data accessed, in an ideal world alongside a rationale for said access, either at the time of access or shortly after.

However, the mechanics of the audit trail mattered less than knowing that something would be in place to maintain accountability.

> *"It will all be segregated and organised and the name and date of who accessed a particular screen, (and) there would be consequence for actions for something you didn't need."*
>
> *Portsmouth, female, Workshop 3*

The importance of clear accountability and transparency (with actionable consequences for misuse) was stressed throughout deliberations by participants. Having said this, over the course of the workshops, participants spent time thinking about how far the principle of transparency can be practically taken before the burdens outweigh the potential benefits. For example, the idea of patients receiving an alert when a professional had accessed their record was seen as a step too far.

Participants asked for clear and transparent communication with patients throughout, especially in the context of data security measures – both at the outset and then taken in response to any issues. This was also seen as a prerequisite for building trust levels with the wider patient population.

Ethical standards in vetting and training of professionals

Participants saw professional ethical standards as an important consideration for data access. Health and social care professionals were felt to be generally ethical by way of their choice of career and as reported by participants' anecdotal experiences.

However, there was support for such ethical standards to be reinforced if introducing a single patient record. Added vigilance in terms of the vetting of professionals who may potentially access a single patient record was sought.

This was felt to be especially important for staff such as care home and administrative support staff. Participants expected that the most senior members of staff should have responsibility to manage access within that organisation, and so be accountable for all access by other staff in that setting.

> *"I think it's part of a wider education piece, so (it is) that understanding of your responsibility as someone who can access personal data and understanding what will happen if you don't use it appropriately."*
>
> *Portsmouth, female, Workshop 3*

6.5 Time limits on access

Participants felt that professional access to a single patient record should be time sensitive in most cases. However, this should be tailored in accordance with the levels of access in a roles-based tiered system except for emergency services. Urgent care was the most compelling use case for a single patient record for participants in general.

> *"If you're going to a dentist…they're only seen twice a year, you wouldn't want them to have access to your records all year around."*
>
> *Leicester, female, Workshop 1*

6.6 The importance of patient control

Participants expressed a desire for control over whether the most sensitive information is visible upon access. Participants supported the idea of a 'cut-out', with patients choosing who can see information considered most sensitive. In this case, sensitive information included mental, sexual and domestic abuse history, and especially in-depth GP notes concerning these matters. There was an appetite for an extra element of control around this information.

Lastly, there was some misunderstanding around opt-out and when it applies. Participants were rarely aware that the National Data Opt-Out and most other related opt-outs do not apply to direct care. This even led to discussion around individual patients giving permission for professionals to access a single patient record on a case-by-case basis – in effect a system of consent, not opt-out, until other participants pointed out the practical unfeasibility of such a system. However, wider opt out discussions fell outside the scope of cohort 2 deliberations.

It's important to note here that this is typical of discussions in cohort 1 – the public, and our participants, have little awareness of their opt-out choices or the current mechanism for opting out.

> *"Is there maybe a way of when it's set up everyone who's choosing to opt in or out being sent a form."*
>
> *South London, male, Workshop 1*

6.7 Tier 2 considerations for roles-based access

There is broad agreement that there should be a tiered system for roles-based access. Most agree that specific healthcare professionals should be given full access automatically, e.g., paramedics, GPs, A&E staff. Others should have to request access, such as pharmacists and dentists, with patients being able to approve access, for example via the NHS App.

Conditions

Audit trail

Participants across all three tiers wanted to be able to see who has accessed their single patient record. In an ideal world, participants also wanted to see why their record has been accessed. They felt that this will limit the instances of misuse by health and care professionals, and provide patients with more confidence.

> *"Someone made a good point that you could be notified if someone accessed your records. Obviously, if you're having treatment in a hospital or you're at the GP, then it's going to ping. But if my dentist all of a sudden looks at my records and I'm not due to go, I'd find it quite odd."*
>
> *LGBQ+, Workshop*

Patient consent & control

Patients' ability to withdraw access from NHS staff is especially important for those who are most likely to experience discrimination in health and care settings – specifically transgender and non-binary people, sex workers, care experienced adults, and those with prior involvement with the justice system. Participants knew the implications of this, but felt it was essential to protect themselves from discrimination by specific individuals.

> *"Perhaps you could revoke access if a healthcare professional started misgendering you, for example, and making you feel uncomfortable…I think it's important to have autonomy and control over who has access."*
>
> *Transgender person, Workshop*

Concerns

Specific audiences have heightened concerns about those not involved in their care having access to their health and care record. Those from close-knit community groups (ethnic minority participants in particular) expressed concerns about extended family being able to see private information such as sexual or mental health information. Domestic abuse survivors were concerned about the potential for their abusers to be able to access their or their children(s) health record. This could allow them to commit further abuse or be manipulated in custody battles.

> *"If everything's available to everyone within the NHS and you might have friends and family that work in the NHS and you don't want them seeing your data. I know that would be my thinking – I have a cousin who works in the NHS but I wouldn't want them sort of snooping."*
>
> *Domestic abuse survivor, in-depth interview*

6.8 Tier 3 considerations for roles-based access

In the Tier 3 deliberative survey, 83% of respondents agreed that there are some circumstances where they would want a healthcare professional to have access to all the data in a single patient record.

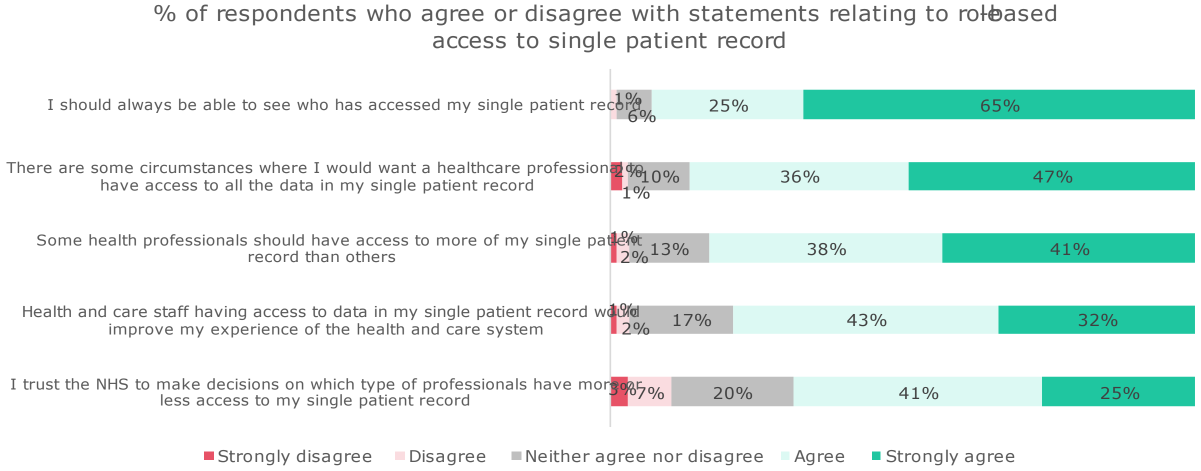


Figure 9: *Tier 3 deliberative survey, Q7: Thinking about your single patient record, to what extent do you agree or disagree with each of the following statements?*

Similar to the previous audiences, Tier 3 respondents showed an appetite for an audit trail. Almost all (90%) respondents agreed that they 'should always be able to see' who has accessed their single patient record. Only 76% of those aged 18 to 24 agreed that they should be able to, compared with 92% of those aged 31 or older.

When asked what they would like to see in place, Tier 3 respondents preferred a system that would allow them to know why their record had been accessed and which data was accessed (92% interested), as well as knowing which specific professional had accessed their records (90% interested). There was also interest in having a log that could be requested or accessed via the NHS App (87% and 85% respectively). While the option of being alerted every time their single patient record was accessed was slightly less popular – 79% of respondents were still interested in this.

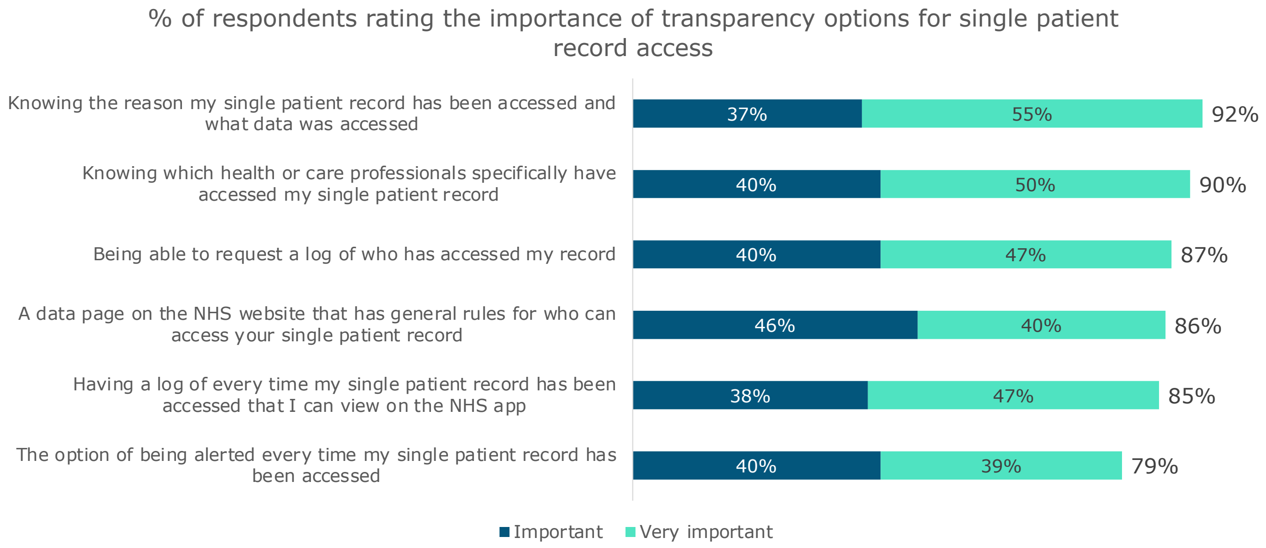


Figure 10: *Tier 3 deliberative survey, Q9: Thinking specifically about the issue of transparency around who has accessed your single patient record. Which of the following would you personally be interested in having?*

7. Views on patients being able to see their own single patient record

Key findings

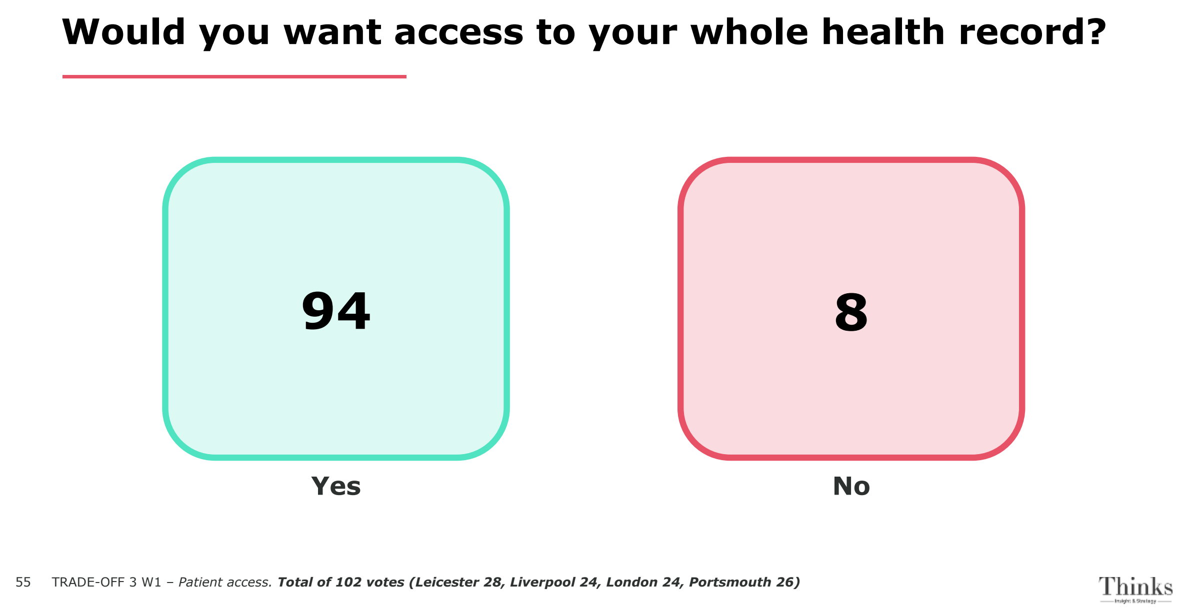
When asked whether they would want to have access to their own record, the answer was a resounding yes from the vast majority of participants.

The perceived benefits of this included improving care, helping family carers, and access to their information while travelling. Some concerns were raised around cybersecurity, access for ill-intent and health anxiety. However, participants felt these could be mitigated, particularly by limiting what sensitive information is shared, or providing patients with a summary record only.

7.1 Tier 1 views on patient access to the single patient record

Tier 1 participants were broadly in favour of patients having access to their own single patient record, which they generally envisaged as being accessed on the NHS App.

In the first workshop, participants were asked whether they would want access to their patient record. 94 voted that they would want access to their whole record, while 8 voted that they wouldn't want to access this data.



Would you want access to your whole health record?

94	8
Yes	**No**

55 TRADE-OFF 3 W1 – *Patient access.* ***Total of 102 votes (Leicester 28, Liverpool 24, London 24, Portsmouth 26)***

Figure 11: *The results of the patient access voting exercise for Tier 1 participants*

Arguments in favour of patient access

There was a strong consensus that patients have the right to access this data and to know what is included as part of their record, as this data is about them.

> *"I don't want anything written about me that I can't read."*
>
> *Leicester, female, Workshop 1*

Those who were in favour of patient access to their own single patient record also saw a range of reasons for needing this access:

- It empowers patients to know more about their own health, which enables them to make healthier decisions and to take a more active role in their own care. This, in turn, improves the care patients receive.
- Many also wanted to check that the data on them was accurate and up to date, with some participants mentioning instances when they realised their records were incorrect.
- It acts as a safeguard when travelling overseas, ensuring that patients have access to or can share an accurate medical record if they receive treatment while on holiday or living abroad.
- It provides unpaid carers with access to accurate and up to date information about their loved one via a single patient record. This could also support multiple family members supporting with the care of an elderly family member. While this was spontaneously raised in these workshops, this was not explicitly covered with this cohort as it is being explored as part of a different programme of work.
- It supports patients filling out forms necessary for insurance or benefits applications such as Personal Independence Payments (PIP).

> *"We're not healthcare professionals, but from my own experience I was involved in a car accident, and they hadn't picked up on it. If I could have seen my own scans, I could've flagged it."*
>
> *Leicester, female, Workshop 1*

Concerns around patient access

However, there were also concerns raised around patient access.

Those who did not see value in having access to their own record felt they would not be interested and would have little need to access it themselves. This cohort tended to think this was a waste of NHS resources and raised a number of concerns around patient access to records.

> *"I mean yes, I would want to see it, but it's going to cost to make it that detailed for everyone, and we wouldn't be able to necessarily understand. What benefit is there?"*
>
> *London, male, Workshop 1*

Concerns raised by those who were both in favour of and opposed to patient access to their own records focused on:

- Impacts on health anxiety, as some patients may ‘obsess’ over their medical record.
- Increased risks of data breaches if patient data is more easily accessible (i.e. on the NHS App).
- Individuals accessing others’ data inappropriately, without consent or with ill-intentions, especially in cases of domestic abuse.
- The risk of patients finding out about new diagnoses from their record rather than in a healthcare setting and therefore learning potentially upsetting information without the appropriate guidance or support.

> *“There’s a lot of people I know for whom having this access will be a disaster for their health anxiety.”*
>
> *Liverpool, male, Workshop 1*

Conditions for patient access

Ultimately, Tier 1 participants wanted to see a number of key conditions for patient access to their care records.

Firstly, participants wanted to see robust and secure processes in place to protect cybersecurity – an absolute necessity and a clear expectation.

Most also wanted flags or safeguards limiting what can be seen by patients. Participants felt this would limit what patients could learn about their past health which could be upsetting (especially in the case of mental health care). They also felt this would help protect patients from others with ill-intentions, such as abusive partners. Those in favour of an option to hide certain pieces of information felt this would allow a tailored, personalised record for each patient. Including the option of a summary record to patients, rather than access to their full record, would help manage anxiety.

Support should also be in place to manage additions of new information, such as test results or new diagnoses.

While most Tier 1 participants saw patient access to a single patient record as important, this was not universal. Questions around the resources involved in delivering patient access meant that participants felt the NHS should prioritise making a single patient record accessible for staff first. Participants felt this would have an immediate impact on patient health outcomes, whereas patient access would pay off in the longer run.

> *“Personally, it doesn't worry me because this is going to cost money and if that money can be spent somewhere else then it should go somewhere else.”*
>
> *London, male, Workshop 1*

7.2 Tier 2 views on patient access to the single patient record

Tier 2 participants were overwhelmingly in agreement that being able to access one's own health record would support patients in the following ways:

- Managing their own health and care.
- Ensuring information on healthcare records is accurate and up to date. This was especially important for communities who are more likely to experience discrimination in healthcare settings, such as transgender people, migrants and care experienced adults.
- Empowering patients to be fully informed when it comes to making healthcare decisions. This was especially important for those with long term health conditions who expressed feeling out of control when it came to their health.

> *"I would like to see what's kind of been documented… if something's been maybe documented that I haven't necessarily agreed with and I'm not aware that it's on my record. I like to know what's been put on my record just because of some of my personal history, being in foster care and with mental health. I'm quite conscious of what's on my health record"*
>
> *Care experienced person, in-depth interview*

Tier 2 also raised similar concerns to Tier 1 around the impact of patient access on those with health-related anxiety or OCD. They felt that having constant access to their healthcare data could have a negative impact on these people.

7.3 Tier 3 views on patient access to the single patient record

Tier 3 respondents echoed the views of Tier 1 and Tier 2 when asked about the importance of taking different factors into account when developing the single patient record. A total of 92% of respondents said it was important that patients have access to their own records – with 69% of respondents saying it was very important.

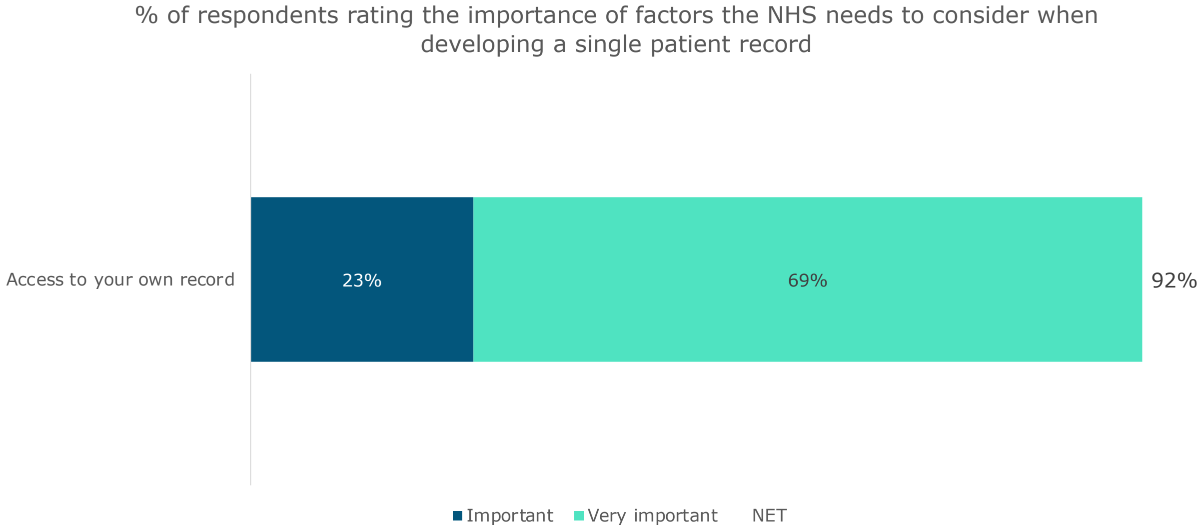


Figure 12: *Tier 3 deliberative survey, Q5. How important, if at all, would you say each of these ideas are for the NHS to consider when developing single patient records?*

8. Policy recommendations for a single patient record

It is evident from the deliberations that the concept of a single patient record is strongly supported. In fact, they are enthusiastic about the implementation, believing it to be an overdue development. They easily see the ways it could significantly improve their experience and improve health outcomes.

These benefits are clear to the public, without the need for prompting and deep deliberation. Therefore, there are several clear, inter-related recommendations for the implementation of this policy; the primary one being to proceed with pace to deliver something that the public instinctively believe is needed.

Policy recommendations

- **Proceed at pace.** A single patient record feels like a long-overdue solution to many of the frustrations the public feel across multiple health and care settings.
- **Include a record of access.** An audit trail will provide reassurance that access is subject to constraints and oversight.
- **Tiered access is essential.** Constraints on access are essential to the public trusting a single patient record. The idea of open access to all health and care professionals is roundly rejected.
- **Ensure rigorous training in data use and data security.** Any health and care professionals accessing a single patient record should be trained. This will reassure the public that their data is being used safely and appropriately.
- **Patient access is a must.** This can help patients better manage their own health. And it is seen by many as their right to access data about them. While important, was a lesser implementation priority compared to access for health and care professionals – which, they assumed, would have more immediate benefits for health outcomes.
- Focus on and demonstrate **high levels of data security.**
- **Be transparent from the start during implementation, as well as in day-to-day operation** – acknowledge risks up front and ensure patients have a say in implementation.

A single patient record should include a record of health and care professional access. There should ideally be a justification provided alongside access as well, if access to a patient's full record has been granted on a case-by-case basis (for health and care professionals who are seen as rarely needing access to the full record), rather than automatic approval (for example, for a GP).

Patients felt they should be able to see the log of who has accessed their health record if they wished to check who had access or had concerns about certain members of staff. There is little enthusiasm for notifications or alerts each time access occurs, but a record must be kept ensuring transparency.

This also ensures that the relevant authorities, responsible for upholding the legal obligations of providers of care and suppliers, can track access in the event of something going wrong – for example, a patient’s privacy being invaded, whether maliciously or not.

Tiered access is another central requirement for a single patient record. The guiding principle here should be that health and care professionals (both clinically and non-clinically trained staff) are granted no more access than is relevant to their responsibilities and the specific circumstances. And there is a recognition that non-clinical roles will need to access at least part of a single patient record.

There is also a desire for tiered access to be limited to the period of time that the patient is in that professional’s duty of care and, where possible, automated. Decisions around who has access to a patient record should not be made by any single individual, and oversight would provide reassurance that access will only happen when justified. A further layer of reassurance will be provided by ensuring all staff who access a single patient record undergo rigorous training on data access and security.

Patient access must be a central feature of a single patient record. This is rooted in two principles:

- Data about oneself must be accessible when requested;
- Access to a single patient record can help individuals better manage their own health.

That said, this is not an immediate requirement. Access for professionals should come first, as this is what will realise the primary benefits of improved experience and improved outcomes. It is important to note that further engagement on patient access would support a deeper understanding of patient priorities. In-depth exploration of how the public feel about potential benefits of patient access – such as reducing burden, removing delay, and greater patient activation – was beyond the scope of this cohort.

Patients should be able to access a summary version of their record, which they can tailor to their own preference – for example, by leaving out information considered sensitive that they do not want to always see. Careful consideration needs to be made in the design of a single patient record about the addition of new information which might be upsetting or difficult to interpret correctly. For example, there were clear suggestions that test results should not be added to a single patient record without first being explained by a health professional.

Implementation should happen in a transparent manner. A trial rollout would provide reassurance. The potential risks and benefits should be made clear, and consideration should be given to what choices are offered to the public about how their data is used and accessed.

As we saw in cohort 1, security is a primary concern for the public when thinking about how their health and care data is used and accessed. It underpins any confidence the public will have in a single patient record.

A large majority (86%) of Tier 3 respondents say they would feel fairly or very confident about the security of a single patient record. This high level of confidence is predicated on measures to ensure several of these other recommendations (e.g. tiered access, patient access) are in place.

Part B:
GP data for secondary uses

9. Introducing secondary uses of GP patient record data

9.1 Context

The GP health record is the most complete source of information about a person’s health. It is held separately from all other health data. Currently, GPs are the ‘data controllers’ for the data held in this GP health record – unless, and until, controllership passes to another controller. They decide if patients’ de-identified data is used for population health, planning or research purposes, and are legally responsible if patient data is misused.

Alternative approaches to legal responsibility and decision making for this data could see the responsibility for use of the GP health record move to either a regional or national model of decision-making.

This national engagement on data provided an opportunity to examine the current system for secondary uses of GP patient record data and look at the case for change.

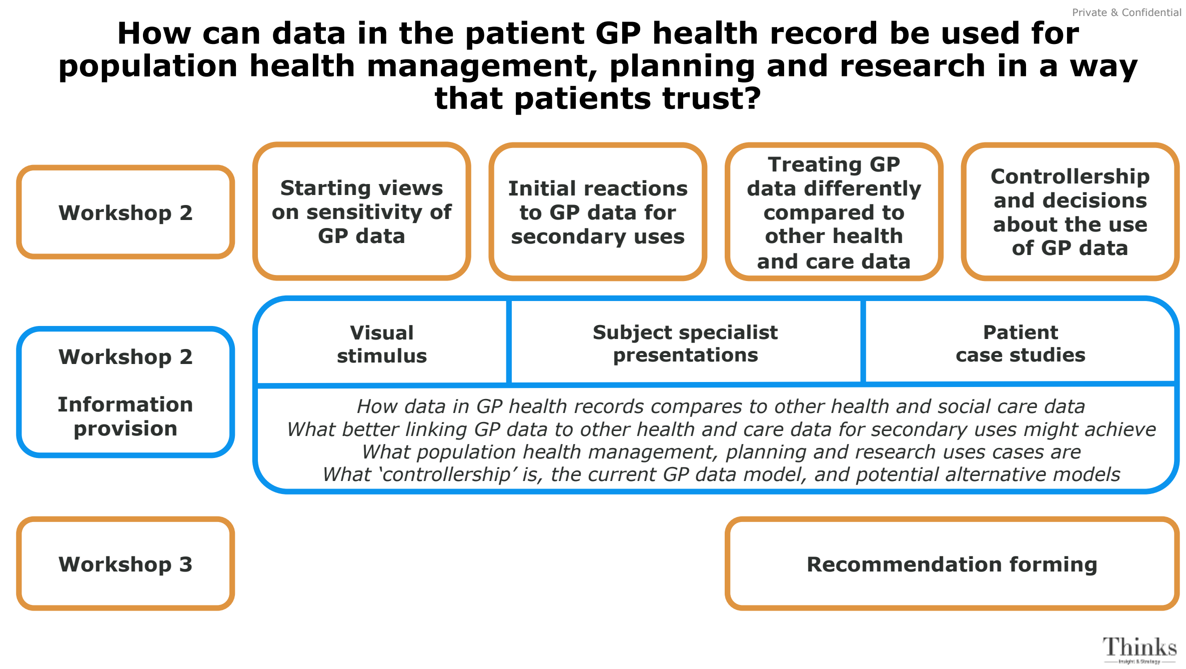
9.2 What we explored with participants

Tier 1 (core deliberation) and Tier 2 (inclusive engagement) explored:

- How data in the GP patient record can be used for population health management, planning and research in a way that patients trust.

To help answer this overarching question, we asked:

- Initial views on the sensitivity of GP patient record data and of secondary uses.
- Whether data held in the GP patient record should be treated differently to other health and social care data.
- Who should make decisions about how GP patient record data is used.



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How can data in the patient GP health record be used for population health management, planning and research in a way that patients trust?

Workshop 2

Starting views on sensitivity of GP data

Initial reactions to GP data for secondary uses

Treating GP data differently compared to other health and care data

Controllership and decisions about the use of GP data

Workshop 2

Information provision

Visual stimulus

Subject specialist presentations

Patient case studies

How data in GP health records compares to other health and social care data

What better linking GP data to other health and care data for secondary uses might achieve

What population health management, planning and research uses cases are

What ‘controllership’ is, the current GP data model, and potential alternative models

Workshop 3

Recommendation forming

Figure 13: *Flow of core deliberation workshops and information provided to participants*

The UK General Data Protection Regulation (GDPR) determines who is a controller for data. GP practices will always remain a data controller for the personal data they process when they deliver healthcare services. Cohort 2 only discussed whether to alter the decision-making process (and responsibility) around how data in the GP patient record is used for secondary purposes, not direct care.

In the Tier 3 (deliberative survey) we tested:

- Spontaneous attitudes towards the sensitivity of the GP patient record (including support for sharing data for secondary purposes).
- More informed attitudes towards connecting the GP patient record with other sources of data (including looking at coded and non-coded data).
- Support for moving away from the current model of GP controllership for all uses of GP patient record data and the factors most important to any future model of decision-making.

9.3 Information provided to participants

Tier 1

In the core deliberations, we presented a broad range of information comprising of visual stimuli and presentations by subject specialists. Case studies were introduced to help draw out the trade-offs involved in any change to the current system of use of GP patient record data for secondary purposes.

We presented the potential risks and benefits of GP patient record data being used more widely for planning and research. The risks and benefits were examined from the patient and GP perspectives.

We delivered subject specialist presentations to provide information on:

- How data in GP patient records compares to other health and care data.
- What de-identified data is.
- What ‘data controllership’ means and why the current model exists for GP patient records.
- How some GPs are eager or reluctant to change this.
- Potential alternative models for decision-making and the merits of each.
- What linking GP patient record data to other health and care data for secondary uses might achieve.
- What population health management, planning and research use cases are, how data is currently used for these purposes (including existing regional variations).

Case studies were used to explore the following:

- Population health management and planning: How hospital admissions may be reduced by utilising comprehensive datasets and how different areas can better plan services with access to the GP patient record.
- Research: One looked at the benefits of a medical research charity using 1 million GP health records to research diabetes in children. Another looked at a theoretical pharmaceutical company looking to develop a new drug to combat arthritis.
- Potential regional and national models for decision-making: A case study about the NHS in Birmingham attempting to carry out a clinical audit on obesity. In this, the NHS and a group of universities are working to research what factors impact wellbeing in people who are living with obesity and must request data from across England. We divided up participants into groups to debate the merits of the two different approaches.

Tier 2

In the Tier 2 inclusive engagement, we showed participants a truncated version of information to suit the time spent with participants in the different settings (two to three-hour workshops and one-hour in-depth interviews).

Tier 3

In the Tier 3 deliberative survey, we provided basic information about information held in the GP patient record, secondary use cases, information about the current controllership model, and potential alternative models. Additionally, we tested ideas on different models of decision-making generated in the core deliberations with respondents.

10. Where participants started from

Key findings

The GP patient record was felt to hold a more detailed longer-term record / life story than other healthcare practitioners across the NHS. This, in turn, enables them to provide a more holistic approach to patient care, but results in more sensitive data being present in the GP patient record.

The most sensitive issues were those that were viewed as more personal such as mental health, certain sensitive health conditions, or history such as domestic abuse records.

For participants who were uncertain as to whether they felt GP patient record data was more sensitive than other types of healthcare data, it ultimately depended on the condition being discussed and context in which the care was being provided.

This chapter explores where the public started in terms of their feelings around the sensitivity of GP patient record data in comparison to other healthcare data. Before deeper deliberation on the secondary uses of GP patient record data, we wanted to explore with participants their spontaneous views of how this data compared to other health and social care data.

The chapter begins by exploring the unprompted views on the sensitivity of GP patient record data, then looks more deeply into what types of data are felt to be more or less sensitive, including why and how this is influenced by type of condition and context.

10.1 Tier 1 - spontaneous views on the sensitivity of GP patient record data

Tier 1 participants were inclined to see a distinction between data held by GPs and other types of healthcare data. They suggested that more detailed information about them sits with their GP, even if participants rarely saw the same GP multiple times. They felt GPs had a more holistic and long-term overview of individuals. Furthermore, issues discussed with the GP are often more personal.

However, it is important to note that many participants also felt that other health and care providers held ‘sensitive’ data about them, such as pharmacists and sexual health clinics. In many cases though, they felt that their GP may also hold some of this same ‘sensitive’ information.

More detailed information sits with the GP

Participants highlighted the type of relationship and conversations they have with their GPs being more conversational and in-depth than those with other healthcare professionals.

> *"I think it's more chatty and personal and therefore more sensitive. I'd be more concerned about them finding that out than what meds I'm taking. It's more embarrassing."*
>
> *Leicester, female, Workshop 1*

Participants described nuanced conversations about lifestyle or how they are feeling generally as being central to interactions with GPs. These conversational details that are shared with GPs can feel more sensitive than other types of health and care data.

Long-term records

Another point raised by participants was that GPs hold long-term records, often outlining the entirety of a patient's lifelong medical history, in a more detailed way than other health or care settings. The relationship between GP and patient can feel personal and trusting. This, in turn, leads to more detailed sharing than might be the case with health and care professionals they encounter in a one-off, or less regular, scenario.

> *"I have a long-term relationship with my GP I know him, he knows me. There is an extra level of them knowing you better, different from when you walk into a health centre."*
>
> *Liverpool, male, Workshop 1*

When reflecting on this point, participants felt that this made GP patient record data feel more sensitive than other health and care data recorded about them.

More holistic overview

Linked to the above two points, participants felt that GPs generally took a more holistic approach to healthcare – in contrast to the focus on specific individual issues, for example, when receiving emergency care at a hospital. Again, this led to GP patient record data being viewed as more sensitive, as it could be linked to a range of other pieces of information considered sensitive.

Issues discussed with GP are viewed as more personal

Finally, issues that are often seen as more personal, such as mental health, certain health conditions, and family history related to factors such as substance misuse, or domestic abuse are discussed with GPs.

> *"I think it's more sensitive, I think because people open up more to their GPs about their personal life and history. Particularly you said about mental health, things like abuse and domestic violence… I feel fine about it because I trust my GP"*
>
> *Liverpool, female, Workshop 1*

These types of personal issues are viewed as distinct to the issues discussed with other healthcare practitioners, making GP patient record data feel different to many participants. However, participants did recognise that, often, other health and care professionals would hold data that feels similarly sensitive – for example, sexual health clinics or mental health services.

Context Matters

For those who remained uncertain as to the extent that GP patient record data is more sensitive than other types of healthcare data, it ultimately came down to condition and context.

> *"I think it depends on what conditions are on the record. Athlete's foot vs clinical depression"*
>
> *Leicester, female, Workshop 1*

As the quote above illustrates, data concerning a common physical health condition is not considered as sensitive as data about mental ill health. The GP holds this all, so for those people left unsure, there was some feeling that it would depend on what from their GP patient record data would be shared, and in what context. Clarity on what would be shared with whom is what mattered most to these participants.

Treating all health and care data sensitively

Despite seeing the GP patient record as holding especially sensitive data, Tier 1 participants felt that it should be, in the most part, treated in the same way as other health and care data. They recognised that other health professionals may also have access to similarly sensitive information about them – even if it is not brought together in the same way as within the GP patient record.

Overall, they wanted to know that all of their health and care data was treated sensitively, and kept safe and secure, as they could see many negatives to that data falling in the wrong hands or being misused.

10.2 Tiers 2 and 3 - spontaneous views on the sensitivity of GP patient record data

In comparison, Tier 2 participants did not express any strong views about the sensitivity of GP patient record data. They generally felt that GP patient record data was as sensitive as most other health and care data recorded about them, except for data that a sexual health clinic might hold on them.

Tier 2 participants with complex health needs often bypassed the GP. They therefore felt that hospitals were more likely to hold more data about them than their GP, and often data that is felt to be more sensitive.

Tier 3 respondents were not directly asked about their views on the sensitivity of GP patient record data.

11. Initial reactions to GP patient record data for secondary uses

Key findings

Participants were largely unaware of the secondary uses of GP patient record data. This echoes the low awareness of other uses of health and care data identified in cohort 1.

What made people feel comfortable about secondary uses of GP patient record data initially were ideas of public benefit / saving lives, improving care and prevention, and speed and efficiency.

What made people feel initially uncomfortable were concerns around data breaches, incorrect data and misuse / profiting, sensitivity of data being shared, bias against individuals, and concerns around re-identification.

This chapter explores initial reactions to GP patient record data for secondary uses. Firstly, it will cover what initially made people feel comfortable with the idea, before exploring what made people feel uncomfortable about using GP patient record data for secondary uses.

It is worth noting that while this section explores participants' views surrounding the use of data for both research and planning, research tended to be the use participants spontaneously focused upon.

11.1 What makes people feel comfortable with secondary uses of GP patient record data

There were some clear initial benefits raised by Tier 1 participants on the positives of the secondary uses of GP patient record data: public benefit through saving lives, improving care and prevention, and providing greater speed and efficiency.

Saving lives

Initial positive reactions to the notion of GP patient record data for secondary uses link to it being for public benefit. The idea that using data for research and planning could lead to improving, and potentially saving lives, made many participants feel much more comfortable.

> *"I struggle to imagine what the concerns are…It could lead to potential cures for diseases and reveal important patterns."*
>
> *Liverpool, male, Workshop 2*

As the quote above highlights, for those people who immediately focused on these benefits, it was difficult to comprehend potential concerns, since the positive outcomes were felt to be so great. Even when possible issues around data being used inappropriately were raised, those participants remained supportive of the use case, as illustrated below.

> *"It is highlighted how secure it is, with appropriate people using it in my best interest and my country's best interest."*
>
> *Liverpool, female, Workshop 2*

They felt confident that there would be appropriate use, and that ultimately it was in their own and the entire population's best interest. This was felt to be enough reassurance for these participants.

Improving care and prevention

Participants also felt more comfortable with the GP patient record data being used for secondary uses if it led to improved care and disease prevention.

> *"Personally, I think everyone's data should be shared because that benefits you, your family, why would you not, your data being shared could eventually cure 'cancer'."*
>
> *Portsmouth, Female, Workshop 2*

They recognised that secondary uses of GP patient record data have the potential to create positive outcomes for the whole population. The potential for these benefits left some participants with a strong feeling that everyone's data should be shared without exception.

Speed and efficiency

Participants discussed the potential to provide quicker and more efficient services, across both prevention and treatment. Given wider concerns about inefficiency in the NHS, and recognising the pressures on health and care professionals, this was felt to be very positive.

> *"Surely, you're saving lives a lot quicker at the end of the day."*
>
> *Leicester, female, Workshop 2*

11.2 What makes people feel uncomfortable with secondary uses of GP patient record data

Five key themes emerged that made Tier 1 participants uncomfortable with secondary uses of GP patient record data:

- concerns around data breaches;
- incorrect data;
- profiting from data use;
- sensitivity of data;
- bias against individuals; and
- concerns around re-identification.

Concerns around data breaches

It is important to note that participants spoke about data breaches as data leaks or hacks – either caused accidentally or purposefully.

Concerns around data breaches came up naturally through discussion with some strong opinions surfacing. In particular, there was a sense that data breaches are inevitable. At the same time, ensuring the right consequences were in place, would increase people's levels of comfort.

> *"I think it is not safe for people but I think if they have the laws to protect the security of the information then that's good. Build stronger laws."*
>
> *London, male, Workshop 2*

Another factor that increased reassurance was the feeling that the NHS would be invested in doing whatever they can to avoid such a breach, because of the reputational damage and impact on trust it would have.

> *"Any breach would be really detrimental not just to us but to the people involved in this too, so they would do everything they can to avoid breaches."*
>
> *Leicester, female, Workshop 2*

Incorrect data and implications

Linked to the above, there were concerns raised around data not being correct and the implications of this on secondary uses. Some participants based these fears on negative past experiences with GPs.

Profiting from data

Concerns were raised around the risk of GP patient record data being used to unfairly profit. Participants were especially concerned that private companies, specifically pharmaceutical companies, would in some way 'misuse' their data, selling it or using it to make a profit rather than for the public good. They also worried that individuals or companies would use their data for purposes beyond what the NHS would agree to, again, to make further profits at the expense of patients.

> *"If its external organisations trying to access the data, I'm unsure, and obviously some might be amazing, but others might be trying to use it as a profit base."*
>
> *London, male, Workshop 2*

Despite this fear, there was a recognition from many participants that private companies could utilise GP patient record data with positive impacts too.

Sensitivity of data

Another area of concern was around data that is considered sensitive. As highlighted in other areas of this report, this was particularly the case when it came to data linked to issues such as mental health or substance misuse.

Some participants felt that the topic of the research or planning activity would have a direct impact on people's level of comfort and that consent choices should be linked to sensitivity level.

> *"Researching arthritis would be different from researching something in mental health for example. You have to separate the consent for those."*
>
> *Leicester, female, Workshop 2*

Bias against individuals

Concerns were raised around the potential for bias against individuals. It was not always clear what participants imagined the implications of this might be, rather a general sense it could be used against you in some way.

> *"What if in the future that gets used against you. How do we know information won't be used against you."*
>
> *Liverpool, female, Workshop 2*

Some specific areas of concern were highlighted. In particular, there were questions about whether the data would be shared with bodies like the Home Office or immigration departments.

> *"Do the GPs share data with the Home Office? Or immigration?"*
>
> *London, male, Workshop 2*

If this were to be the case, the outcomes were felt to be potentially very detrimental, leaving some participants feeling a lot less comfortable about the notion of sharing GP patient record data for secondary uses.

Concerns around re-identification

Finally, there were questions raised around whether the data could be re-identified. This was felt to be particularly problematic regarding GP notes, which are often filled with more nuanced free-form text.

> *"You can't really deidentify the free text narrative, you can take out the NHS number but there's so much info about people in there, there's always things that are going to slip through."*
>
> *Liverpool, male, Workshop 2*

This was felt to be a lesser risk for coded data. That said, some worried that people with very specific conditions or needs could potentially be identified, even if precautions are taken.

The possibility of re-identification of data, often coupled with other concerns highlighted above, played a significant factor in some people’s level of comfort.

11.3 Views on secondary uses among Tier 2 audiences

Overall, Tier 2 audiences felt the benefits of sharing GP patient record data for secondary uses outweighed the risks. As with Tier 1, the benefits for improving public health felt clear to them, particularly improving the speed and efficiency of healthcare services.

Comfort with secondary uses

For those with long-term health conditions and carers, improved healthcare delivery would have a significant and tangible positive impact on their lives. For example, improving treatments for people with chronic conditions, and relieving some of the care burden. These audiences were particularly comfortable with the sharing of GP patient record data for secondary uses and consider it an important use of data.

> *“I do think it's vitally important that secondary uses are developed further because it's the only way we can all learn from things, isn't it? Thinking about research, that is absolutely vital in the future for developing cures.”*
>
> Carer, in-depth interview

Concerns over secondary uses

While the benefits of linking GP patient record data for secondary uses in the models presented were clear, certain Tier 2 audiences raised concerns about data security, privacy, and misuse. This was similar to initial reactions to the single patient record.

Similarly, worries about the risks associated with data breaches, misuse of data, and unauthorised access to information considered sensitive were more pronounced among stigmatised audiences – namely sex workers, LGBQ+ and transgender people, and those with neurodiversity and/or long-term health conditions. For these groups the consequences of data breaches were felt to be more severe. Privacy concerns were also notable among domestic abuse survivors, because of the unique risks they face from abusers who may attempt to use digital tools and data to monitor, control, or harm them. An audit trail of who has seen/use their data and how it has been used could help alleviate these concerns.

> *"From a survivor's point of view... We don't really want our perpetrators to know where we are or where we live because we're constantly being threatened. So, there is that additional element of safeguarding which will be necessary to ensure that this information is kept as confidential as possible."*
>
> *Domestic abuse survivor, in-depth interview*

Seldom-heard audiences also raised concerns about being reidentified if they have more unique data in their GP patient record. Even if it is anonymised, they felt there might be enough detail there to re-identify patients.

> *"I think there are some really murky details [when it comes to secondary uses of GP patient record data]. For example, deanonymisation when it comes to piecing together data. Like if you're the only patient in your area who is trans and has a specific long term health condition, you could search that and maybe that person has discussed their condition online or something."*
>
> *Transgender person, workshop*

LGBQ+, transgender, and sex worker audiences were also more likely to emphasise the importance of choice over how their data is used. They felt that an opt in system would respect the wishes of those individuals who do not want their GP patient record data used for secondary purposes.

11.4 Tier 3 support for different types of data being used for secondary uses

Tier 3 respondents were asked which types of de-identified data they supported being used for secondary uses, without being provided any upfront information. There was most support for GP patient record data (82% supported this, and 35% strongly supported), closely followed by hospital data (82% supported, 33% strongly supported). While support was still relatively high for data collected by a mental health professional (72% support), it was lower for data collected by a care professional (63% support). The proportion of respondents answering neutrally is worth noting, as this may be due to respondents having fewer experiences with mental health or in-home care services.

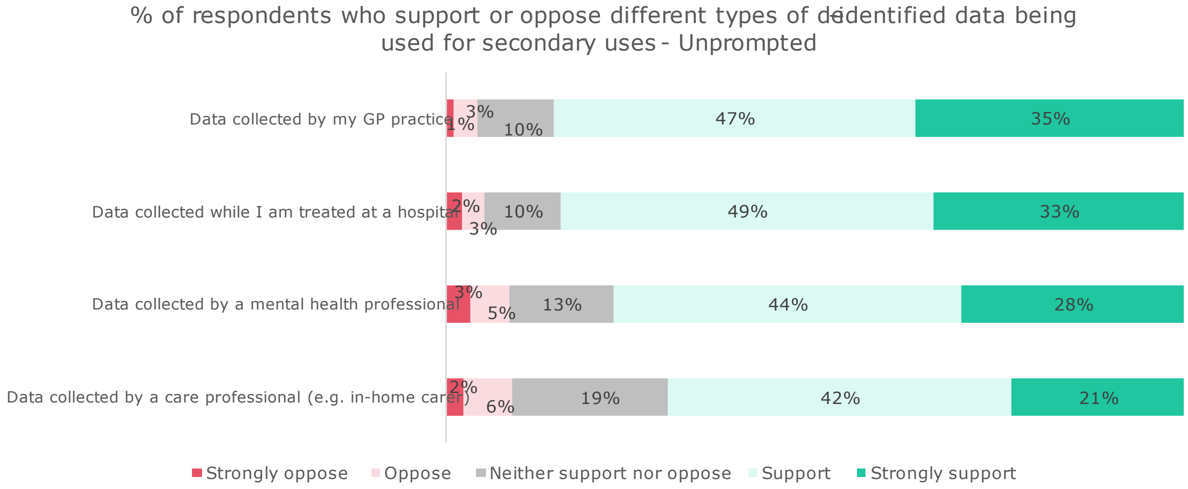


Figure 14: *Q2. To what extent would you support or oppose the following types of de-identified data being used for these secondary uses? Base: n=1004*

After being provided information about health records and the data they include, particularly for GP health records, respondents were asked the same question again. Support for the use of different types of data was broadly unchanged, particularly when it came to support for the use of GP patient record data. Support remained high for GP patient record data (82% support, unchanged) and hospital data (81% down from 82%), and lower for mental health professionals (71% down from 72%) and care professionals (63%, unchanged).

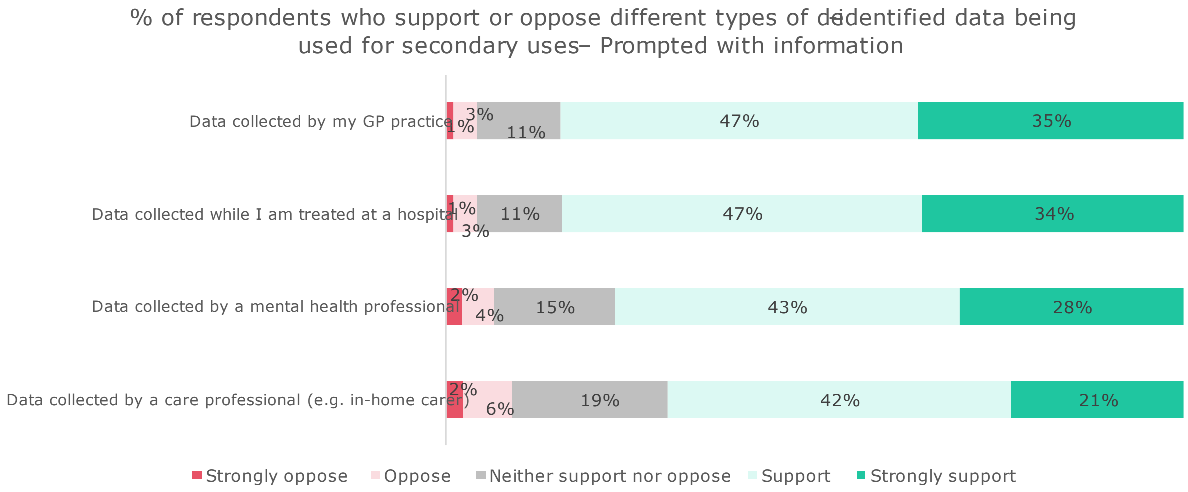


Figure 15: *Q4. Given this information, to what extent would you support or oppose the following types of de-identified data being used for these secondary uses? Base: n=1004*

Tier 3 respondents were asked how they felt about their de-identified GP patient record data being used for secondary uses. Two thirds (66%) felt that if their GP records were de-identified, they were happy for them to be used for research or healthcare planning. Only 14% said there were parts they wouldn't want to be used for research or healthcare planning, even if they were de-identified.

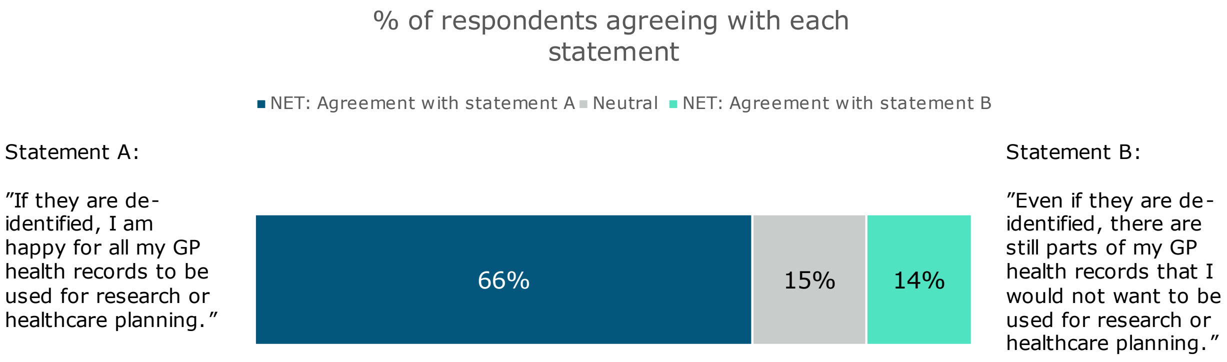


Figure 16: *Q7. Below are a number of statements about your GP health record. For each, move the slider towards the side you agree with the most. Base: n=1004*

When asked about whether they would be happy for some of their record being used for secondary uses, 69% said they would be happy as long as the whole record wasn't shared. And 1 in 10 (9%) said they did not want any of their de-identified GP records to be used.

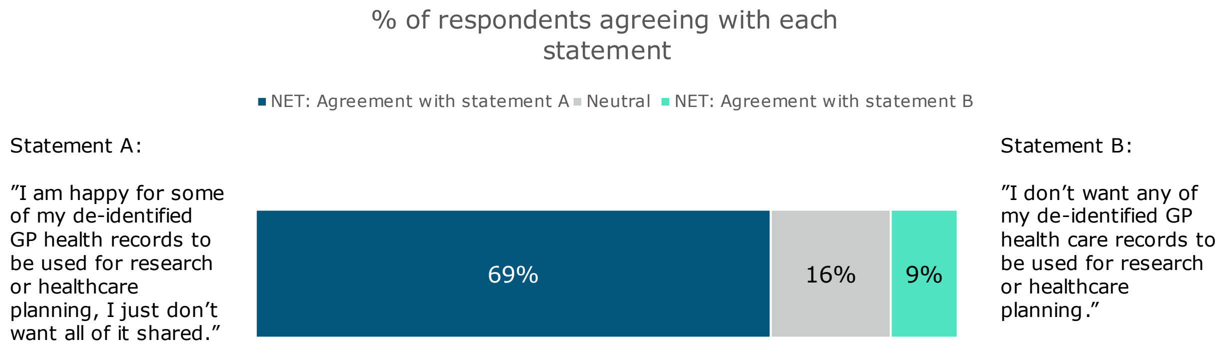


Figure 17: *Q7. Below are a number of statements about your GP health record. For each, move the slider towards the side you agree with the most. Base: n=1004*

Initial conclusions

The benefits of secondary uses of health and care data seem clear to the public – they see how it can improve care for people across society. As Tier 3 demonstrates, they support the use of data for research and planning, even without the need for in-depth deliberation. This widespread support means that policy makers should not be shy in making the case for these uses.

Yet the public also have concerns about the security, privacy and risk of re-identification of this information that is seen as sensitive. As subsequent chapters explain, it is important to demonstrate the steps being taken to keep data safe and secure, and to outline the consequences of misuse. This dovetails with the findings from cohort 1 and much of the wider work on public attitudes to the use of health and care data.

12. GP patient record data compared to other health and care data

Key findings

Participants expressed mixed views on whether GP patient record data should be treated differently to other health and care data when it comes to planning and research use. On the one hand, those participants who felt that GP patient record data needs to be treated differently did so because it is likely to contain more intimate information – and therefore there is a greater risk to the individual patient if the data is misused. Conversely, those who felt that GP patient record data should not be treated differently believed that it is vital to ensure a comprehensive dataset to achieve high-quality planning and research outputs. They were reassured by de-identification, training and regulation.

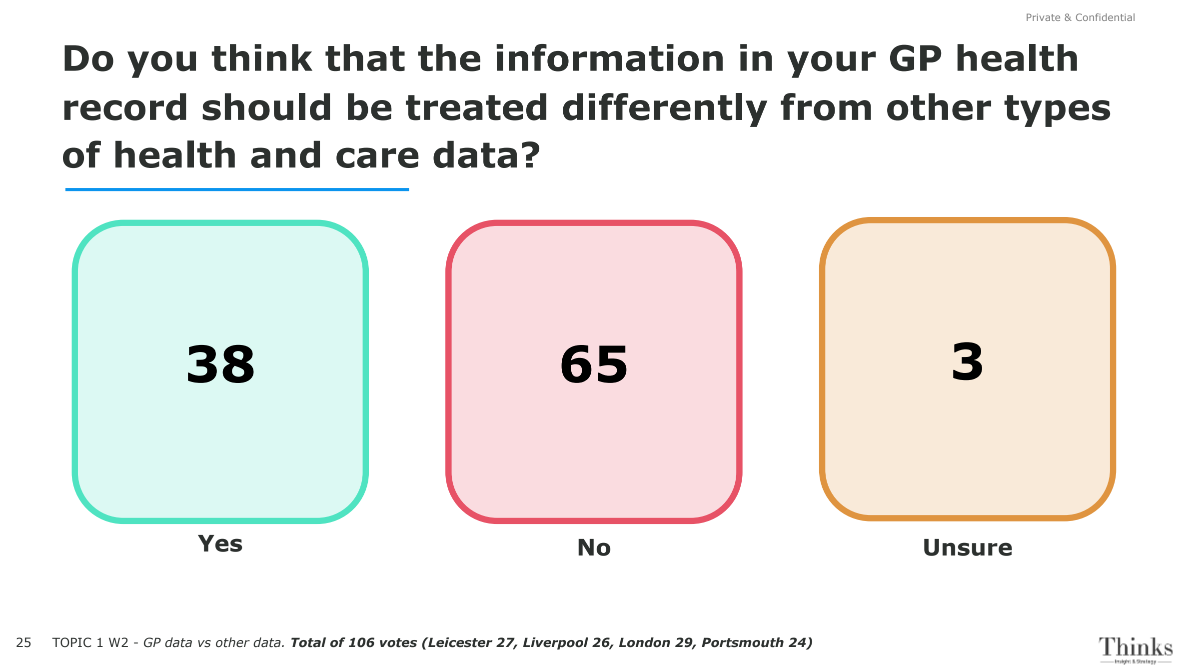
Among Tier 2 participants, the view tended towards GP patient record data being more sensitive, if not the most sensitive, compared to other health and care data.. However, they also felt that this should not preclude GP patient record data being used for research and planning, as long as strict safeguarding is in place to ensure security and privacy.

In Workshop 2 of Tier 1, following an initial discussion about GP patient record data being used for planning and research, we asked participants to consider whether GP patient record data should be treated differently to other types of health and care data when it came to those secondary uses. We asked participants to vote on the following question: “When thinking about how the information in your GP health record could be used for planning and research, do you think that should be treated differently from other types of health and care data?”. Participants returned to the issue in Workshop 3 a week later. We showed them the result from their vote and asked them to reflect further on the topic, and to indicate whether they had changed their minds on the issue in the intervening week.

12.1 Mixed views on whether to treat GP patient record data differently

Tier 1 participants expressed mixed views on the topic, and this was reflected in the result from their vote:

- 65 participants voted “no” (61% of participants): GP patient record data should be treated the same as other health and care data for planning and research.
- 38 participants voted “yes” (35% of participants): GP patient record data should be treated differently to other health and care data.
- 3 participants (2%) were not sure about the issue.



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Do you think that the information in your GP health record should be treated differently from other types of health and care data?

38	65	3
Yes	No	Unsure

25 TOPIC 1 W2 - *GP data vs other data.* ***Total of 106 votes (Leicester 27, Liverpool 26, London 29, Portsmouth 24)***

Figure 18: *Results of the GP patient record data vs. other health and social care data voting exercise for Tier 1 participants*

12.2 Arguments for treating GP patient record data the same as other health and care data

Among those who argued that GP patient record data should be treated the same, some participants felt that the benefits of using the data – to improve planning and research – outweighed the potential risks. They stressed the importance of having aggregated data that was as comprehensive as possible, in order to achieve greater accuracy and high-quality outputs for planning and research.

> *"Resources would be used more efficiently. I'm sure there is a lot of money wasted on certain initiatives because they don't have the data and so it is not going where it should be."*
>
> *London, female, Workshop 3*

Some participants were reassured by the process of de-identification. If properly implemented, this would ensure that individual patients are not exposed to the risk of their personal details being misused or traced back to the individual.

> *"I said no, because if data is de-identified then it's technically secure. If you have limited data, then it's pointless because you only get half the picture."*
>
> *Leicester, male, Workshop 3*

Others stressed the importance of a rigorous regime of training and regulation. If properly implemented, NHS staff and external parties (e.g. researchers) would have clear systems and guidelines to follow about the correct use of data; there would be systems in place to monitor data usage and to identify any misuse; and there would be effective and serious consequences for any rule breaking and misuse.

> *"I think people want it both ways. They want to open up the data to help with research and help with public services, but they still want privacy."*
>
> *London, male, Workshop 3*

There were those who argued that they would be reassured by an opt-out system, which allowed patients to decide whether their data is used for specific secondary purposes. We did not explore this issue in depth, as this will be the focus of cohort 3.

12.3 Arguments for treating GP patient record data differently from other health and care data

Among those who argued that GP patient record data should be treated differently, participants were especially concerned about the intimate nature of this data – and therefore the greater risk to the individual patient if the data is misused.

> *"There's more sensitive information. If there was a breach, that could be dangerous."*
>
> *Leicester, female, Workshop 3*

Participants argued that GP patient record data differs from other health and care data because it is a more comprehensive record and likely to include more sensitive personal details – that is, details that individuals would not want to be shared more widely. Over the years, an individual patient will consult their GP about a broad range of concerns. These discussions will often be exploratory and free ranging in nature, touching upon different areas of the patient's life, as the GP seeks to identify the medical problem. Participants cited sensitive areas such as mental health, sexual history, relationships, domestic violence, and personal/household circumstances. By contrast, their data sharing with a specialist consultant is likely to be more narrowly focused on a specific medical condition, often across a more limited time period.

> *"When speaking to your GP, it's like speaking to a priest. It's not just medical. There is social stuff as well, some parts are subjective. That social data should stay with the GP. It's not totally anonymous. I think it's too risky."*
>
> *Portsmouth, female, Workshop 3*

Some participants were concerned that misuse of GP patient record data – or the fear of misuse – would undermine patients' confidence in the special and confidential relationship that is seen to exist between patient and GP. However, some participants argue that this special relationship no longer exists, or has considerably weakened over recent decades, since they do not necessarily see the same individual GP when they attend a GP practice appointment. Those who expressed concerns that some patients might withhold or 'edit' the information that they share with the GP, worried that this might hamper the GP's ability to identify a correct diagnosis and pathway for the patient.

> *"The rational side says if my name isn't on it, it has nothing to do with me once it is out there. But I think the relationship with the GP is so important, and how do we reassure people that what is said to their GP stays with the GP?"*
>
> *London, female, Workshop 3*

Therefore, some participants either rejected the use of GP patient record data for secondary purposes or argued that there should be extra levels of security protections and permissions required for the use of GP patient record data. This was because there is greater potential harm to the individual if the information is improperly accessed or shared.

As mentioned earlier, some participants were reassured by the idea of de-identification, which they felt removed the risk of a person's more intimate details being mishandled.

However, this was not as reassuring for other participants – these remained concerned that a patient's data might still be traced back to the individual patient. These concerns were reinforced when they were provided with case studies that suggested analysts would be able to re-identify people who are at risk. This undermined the reassurance that de-identified data could never be traced back to an individual patient.

12.4 How Tier 2 audiences viewed GP patient record data compared to other health and care data

Tier 2 participants saw the value in using GP patient record data for planning and research. The fact that the data is de-identified, and that there are careful processes in place around re-identification, provided reassurance.

GP patient record data was considered more sensitive than other health and care data. However, most Tier 2 participants did not think their GP patient record data should necessarily be treated differently to other health and care data. They felt that all data, as a principle, should be highly protected, so wanted to see similar levels of protection for all types of health and care data.

Sexual health data and mental health data in GP records were seen to be particularly sensitive, and there were concerns about it being used in a prejudicial way. For example, GP patient record data could be used by researchers to develop hypotheses which would prejudice certain groups, or those with specific mental or sexual health conditions.

> *"I have some stuff to do with my mental health on my record. I've had issues with fertility and I know that it would be quite easy for somebody to say, oh, well, like, maybe your menstrual cycle is affected by stress. So I do feel like people with mental health stuff, or women in general will probably have to advocate harder."*
>
> *Person with mental health condition, in-depth interview*

There were concerns among Tier 2 participants that GP patient record data is more subjective and qualitative than hospital data which feels more quantitative. For example, some social groups may be more forthcoming about their health conditions when speaking to a GP about their health compared to other social groups. Participants worried about this, even when speaking about de-identified data, but had fewer reservations around coded data. This may lead to unequal outcomes when used in research.

> *"I just worry about the subjectivity. I would hope that they understand that, like the data is perhaps not very good quality data. As someone from the North, I'm aware that a lot of people just don't go to the GP because there is less access to the healthcare system. So they just live with these diseases, whereas in a richer area, more people will get diagnosed with asthma than in a poor area."*
>
> Neurodiverse, in-depth interview

Notable differences of views among Tier 2 audiences

Those who have more data they consider sensitive on their GP patient record were typically more protective of their GP patient record and how it might be used. This tended to include those with mental health conditions, those who are transgender, and domestic abuse survivors. Their main concern was that the information in their GP patient record could be used by researchers to discriminate against them and others like them. This was especially salient for transgender people, who cited the Cass Report as healthcare policy research that directly discriminates against transgender people.

Tier 3 participants views are covered in the previous chapter.

13. Controllership and decisions about the use of GP patient record data for secondary uses

Key findings

Tier 1 and Tier 2 participants had concerns around the current model of GP patient record data controllership for many secondary uses of data, particularly around the burden it places on GPs. They wanted to see a new national or regional model of decision-making for secondary uses. They felt this would allow for GP patient record data to be used faster and more efficiently, overcoming the challenges of the current system and unlocking the benefits of research and planning. They also felt this would allow for greater consistency of approach, transparency, and accountability.

Participants identified positives and negatives to both a national and a regional approach to decision-making. If possible, they preferred a combined approach, which would allow for the efficiency and consistency of a national approach, while allowing for regional priorities to be taken into consideration. The composition of advisory groups was essential in making this model successful. Participants wanted to see professionals from a wide range of health – and other – backgrounds, including GPs, and representation of people across the country.

However, Tier 3 respondents – with less time and space to engage with the topic – were more resistant to a move away from the current model. This greater reluctance to change demonstrates the need for careful communication with the public about the topic if any changes were to be made.

This chapter explores the public's views on how decisions should be made about sharing GP patient record data for secondary purposes only, discussing their views on the current model, principles for a new model of decision-making around secondary uses of data, and the pros and cons of decision-making at a regional and national level.

13.1 Tier 1 views on the current model

Overall, Tier 1 participants wanted the current model to change so that GP patient record data can be used faster and more efficiently, to better realise the potential benefits of better research and planning. They felt that the current system is excessively slow, burdensome, and inefficient. Instead, they wanted to prioritise making high quality data available that can be used for research and planning, and saw this as closely linked to improved health outcomes in the short and longer term.

Additionally, they felt a shift away from GPs being the decision maker about how data is shared for secondary purposes would remove pressure from GPs. This was mostly seen as a change that would reduce GP workloads so they can focus on providing care to patients. They also felt that GPs may not be (nor should be expected to become) experts in information governance – which in itself may pose a risk to how decisions on the use of data are made.

Throughout deliberation, participants also saw benefits to removing GPs’ legal liability for data breaches and misuse. They worried that GPs would be penalised and driven out of work by issues around data use for secondary purposes and misuse that were largely out of their control, and beyond the remit of what they would expect GPs to be focusing on.

> *“I think we all realise that GPs are under so much pressure, so understaffed… it’d be just to help them, rather than bypass them. But they might not see it that way.”*
>
> *Liverpool, male, Workshop 2*

But to a minority of Tier 1 participants, the current system worked well as it is. This is covered in more detail below, with only 4% of participants saying they wanted to keep the current model of decision-making. They had a high level of trust in GPs to be making the best decisions when it comes to the way patient data is used.

13.2 What should a new model of decision-making look like?

Participants were asked about their views and expectations on how decisions around the use of GP patient records for secondary purposes should be made. This included who should be involved in these decisions, and the pros and cons of governance at a national or regional level. Overall, they wanted any new model to be independent, transparent and consistent, with accountability and penalties for misuse. Tier 1 participants felt that decisions should be made by the NHS, on advice from advisory committee(s), similar to existing Data Access Committees, to involve a wide range of professionals and perspectives, including GPs.

Data security

This was a key factor for participants throughout conversations about secondary uses and controllership. They expected appropriate cybersecurity and training measures to be in place to ensure that GP patient record data remained secure.

Accountability and transparency

Overall, participants wanted decisions around the use of GP patient record data to be made using an independent model – with efforts made to ensure this process considers the needs of patients, the NHS and researchers. Participants wanted a clear audit trail, with a record of decisions made available to the public and clarity on how these decisions were made. Participants also wanted to see independent oversight and governance, operating transparently.

There should be clear and significant penalties in place for cases of data misuse or data breaches – both for research organisations and researchers who used data inappropriately.

Consistency

In the interest of efficiency, participants wanted to see a consistent and uniform approach to governance, either regionally or nationally, discussed below. They also wanted a systematic approach to accrediting researchers and research organisations who would have access to patient data, to ensure they will use data appropriately and sensitively. Participants felt having a clear approach would help those in charge manage how GP patient record data is being used.

> *"It's going to be easier if there's one body making a decision, as soon as you have several different groups, you are introducing a different process and therefore inconsistency and silo thinking."*
>
> *Portsmouth, female, Workshop 3*

Public information

Patients should be informed about how their GP patient record data might be used, and the process should be explained in a way that is accessible and easy to understand. While it was explained that the current system is opt out, rather than opt in, participants felt there should be mechanisms to record patient choice and consent. They felt that patients should be able to have choice around whether their GP patient record data is used in this way, potentially through the ability to opt out of secondary uses of data. Opt-out mechanisms and their consequences are the focus of cohort 3 of this study, so were not explored further here in cohort 2.

Considerations for access by private companies

Finally, participants wanted to additional safeguards around the use of GP patient records by private companies. They wanted a way to ensure these are used for the public good, and not solely to increase profits of private companies and ultimately lead to disbenefits for the public.

> *"I think it needs to be in the NHS, the people that sit on this board need to be NHS employees because there needs to be protection from lobbying by private companies and we need to make sure they make decisions based on public good."*
>
> *Portsmouth, female, Workshop 3*

Advisory groups or committees

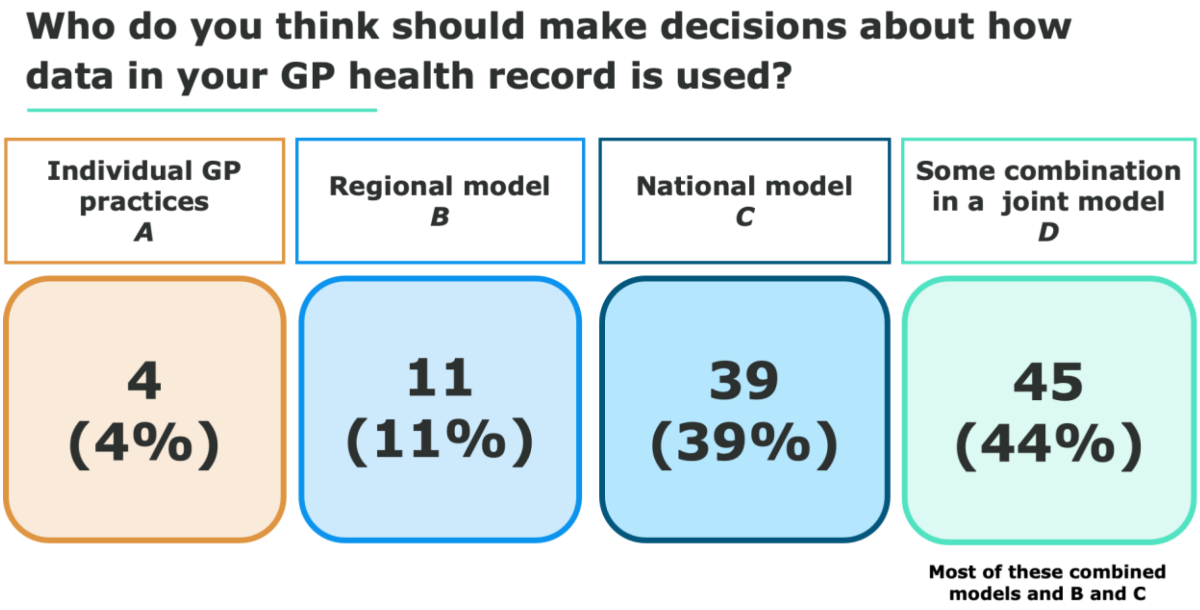
Many participants were reassured by the presence of advisory groups to make decisions on how healthcare records would be used. However, questions were raised about who would be involved in these groups and how their independence could be maintained. Participants wanted to see the following involved in decisions about how GP patient record data is used for research and planning:

- GPs: Participants wanted to keep GPs or GP representatives involved in decision-making for secondary purposes, usually as part of a decision-making panel.
- Other healthcare professionals: They felt that a range of professionals should be consulted, matching specialists to the conditions being researched.
- Data experts, to provide a technical understanding and an understanding of data security.
- Patient and public representatives, for instance through patient representation charities, to ensure that issues affecting patients (i.e. privacy, access to data seen as sensitive) are considered.
- Regional and national representatives to ensure that both perspectives are taken into account.
- Ethics or legal experts.

> *"[There needs to be] either patients or a representative like a charity that advocates for patients. I think it needs to be balanced not just on benefits for NHS staff but also for the greater population."*
>
> *Leicester, female, Workshop 3*

13.3 A national or regional approach to decision-making

We then asked participants how decisions should be made about whether or not to share data from GP patient records. Participants were asked whether they preferred to keep decision-making with GPs alone, or move to a national or a regional model of decision-making. A national or regional approach was preferred over the alternative of maintaining GP controllership for secondary uses. However, Tier 1 participants were more split when it came to a national, regional, or an approach that combined the two. What was clear is that decision-making should be as independent as possible from politics and politicians, reflecting wider mistrust. There was a strong sense that a considerable degree of independence would help ensure long-term thinking, isolating decisions from short-term political challenges or changes of government.



Who do you think should make decisions about how data in your GP health record is used?

Individual GP practices *A*	Regional model *B*	National model *C*	Some combination in a joint model *D*
4 (4%)	11 (11%)	39 (39%)	45 (44%)

Most of these combined models and B and C

TOPIC 2 W2 – *Data controllership*. . ***Total of 99 votes (Leicester 27, Liverpool 22, London 26, Portsmouth 24)***

Figure 19: *Results of the decision making for GP patient record data usage voting exercise for Tier 1 participants*

Views on a national approach

Those in favour of a national approach felt that it would offer the simplest and most consistent approach, and therefore be cheaper and more efficient. Participants also felt this would allow for quicker decisions to be made, allowing for the benefits of research to be realised earlier. A national approach would also allow the country to approach issues holistically, and to form a national response. While there were concerns about the ability to understand regional differences, many felt it would still be possible to understand what is happening locally through a national lens. Finally, for those in favour of a national approach, having decisions and access concentrated in one centralised system felt like the most secure option to many participants, as they felt it could have the highest level of protection and regulation.

> *"My understanding is if you have any data then the national data will be able to regionalise the data. They will collate the data for each region and still have the data for each individual region's data."*
>
> *Leicester, male, Workshop 3*

However, concerns were raised about concentrating decision-making power within the hands of a few, and the potential for bias and corruption. Compared to a regional approach, some participants were concerned that a national approach would miss out on regional nuances, and ignore regional needs and priorities, showing preferential treatment to certain areas (i.e. being too London-centric). Participants also worried that a national process or committee would be distant from the public, their needs and wishes.

> *"I do not like NHS England being over it. I like the regional approach. You have different disparities. England as a whole, and NHS England just makes me think it could be ways to benefit certain areas and leave other areas out."*
>
> *Liverpool, female, Workshop 3*

Views on a regional approach

Those who advocated for a regional approach felt it would allow for greater accuracy and responsiveness to local needs. They felt this approach would enable a more targeted and personal approach to data use, while avoiding inequalities between different areas. Those in favour of a regional approach felt it would allow for greater speed and agility than a national approach. A smaller, more local and coordinated response to access requests could also allow for better consideration by decision-makers, and give access to more researchers.

Conversely, participants worried that a regional approach would lead to inefficiencies, with multiple bodies replicating efforts across the country. They worried this would waste investment, as well as create a chaotic and fragmented system. Ultimately, they worried that certain regions may be opposed to sharing data for certain purposes, impacting the quality of the data across the UK, and the quality of research that can be carried out. This closely aligns with the findings from Cohort 1, where Data Access Committees were discussed.

> *"A concern I have is if it's being replicated 41 times, but what if only 30 [regions] say yes? Do they just use the data from the 30 who say yes and not the 11 who say no? Then the research could be unrepresentative and generate much less comprehensive care."*
>
> *Liverpool, female, Workshop 3*

Views on a joint model

A combined approach was also suggested by some, with regional committees or representatives feeding into a national decision, ensuring both regional sensitivity and a consistent approach. Again, participants wanted the same principles of transparency, accountability, and data security to be in place.

Tier 2 views on decision-making

Overall, Tier 2 participants had a similar view on how decisions are made to Tier 1 participants. They wanted to see a move away from the current model, and preferred a combined approach of the regional and national models.

Those who didn't want to change the current model of decision making about secondary uses felt it gave them more direct control over their own data, as they would be able to opt out or in by speaking to their GP.

> *"I think GP controllership makes it easier for someone to be able to opt out because they can talk to their GP. Whereas a regional or national model, who would they talk to?"*

Sex worker, in-depth interview

Feelings towards the current model of decision making often depended on how much individuals trust their own GP. Those with a close relationship felt more comfortable with GPs' making decisions about secondary uses, while those who feel distant or have had past disagreements with their GPs were keener on change.

Tier 2 views on the regional model

Participants from ethnic minority backgrounds tended to favour the regional model, as they felt it was most likely to reflect their best interests and the interests of their community.

> *"I like the regional model because I feel like a national model might be like going back to the north-south divide; it might be devised by people from the south. Like if it's a regional model, that forces the bodies to think about their own needs."*

Neurodiverse, in-depth interview

Tier 2 views on a national model

As with Tier 1 participants, those who opted for the national model felt that this would offer the most consistent and efficient approach to decision-making.

> *"I think, I personally think that a national model is probably a lot easier because then you've got one system in place where you could pull data. With the national approach, the data is controlled by one body, they make the decision for everyone and it's more easy to control."*

Carer, in-depth interview

Tier 2 views on advisory groups and committees

Tier 2 participants felt it vital that there is strong representation of seldom heard and marginalised groups on advisory committees (examples given specifically by people from ethnic minority backgrounds, LGBQ+ and transgender people – rooted in these communities' low levels of trust). This was a key driver in Tier 2 audiences' preference for a regional model as they felt this would offer better representation of the local communities. For example, examples given by participants included suggesting an area with a higher population of people from a specific ethnic background should have this reflected in their data committee.

Transgender participants also discussed including an ethical board as part of the model to ensure that the views of different backgrounds are considered when decisions are being made about data for secondary purposes. Transgender participants also put emphasis on patients being contacted and able to opt in to research themselves (with this intention of ensuring broader representation in research and trials). Generally, this audience was more sceptical about who is carrying out research and for what purpose.

13.4 Tier 3 views on decision-making

Tier 3 respondents were much less certain on the topic of data controllership than Tier 1 and 2 participants. When asked for their preference between maintaining the current model of GPs being the only decision makers, or moving to a national or regional model, an average of 30% neither opposed nor supported each model.

However, it was clear Tier 3 respondents were also supportive of maintaining GP involvement. Over half of respondents (52%) wanted to keep decision-making about secondary uses of GP health records with GPs, while 43% wanted to see a joint model involving GPs alongside a regional or national model.

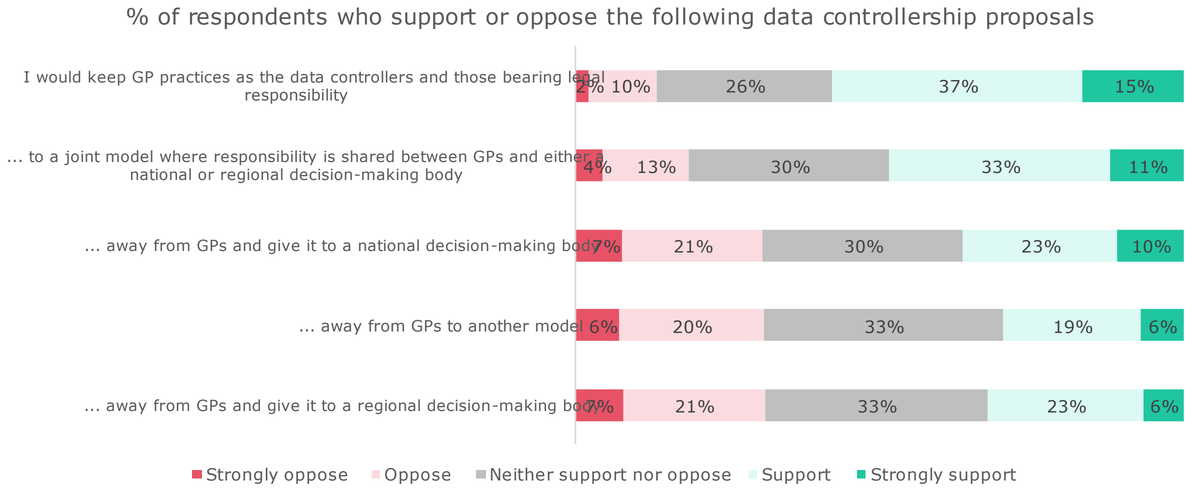
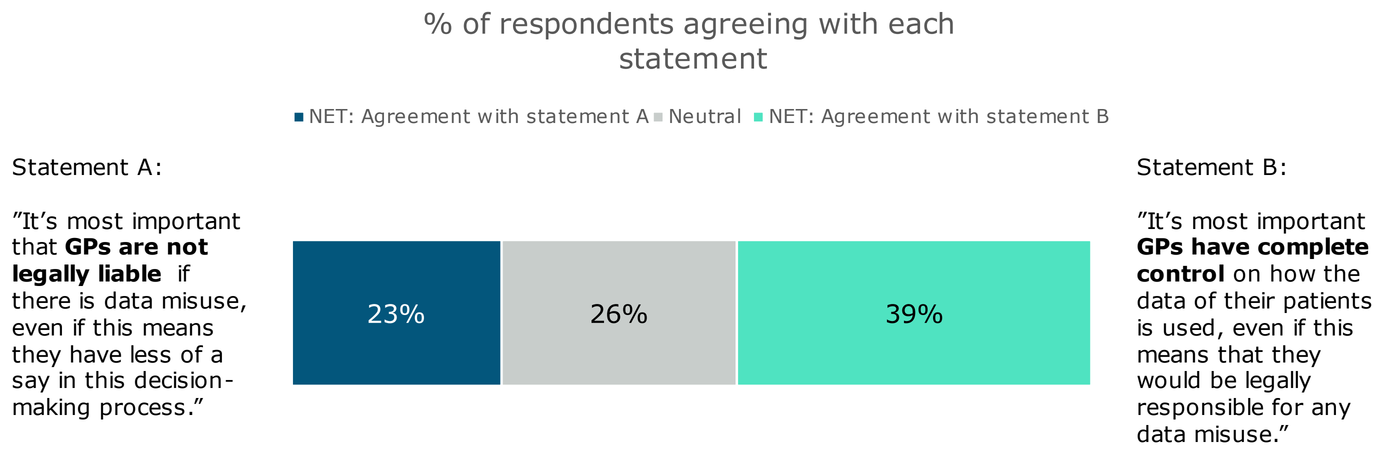


Figure 20: *Q10. To what extent, would you support or oppose the following proposals that would transfer legal responsibility and decision making for your GP health record... Base: n=1004*

Tier 3 respondents were also asked whether it was more important to take legal liability from GPs, or whether it was more important for GPs to have complete control over how their patients' data is used. Over a third (39%) wanted to prioritise GPs remaining the primary decision-makers, while 23% wanted to prioritise taking legal liability away from GPs. A quarter of respondents (26%) were neutral on the topic, while 12% didn't know – showing a high level of uncertainty.



Statement A:

”It’s most important that **GPs are not legally liable** if there is data misuse, even if this means they have less of a say in this decision-making process.”

Statement B:

”It’s most important **GPs have complete control** on how the data of their patients is used, even if this means that they would be legally responsible for any data misuse.”

Figure 21*: Q11. Below are a number of choices about what is most important to consider when thinking about how this decision-making process should work. For each, move the slider towards the side you agree with the most. Base: n=1004*

The main difference between Tier 1 and Tier 3 participants is the level of information they were given, and specifically the information provided directly from GPs. Both showed relatively high levels of trust in GPs which likely shaped their views. However, Tier 1 participants spent more time discussing the topic, and reflecting on their experiences with GPs, potentially highlighting negative experiences with GPs. They also heard directly from GPs who found aspects of data controllership challenging, worried about legal liability, and did not feel they were experts in managing data day-to-day, despite professional training that ensure GPs are trained in information governance. Without hearing this context directly from GPs, Tier 3 audiences may have been more likely to want to keep the current system in place.

Tier 3 views on regional and national decision making

Similarly to the Tier 1 audience, Tier 3 respondents valued the consistency in having decision-making done at a national level. When asked whether it was more important to have consistent decisions across the country, or ensuring that their local area had a say, participants wanted to prioritise consistency (41% selecting consistency, versus 27% selecting local areas having a say). It is worth noting that a significant minority (24%) answered neutrally.

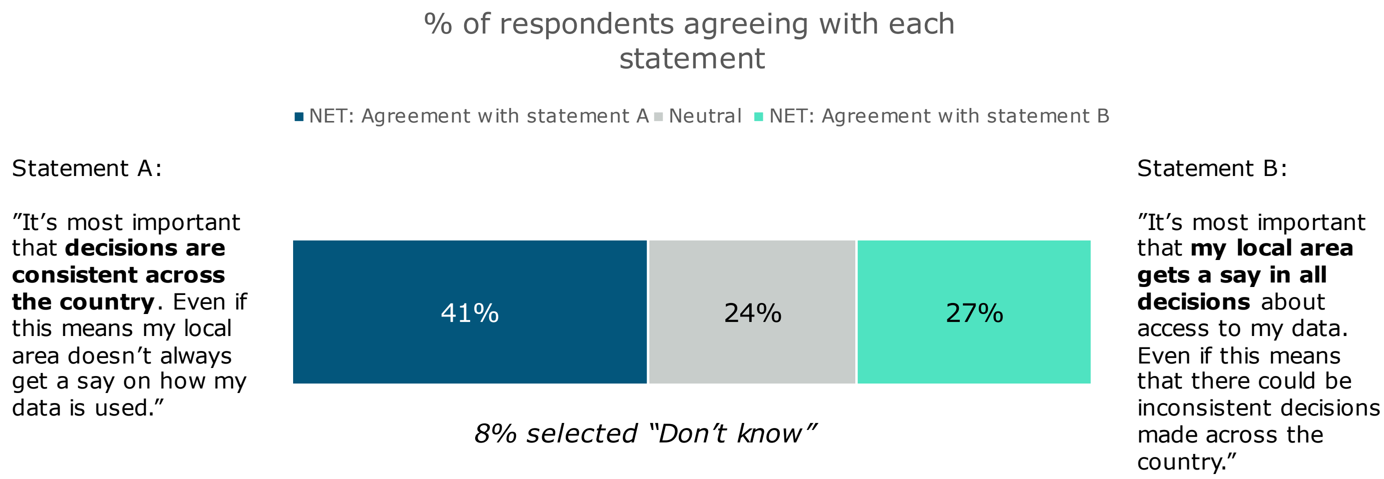


Figure 22: *Q11. Below are a number of choices about what is most important to consider when thinking about how this decision-making process should work. For each, move the slider towards the side you agree with the most. Base: n=1004*

Tier 3 considerations for a new model of decision-making

Tier 3 respondents also rated security (70% of respondents selected this condition), accountability (61%) and transparency (47%) as the top three considerations. However, consistency (30%) was seen as less of a priority for Tier 3 than it was for Tier 1 participants – although it’s worth noting that Tier 1 participants were not ranking their considerations in the same way that Tier 3 respondents needed to.

When it came to the composition of advisory groups, the Tier 3 audience were more supportive of GPs being involved (31%) than they were about members of the public (12%).

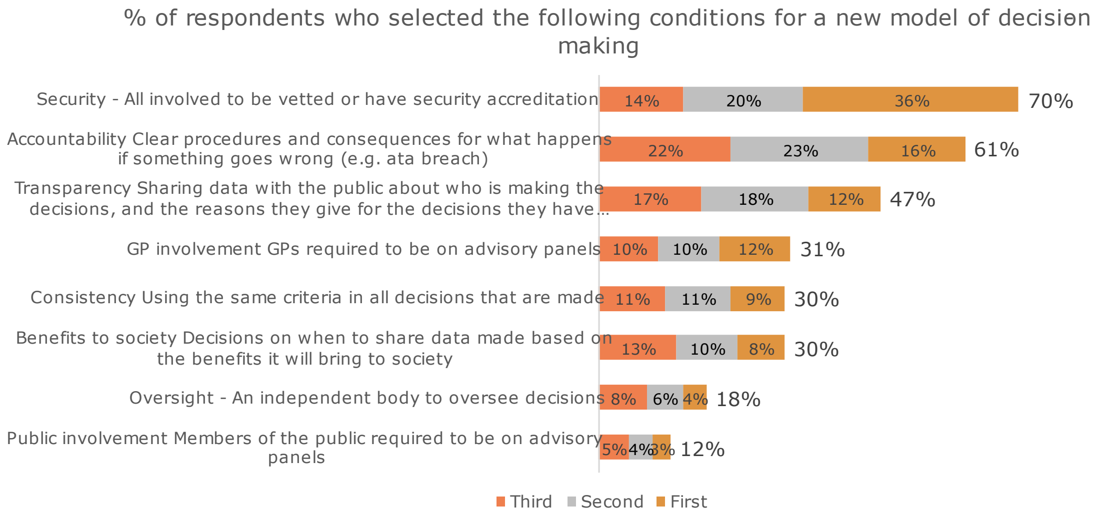


Figure 23: *Q12. If a new model of data controllership was introduced, conditions would need to be put in place to ensure the data in your GP health record is treated securely and used appropriately. Which of the following conditions are most important? Base: n=1004*

14. Policy recommendations for secondary uses of GP patient record data

There are several important policy considerations that emerge from this part of the cohort 2 deliberations, based on the criteria that participants wanted in place to ensure they are comfortable with the way GP patient record data is shared.

Policy recommendations

- **Decision making should move to a model that balances the need for national consistency and regional responsiveness.** When they consider the topic in detail, participants conclude that new arrangements should be put in place so that decisions about use of GP patient record data for secondary uses does not sit with individual practices. But it's not obvious to those considering the topic for the first time, so there's a need for clear communications.
- **Participants gave clear justification for changing how these decisions are made.** The core reason people want change, is to let GPs focus on their primary role of delivering care, not managing data access. People also see the benefits of secondary uses of primary care data, and want to remove the barriers around using it for public good.
- **There are clear criteria for a new approach to decision making. Any new decision-making model should include the voices of lay people, experts in data security, and GPs.** Any new approach must demonstrably support GPs to focus even more on their role as care providers. And GPs should not be liable for any mistakes or errors that happen during secondary uses of this data. Additionally, any new approach must be transparent (including public communications), with some independence from political control (thus ensuring long-term thinking and consistency), and be consistently applied across the country.
- **And sensitive data must be secure.** GP patient record data is sensitive, and people want to know what steps are being taken to keep it secure, for example through SDEs.

Following deliberation on the topic, Tier 1 and Tier 2 participants show a clear desire to move away from GP decision-making around sharing data for secondary uses. Instead, they want decision-making to move to a national, regional or combination model, with a sample of GPs bringing their expertise (and knowledge of general practice) to the decision-making process.

This is rooted in a desire to improve both the care GPs can provide, and improve access to data for planning and research.

Generally, participants feel that the requirements of data controllership – the time and resource required, and the legal liabilities associated with controllership – are things that should not sit with GPs for uses outside of direct care.

The public’s support for change is strongest when they have the time to develop their understanding of the consequences of the current model and explore alternative models in detail.

But some caution is required. Without the time to consider the topic in detail, there is a great deal more uncertainty and opposition among the wider public about whether change should happen, and what it should look like.

There is a need for careful explanation of any potential move away from the current model, explaining the positives for GPs and how this could help them to focus on what the public sees as their central role – delivering care.

Explaining the benefits for research and planning in terms of how better data leads to better outcomes is also important. This is especially the case for planning, as the benefits of this felt less intuitive to Tier 1 participants.

A new model of decision making over how data is used should be consistent across the country and ensure GPs voices are included.

Participants outlined some clear priorities and considerations around decision-making, including transparency, independence, accountability, and public information provision.

There is also a need to reassure the public about the safeguarding of data when being accessed by private companies – and about the uses to which that data is being put.

A consistent and efficient approach will be important, through a national approach with mechanisms to ensure that regional perspectives are taken into account.

Who is involved in decision-making is a key factor in building trust in any new model. There is a clear call from the public to demonstrate independence and transparency through advisory groups and committees. Experts across a number of different disciplines should be included – notably GPs.

It is important to emphasise the benefits of secondary uses. People feel more comfortable about secondary uses of GP patient record data when they can clearly see the benefits in terms of improving care outcomes, stronger prevention, and greater efficiency of services.

As we have seen throughout cohorts 1 and 2, data security is important to the public. Addressing what will be done to minimize data breaches, preventing misuse of data, and addressing concerns about re-identification are essential. In particular, demonstrating the role of SDEs and how they support data security is central to building trust in secondary uses.

Data security is of special importance to building trust in seldom heard audiences, who have even more pointed concerns about data security than the wider public.

It is clear that participant preferences mean a significant change to the structure of decision-making about uses of GP data for secondary purposes. Further public engagement will be required to understand public preferences for how controllership and data access is operationalised in a way that stays true to their preferences.

15. Sample profiles

Tier 1 workshops and deliberative paper survey sample profile | November 2024

Sortition

Table 1: Sortition recruitment tier 1 workshops sample profile (Total:78 participants)

Demographic	Leicester (21)	Liverpool (18)	S London (19)	Portsmouth (20)
Age: 16-24	4	4	3	3
Age: 25-39	7	6	5	6
Age: 40-54	3	3	5	4
Age: 55-69	5	4	4	4
Age: 70-99	2	1	2	3
Gender: Male	10	7	9	10
Gender: Female	11	11	10	10
Gender: Other	-	-	-	-
Ethnicity: White British	7	13	7	16
Ethnicity: White Other	2	1	3	9
Ethnicity: Black or African or Caribbean or Black British	2	2	4	2
Ethnicity: Asian or Asian British	8	1	2	2
Ethnicity: Mixed or Multiple ethnic groups	2	1	3	-
Ethnicity: Other ethnic group	-	-	-	-
Segment: Confident	-	-	-	-
Segment: Sceptic	-	-	-	-
Segment: Unfamiliar	-	-	-	-

Segment: Apathetic	-	-	-	-
Segment: Disengaged	-	-	-	-
Segment: Cautious	-	-	-	-
Segment: Unassigned	21	18	19	20
Disability or LTHC: No	18	13	15	17
Disability or LTHC: Yes	3	5	4	3
Education: Level 3 or below	14	12	9	13
Education: Level 4 or above	7	6	10	7

Note: This is inclusive of all participants who attended at least 1 workshop

Purposive

Table 2: Purposive recruitment Tier 1 workshops sample profile (Total:29 participants)

Demographic	**Leicester (7)**	**Liverpool (8)**	**S London (9)**	**Portsmouth (5)**
Age: 16-24	1	3	1	1
Age: 25-39	1	1	2	1
Age: 40-54	3	1	4	1
Age: 55-69	1	2	2	1
Age: 70-99	1	1	-	1
Gender: Male	2	4	2	2
Gender: Female	5	4	6	3
Gender: Other	-	-	1	-
Ethnicity: White British	2	7	3	5
Ethnicity: White Other	-	-	-	-
Ethnicity: Black or African or Caribbean or Black British	1	-	3	-
Ethnicity: Asian or Asian British	1	1	-	-

Ethnicity: Mixed or Multiple ethnic groups	-	-	3	-
Ethnicity: Other ethnic group	3	-	-	-
Segment: Confident	-	4	1	0
Segment: Sceptic	3	-	2	3
Segment: Unfamiliar	-	-	-	-
Segment: Apathetic	1	4	2	1
Segment: Disengaged	1	-	3	-
Segment: Cautious	2	-	1	1
Segment: Unassigned	-	-	-	-
Disability or LTHC: No	5	4	4	2
Disability or LTHC: Yes	2	4	5	3
Education: Level 3 or below	2	5	3	-
Education: Level 4 or above	5	3	6	5
Education: Undisclosed	-	-	-	-
Carer: Yes	-	1	4	2
Carer: No	7	7	5	3
LGBTQ+: Yes	1	1	-	1

Note: This is inclusive of all participants who attended at least one workshop

Tier 2 depth interviews and workshops sample profile | November 2024

Table 3: Tier 2 depth interviews and workshops sample profile (Total: 77 participants)

Segment	No. participant in in-depth interviews	No. of participants in workshops	Total
Older person with LTHC	2	-	2
Domestic abuse survivors	2	-	2
Sex workers	3	-	3
LTHC / neurodiverse / mental health	8	-	8
Carers	4	-	4
Learning difficulties	1	5	6
Sensory impairments	3	-	3
Care experienced adults	3	-	3
Unhoused people	1	4	5
LGB(Q+)	-	8	8
Trans	-	7	7
Migrants	4	-	4
Younger people with multiple LTHCs	-	8	8
Prior justice system involvement	3	-	3
Ethnic minorities	-	11	11
Total all segments	34	43	77

Tier 3 core survey sample profile | November 2024

Table 4: Tier 3 quantitative survey profile – (Total: 2,008)

Demographic	**Sample size**	
	Survey 1 - GP Health Record (Total: 1,004)	Survey 2 - Single Patient Record (Total:1,004)
Age: 18-24	105	105
Age: 25-30	80	86
Age: 31-40	179	173
Age: 41-50	169	180
Age: 51-60	164	153
Age: 61+	306	307
North East	47	47
North West	132	132
Yorkshire and the Humber	97	97
West Midlands	105	105
East Midlands	87	87
East of England	113	113
London	155	155
South East	165	165
South West	104	104
Gender: Male	485	486
Gender: Female	517	517
Gender: Prefer to self-describe	2	1
Ethnicity: White	826	823
Ethnicity: Asian	97	91
Ethnicity: Black	28	27
Ethnicity: Mixed	34	35

Ethnicity: Other ethnic group	-	8
Segment: AB	264	264
Segment: C1	290	260
Segment: C2	210	209
Segment: DE	239	239
Disability or LTHC: No	774	760
Disability or LTHC: Yes	196	215