March 2025

NHS England | National engagement on data

Cohort 1 Report

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1. Background and methodology

1.1 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. To do so, 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 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 deliberation.

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.

1.2 Structure of the programme

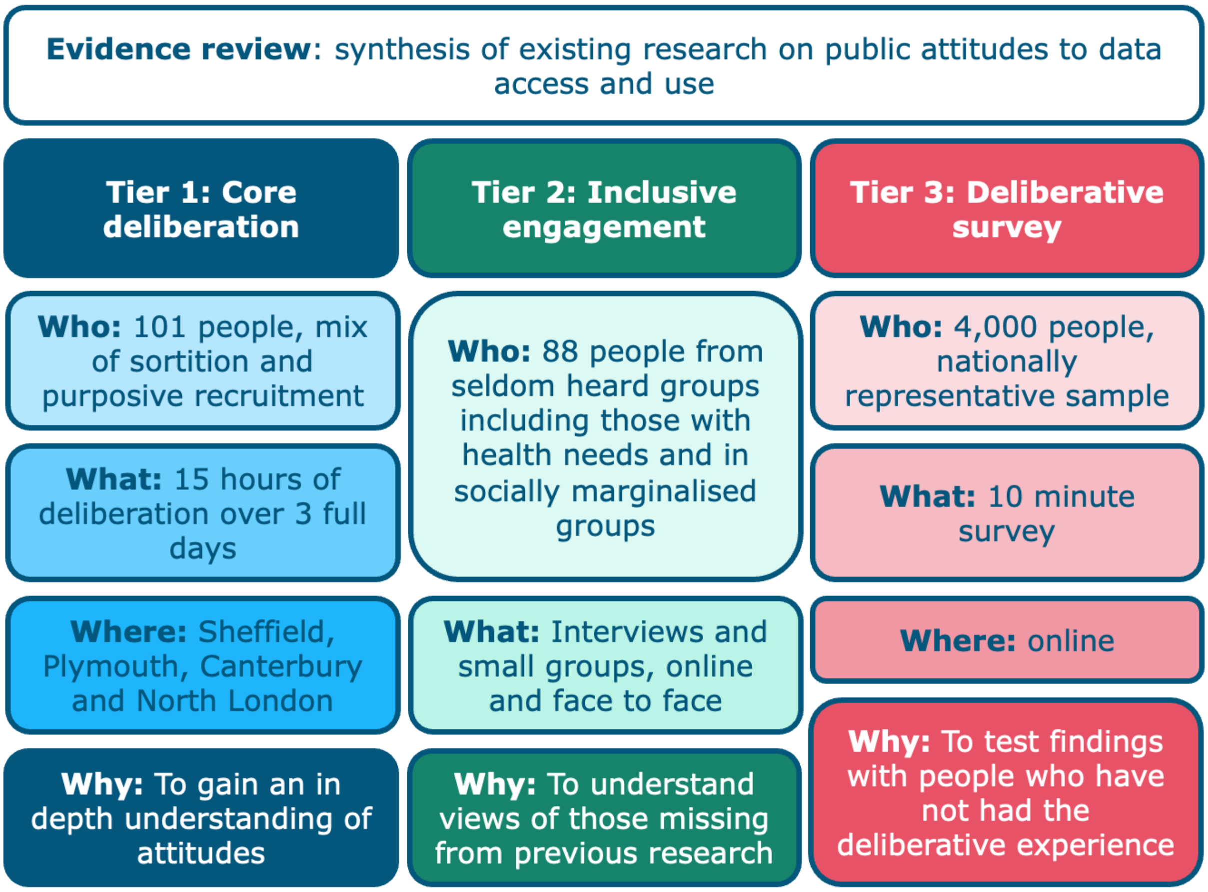
The programme is split into three different cohorts of work across 2024/5. At inception, the three cohorts aimed to focus on different aspects of the use of health and social care data and privacy.

Cohort 1 covers 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.

This report explores discussions and findings from Cohort 1.

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 – specifically though 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. And we have noted where relevant that the issues discussed were constrained by the time available and existing assumptions about realistic policy approaches – for example, tiered pricing was not part of the value of data discussion, on the advice of policy leads.



Evidence review: synthesis of existing research on public attitudes to data access and use

Tier 1: Core deliberation	Tier 2: Inclusive engagement	Tier 3: Deliberative survey
Who: 101 people, mix of sortition and purposive recruitment	**Who:** 88 people from seldom heard groups including those with health needs and in socially marginalised groups	**Who:** 4,000 people, nationally representative sample
What: 15 hours of deliberation over 3 full days		**What:** 10 minute survey
Where: Sheffield, Plymouth, Canterbury and North 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 4 - The Tier structure for Cohort 1

- Tier 1 covers immersive deliberative engagement. For each cohort, it includes a series of three day-long workshops with 120 people, amounting to 15 hours of deliberation overall. Workshops are 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.
- Tier 2 amplified lesser heard voices in a more inclusive and adapted environment, and had accessibility need 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, 88 people took part in Tier 2 for the first Cohort.

- Tier 3 aims to validate findings from Tiers 1 and 2 with a wider public. This is done through a deliberative survey – providing participants with some information alongside asking questions – with a nationally representative sample of 4,000 people.

More detail on the approach taken can be found in the appendix.

Findings from each of the Tiers are presented within each chapter of this report to provide a holistic picture of how the public feel about data use and access. The overall structure and content are driven by Tier 1 – as the core deliberative strand of the programme, this provided the most in-depth engagement with participants.

1.3 Sampling and recruitment

Tier 1

Tier 1 recruited 120 members of the public. Participants for the immersive deliberative engagement were recruited through a mix of sortition and purposive methods. 90 of the 120 participants were recruited by sortition, working with the Sortition Foundation[1]. Sortition refers to the process of inviting members of the public by sending letters to households within a specific area, then randomly selecting from those who respond, to build a representative sample. This approach ensured that invitations were open to all, and to minimised bias in the participant selection process.

The remaining 30 participants were recruited through purposive sampling by specialist recruiters. This helped ensure inclusivity and representation across Tier 1, addressing key omissions from the random sampling. This also helped to demonstrate to those with long-term health conditions and/or caring responsibilities that their participation was being sought thus addressing potential gaps in the take-up of sortition invites.

The purposive sample also allowed us to identify and recruit participants with a more critical perspective on data use and access – i.e. from the Cautious Data Sharers and Disengaged and Health Data Protective segments identified in NHS England’s work on public attitudes to data in the NHS and social care[2]. This ensured that the participants in Tier 1 reflected the range and diversity of attitudes among the wider public.

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[1] https://www.sortitionfoundation.org

[2] https://digital.nhs.uk/data-and-information/keeping-data-safe-and-benefitting-the-public/public-attitudes-to-data-in-the-nhs-and-social-care#chapter-index

The overall sample was designed to include a broad range of demographics, across age, location, attitudinal factors and health status. A full breakdown of the desired and achieved sample can be found in the appendix.

Tier 2

Tier 2 engaged groups to amplify the voices of those who might experience access barriers in Tier 1 and to ensure adapted spaces for discussion of sensitive topics. Participants were recruited through gatekeeper organisations such as community groups or charities, and through specialist recruiters.

The audiences engaged in Tier 2 for Cohort 1 included:

- Carers;
- Those with sensory impairments;
- Those living with acute or long-term health conditions, mental health conditions or neurodivergence;
- Those living with multiple long term health conditions, living either at home or in care homes;
- Those with learning difficulties;
- LGBQ+ people;
- Transgender people;
- Sex workers;
- Those with prior justice system involvement;
- Unhoused people;
- Domestic abuse survivors;
- Care-experienced adults; and
- Those from minority ethnic, religious, and cultural groups.

We recognise that experiences within these groups vary – that one carer doesn't represent all carers, that there will be people who associate themselves with multiple of these categories, and that there were people in Tier 1 that associate themselves with some of these categories. A practical balance had to be struck between the number of participants and the diversity of experiences.

Where findings from Tier 2 were notably different from that expressed across Tier 1, this is noted in the report below. Often, this centred on negative experiences that the Tier 2 audiences shared with us.

Tier 3

An online survey was conducted with a nationally representative sample of 4,000 adults in England. The sample was weighted to be nationally representative by age, region, gender, and socio-economic groups.

Full sample profiles for all three Tiers can be found at the end of this report.

1.4 Aims and objectives for Cohort 1

In the context of the wider programme of work, Cohort 1 aimed to:

- Give direction on the development of the trust products[3] to ensure they instil public confidence and trust that data will be used and accessed in the right way.
- Define public expectations on how the NHS should seek to realise value from their data, and level of appetite for the NHS to generate surplus value through data use and access (SDEs do not include adult social care data, so this was not part of the discussion on realising value).
- Define public expectations on how local governance will federate with national governance, reaching concrete recommendations.
- Give direction on how governance of SDEs can meet public expectations, in the context of a national and regional network.

The structure of Tier 1

Tier 1 participants took part in 15 hours of deliberation, across three day-long workshops. Workshops were held in person, in four locations across the UK, and were joined up via online video conferencing for plenary presentations and to feedback live on discussions to encourage cross-pollination of ideas and recommendations. These workshops broadly covered the following topics:

- Workshop 1: initial attitudes to data use and access; exploring the different use cases (individual care, population health management, planning and improving services, and research and innovation) for health and social care data through case study examples.
- Workshop 2: Exploring attitudes to three topics – governance, secure data environments (SDEs), and data access committees (DACs); and to how value could be released from data for research. Presentations from specialists and stimulus material were used to explain and bring to life these topics.
- Workshop 3: Revisiting the value of data and governance to reflect on discussions from Workshop 2; exploring attitudes towards a Data Pact.

More specifically, participants in Tier 1 were set a range of questions. First, a central “problem statement” was posed: What does the health and social care system need to do for you to feel confident in how your data is being used?

Then, for each of the three main topics covered, participants explored the following questions:

- Governance and data access committees: Do these principles set the right rules for data use and access? Is there anything you would change? What are your priorities for the governance of data access?
- The value of data for research: How important is generating value and benefits when it comes to using data for research? What are your priorities for generating value?

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[3] Resources created to support trustworthy and trusting interactions with the data use and access system, typically transparency and information resources.

- A Data Pact: Does a Data Pact provide reassurance about how your data is used? What would you change? What are the key elements of a Data Pact that should be communicated with people?

1.5 Fieldwork for Cohort 1

Workshops were held on the 11th, 12th, and 18th of May 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 1 were:

- Sheffield
- Plymouth
- Canterbury
- North 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 88 participants in total between the 20th May and 21st June 2024.

The Tier 3 deliberative survey was in field from the 16th to 18th July 2024.

1.6 Data collection and presenting the findings

The findings presented in this report reflect a summary of what participants told us directly during the fieldwork / data collection phase, plus thematic analysis of the recorded data to draw out common points of agreement and disagreement across locations and audiences.

Data from Tiers 1 and 2 was captured via note takers (Tier 1) and audio recordings which were subsequently transcribed (Tier 2). This raw data was then coded. This coding then allowed us to compare responses across locations and identify key themes. The recommendations were then formed by the Thinks team once this analysis was complete, looking at the implications for national and regional policy makers, as well as for future engagement.

Throughout this report, when we talk about "data use" we mean the use of data in health and social care including access by researchers.

1.7 The evidence review

Fieldwork was preceded by a review of the available evidence on public perceptions of and attitudes towards data use and access.

The aim of this evidence review was to synthesise any relevant published and grey literature on data use and access 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.

It focused on the key themes and issues for this cohort of the programme, such as: public perceptions around health and social care data, principles and safeguards for data use and access, and governance and decision-making.

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

2. The starting point: Views on data use and access in general

One of the aims of the data deliberation was to understand how health and social care data can be used in ways that the public feel confident in. To understand this, we needed to know what influences trust in data access, under what circumstances that trust increases or decreases, and what measures can be put in place to ensure the system is trustworthy. This chapter explores how participants, in both the core deliberation (Tier 1) and the seldom heard audiences (Tier 2) felt about data use and access initially, before the information sharing phase. This gives us a baseline that can be compared with the findings of existing research and also allows us to explore how participants' views changed during the data deliberation (Chapter 7. The impact of the data deliberation on trust and confidence in the use of health and social care data).

This chapter also includes findings from our nationally representative deliberative survey (Tier 3), helping us understand where the views of our participants match up with, or differ from, the wider population.

2.1 Key findings

At the start, we found that our participants, whether in the main deliberation, inclusive engagement groups, or in the survey, shared many views that were consistent with the findings of our evidence review. When it comes to 'data' in general people tend to assume this means personal data and are suspicious about who is accessing it and why. Spam emails, marketing phone calls and high-profile data breaches in the news all spring to mind. On the other hand, when asked about health and social care data most participants in all Tiers expressed trust in the NHS to use their data, because they expect the NHS to act with their interests at heart (The Health Foundation, 2023). Understanding more about potential benefits led to increased trust, mitigating some of the fears around unwelcome uses. Almost none of the participants had any awareness of the extent to which data is used currently. This lack of knowledge tended to mean these participants had a cautious outlook towards data use and access (CDEI, 2021). Among those who mentioned specific types of organisations, pharmaceutical companies were instinctively less trusted.

2.2 The context

From the evidence review, we knew some important contextual information on how the public feel about the use of their health and social care data: the perceived benefits, their concerns, and perceptions of trust.

The public are generally positive about data use and access having a direct impact on patient outcomes. In informed discussions, the public recognise a range of societal benefits associated with increased data use and access. They are most positive when they can see a tangible benefit, especially for individuals.

They are also aware that benefits can differ across demographic groups and communities.

However, awareness of how the NHS handles data use and access is low, and it is not a topic the public spend a great deal of time thinking about.

The NHS is highly trusted. However, while it is trusted to have good intentions around data use[4], it is less trusted for its competence in keeping data safe and secure[5]. Given the public's concerns about data breaches, reassurance over data protection and safeguarding is vital to building trust. Furthermore, we know that the public demand transparency around data use and access, meaning this is also vital to fostering trust and confidence.

2.3 Initial feelings of trust in how data is used generally

Benefits for society, offset by day-to-day mistrust

The evidence review found that when asked in the abstract the public are positive about the role data can play in their own lives and across society here and around the world – and this increases when they learn about tangible benefits, and through informed discussion. However, for our participants, when asked at the beginning of Workshop 1 to think about the personal data they share every day, most reactions were negative. They typically described an environment with little transparency about what data is collected and for which purposes. This lack of transparency led to concerns about a range of negative outcomes – which aligns with findings from the evidence review. Many of these concerns were relatively benign, ranging from uncertainty about who is in control of their data to frustration with unwanted communications.

But participants highlighted two more profound concerns that were present across the three workshops, concerns which participants returned to again and again: the fear of data breaches and of unscrupulous behaviour driven by a desire to make money. These concerns were deep-seated and informed participants' final positions on data use even at the very end of the data deliberation (as we will see in Chapter 7. The impact of the data deliberation on trust and confidence in the use of health and social care data).

These two concerns were underpinned by participants not knowing where their data is going. Therefore, there was a belief that data is being exploited in some way, without their consent and without any obvious benefit to them or others. This lack of transparency and consent led participants to suspect their data is unlikely to be held safely and securely, and used to generate money, in secret, and at the possible later expense of the participant.

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[4] https://psycnet.apa.org/record/2008-01400-011

[5] https://understandingpatientdata.org.uk/sites/default/files/2022-04/Diverse%20voices%20on%20Data%20-%20Main%20report_0.pdf

> *"What I don't want is my information monetised. I think cookies are a big thing here – they put your stuff on a database, sell it to a third party, and use algorithms to sell you things."*
>
> *North London, female, Workshop 1*

Those with more strongly-held concerns feared scammers getting hold of their details and using it for nefarious purposes – e.g. scam calls, texts, and emails to try and take money from unsuspecting individuals. They also worried about system failure, data leaks, or data being shared inappropriately. Personal experience of crime played a role here, making people wary of potential consequences.

> *"It's the feeling of being violated. I've been burgled before, and I wouldn't like crooks to know my details."*
>
> *Sheffield, female, Workshop 1*

Among the seldom heard audiences from Tier 2, those who have experienced discrimination and stigmatisation in society, including those from ethnic minority backgrounds and transgender people, were most likely to express mistrust at this point. This is influenced by a broader lack of trust in institutions, as well as concerns that their data would be used to further discriminate against them.

Higher levels of trust

For those with fewer concerns, their higher levels of trust in data use and access had a variety of different causes. For example, faith in the effectiveness of data protection regulations to keep personal data safe, belief in data being used to create benefits for others, or improved services. This aligns with insights from the evidence review that positive attitudes are linked to visible benefits. Others lacked trust but were resigned to having to share data to access goods and services, a situation they were not happy about.

Participants, while being aware of the broader theme of the data deliberation, spontaneously talked about trusting the NHS – largely due to their belief in its good intentions. For these participants, they trusted organisations with their data and didn't mind 'intrusive' uses – i.e. when they are unexpectedly contacted – as long as it's not in the 'wrong hands'.

> *"I trust the NHS more than anyone else. The NHS is there to look after us, why would they abuse my data?"*
>
> *Plymouth, female, Workshop 1*

Those with frequent interaction with the NHS, including those with long-term health conditions, disabilities, or with caring responsibilities, also discussed their trust in the NHS. These audiences acknowledged occasional frustrations with the NHS, particularly relating to perceived under-funding and under-staffing, but largely felt trust in the NHS as an institution that they believe has their best interest at heart. As such, they expressed trust in the NHS' use of their data and could see benefits of this for both them and those in similar circumstances.

> *"I trust the NHS is using my data well, they've been very good to me. I'm very grateful to them, I don't mind them using my data."*
>
> *Older person with long-term health condition, Depth interview*

Similar sentiments were expressed about social care, which was seen by many as a sector that was struggling so much with the day-to-day challenges that it was unlikely to be exploiting data.

> *"I don't think there's a single nursing home out there with bad intentions, they can't afford to do it. They're not taking your money to galivant around the world, they have nurses to pay, cleaning staff, chefs, administrators, carers."*
>
> *Plymouth, male, Workshop 1*

There were mixed feelings about trusting government with data. On the one hand, there was little explicit trust in government, or any specific administration – again related to concerns about competence. However, on the other hand, there was also a willingness to accept that accidents can happen and data leaks from government will occasionally occur.

It is notable that older participants expressed concern on behalf of younger people. They felt that, as "digital natives" who are very comfortable with online spaces and the use of digital technology more widely, younger people were not sufficiently concerned about what might go wrong. This seemed to be reflected in the way younger participants talked – they described having never considered any potential downsides to allowing the use of their data.

> *"I'm still only 20 so I've never thought about it before, what harm is it going to do... I just tick the box and press allow. It's just never crossed my mind, I've never seen it as an issue or anything like that."*
>
> *Sheffield, female, Workshop 1*

In contrast to what older Tier 1 participants believed about their younger peers, the Tier 3 deliberative survey revealed that younger adults were more likely than older adults to say they'd like to be more cautious when it comes to sharing their data. For example, a third (32%) of those aged 18-34 say that they would be likely to opt out of data sharing for health and social care, compared to half as many (15%) of those aged 55+.

Similarly, younger adults are less likely to say that they trust the NHS on several metrics. As the evidence review also found, the public are not especially trusting of the NHS' ability to keep data safe and secure. For example, in the Tier 3 survey, only 49% of those aged 18-34 say they trust the NHS to keep their data secure from data breaches, compared to 60% of those aged 55+.

2.4 Awareness of what health and social care data is collected and how it is used

Initial levels of awareness: predominantly about individual care

As with data use more generally, participants had little awareness of how their health and social care data is used, and the awareness they did have was usually restricted to individual care uses. This is consistent with the evidence review findings that not only is awareness low, but it is also not particularly top of mind for the public.

Beyond individual care, there were concerns about the motives of profit-seeking businesses – e.g. pharmaceutical companies – not aligning with participants' assumptions about the patient-first "good intentions" of the NHS. Even for health professionals, the introduction of a commercial relationship raised concerns. For instance, the surprising information that GPs are contracted to the NHS, rather than being part of the NHS, risked undermining participants' pre-existing assumptions that they would share these good intentions.

> *"I was surprised to hear that GPs were not contracted to share [all] your data and that they were separate owned businesses from the NHS."*
>
> *Canterbury, male, Workshop 1*

There was a widespread expectation among participants that their medical data would be seamlessly shared between what they believed to be different arms of the same organisation, for their individual care specifically – for example, between hospitals and GPs. They were surprised – and alarmed – to find that this isn't always the case.

> *"When people go to the GP, they assume that the hospital is going to know too. It's a massive assumption we have, we think they are under the flag of NHS but, actually, when you go to the hospital, things that are in the GP record are not necessarily in the NHS record."*
>
> *Plymouth, male, Workshop 1*

In contrast those with long-term health conditions and/or disabilities tended to be more aware of current limitations of data systems. They reflected that they are often asked to repeat details of their condition(s) and thus assume their medical data is not being shared between different parts of the NHS.

The consequences of not knowing

When asked how they feel about the way their health and social care data is used, this lack of awareness fed a sense of not being in control and suspicion about motivations.

> *"The problem is we just don't know. I'm not bothered about the NHS, it's what else might be done with it."*
>
> *Plymouth, male, Workshop 1*

The system, participants felt, is highly complex – it is difficult for the public to understand how it works, and little is done to explain it to them. Indeed, the most sceptical participants felt that the complexity and lack of clear explanation of how it works might be deliberately masking bad intentions; that is, that data is being used in ways that the public might not approve of, so the system is finding ways to confuse people and do what it wants regardless.

> *"They've made the whole system so complicated that any decision they make they can change at any time and do what they want whether we agreed to it or not. It's quite clear that is what they said whereby even if you opt out of sharing your data, there are ways your data can be used."*
>
> *North London, male, Workshop 1*

2.5 Initial drivers of trust in use of health and social care data

Trust in data use was supported by faith in the NHS and its motivations, a belief in realising the benefits of data use for oneself or others, and clear guidance on transparency. In contrast, trust was undermined by fears about suspicious actors and the negative consequences of inadequate security systems.

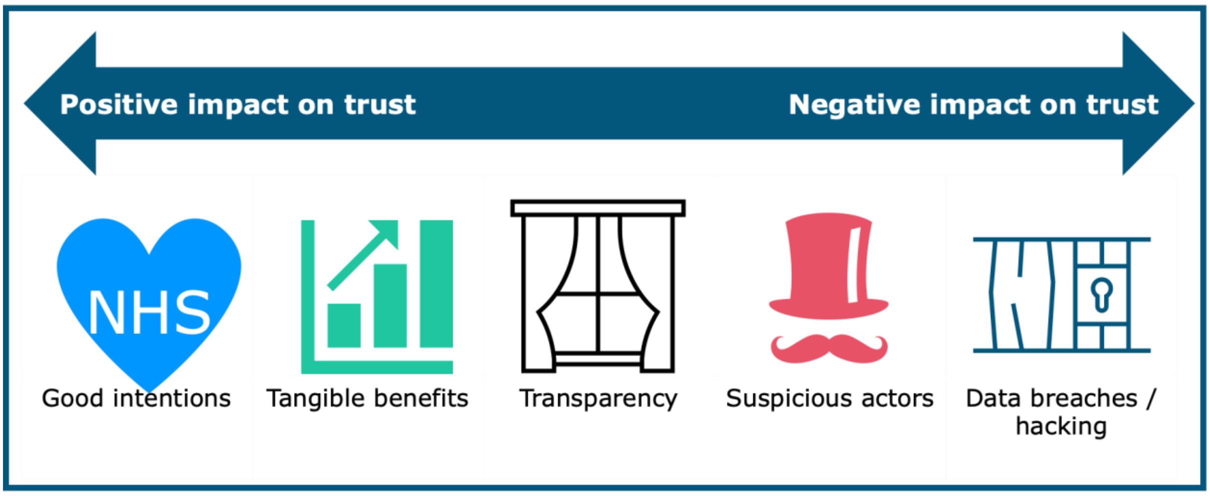
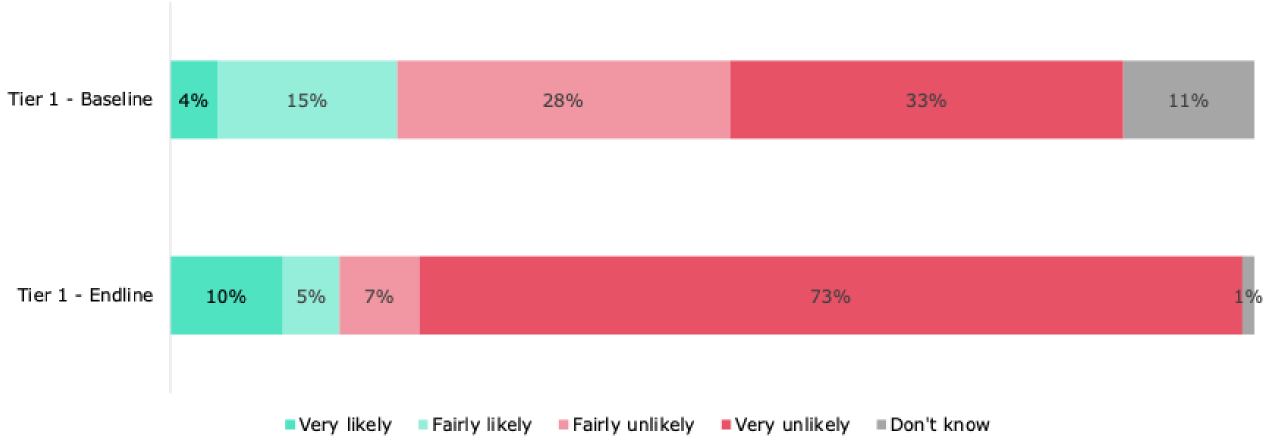


Figure 5 - Drivers of trust

Supporting trust

Despite concerns about transparency and motivations, many participants were prepared to trust the NHS with their health and social care data. We can see this clearly in the likelihood of participants to opt-out of data sharing, shown in Figure 6 below. Both the Tier 1 participants and the Tier 3 survey respondents initially reported similar levels of likelihood to opt out. The "baseline" figures for each show 4% of Tier 1 participants and 9% of Tier 3 respondents saying they are very likely to opt out. And this figure was in turn comparable with the actual national opt out level of around 5% as of May 2024, when fieldwork was carried out.

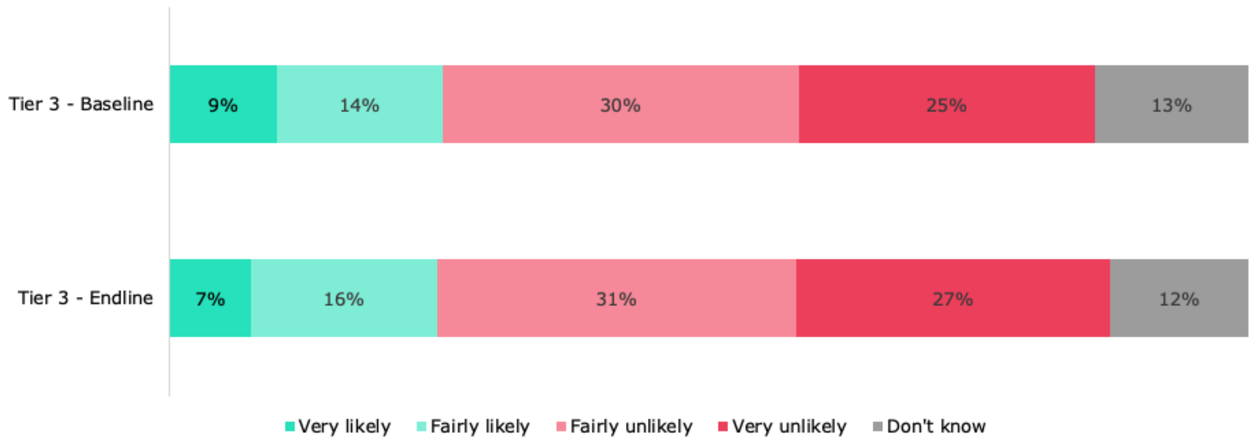
What is also notable is that the proportion of Tier 1 participants who said they are very unlikely to opt out was much larger after 15 hours of deliberation than at the outset. While this is solely a comparison of the Tier 1 participants at the start with those who completed a short survey at the end, the result is stark. In the beginning, a third (33%) said they are very unlikely to opt out. By the end, almost three quarters (73%) said they are very unlikely to opt out. And it is also notable that, while remaining a small minority, the number of participants saying they would be very likely to opt out doubled – from 4% (4 participants) to 10% (8 participants).



Likelihood of requesting to opt out of data being shared by the NHS – Tier 1

Q. How likely or unlikely would you be to request to opt out of your data being shared in this way? All respondents (n=97, n=83)

Figure 6 - Likelihood of opting out across Tier 1 participants



Likelihood of requesting to opt out of data being shared by the NHS – Tier 3

Q. How likely or unlikely would you be to request to opt out of your data being shared in this way? All respondents (n=2001)

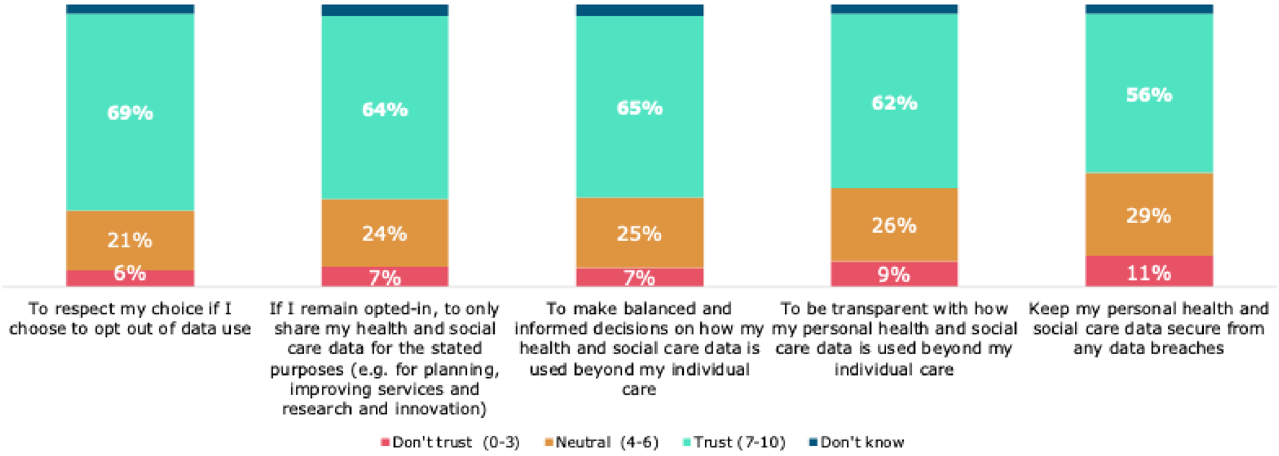
Figure 7 - Likelihood of opting out across Tier 3 participants

One of the primary drivers of this is trust in the NHS itself. As we have seen already and as the evidence review also shows, the NHS remains a trusted organisation.

> *"I think people should trust the NHS to use the information if it benefits everybody."*
>
> *Sheffield, male, Workshop 1*

This trust in the NHS's motivations was reflected in the Tier 3 survey findings, as shown in figure 5. For example, when provided with some high-level information about how data is used in the health and social care system, 65% reported that they trust the NHS to make balanced and informed decisions about their data. We see similar levels of confidence from survey respondents in the NHS to respect their choices, to be transparent, and to keep data safe.

Perceived trust in the NHS for data sharing activities



Q2. On a scale from 0 to 10, where 0 is not at all and 10 is completely, how much do you trust the NHS to … . Base: All respondents (n= 2,001)

Figure 8 - Tier 3 trust in the NHS for data sharing activities

Another strong influence on participants trusting the use of their data – not just health and social care data, but all personal data – was the extent to which they felt there would be benefits, whether to themselves or to others. This sentiment was widespread across the four locations, though especially prevalent in North London and Sheffield, as well as across the seldom heard audiences in Tier 2. They identified specific applications that they felt might realise benefits – from identifying overlooked inequalities and "societal blind spots", to research benefiting "the general public", to specific health services.

Undermining trust

Lower trust was closely associated with concerns about a lack of transparency, fears over data security and the NHS's skills in this regard, and suspicion about the motivations of those with access to data.

Transparency and information were key to much of this. Participants wanted to know what their data is used for, who is given access to it, and why. Without reassurances that data is safe and secure – e.g. information about safety processes and legal frameworks – participants' willingness to trust is undermined. What is important to understand is that participants didn't necessarily want all the detail about what is being done in legalistic specificity – rather, they want guidance on what is being done and what they need to do.

> *"There's not a lot of guidance on what you can do once you realised your data has been misused. Most of us don't understand it, we don't know what to do afterwards. There should be more regulation and guidance of what to do."*
>
> *North London, female, Workshop 1*

While they could be somewhat accepting that data breaches might occasionally occur, participants want to know that this possibility is being taken seriously and mitigations are in place. For example, they wanted clear explanations of how data is made less identifiable. Without this, they mistrust the ways their data could be used.

> *"It depends on how identifiable the data is. The more identifiable it is, the more you are at risk personally. Your name, date of birth, possibly location, would be identifiable."*
>
> *Plymouth, female, Workshop 1*

Those in Tier 2 with specific concerns about data breaches and personal de-anonymised data being shared included domestic abuse survivors, those with prior justice system involvement and unhoused people. These audiences were particularly concerned that a data breach of their identifiable personal data could have serious ramifications for them.

> *"I find it terrifying. Who is monitoring this technology and how safe is it? It all sounds very reasonable, but you have to think about who could get a hold of it and has access to it."*
>
> *Domestic abuse survivor, Depth interview*

Indeed, while trust in the NHS's motivations was relatively high, trust in their ability to keep data safe and secure was lower. Among Tier 3 survey respondents, only 56% of the public say that they trust the NHS to keep their personal data secure from data breaches, the lowest of the five aspects of trust we tested (shown in figure 5 above).

Additionally, the influence of non-NHS users of health and social care data created suspicion and was a barrier to trust. Participants were concerned about organisations putting profit ahead of patient care, contrasting this with the motivations they expect of the NHS.

3. Case studies: The different uses of health and social care data

To get beyond spontaneous perceptions of data use we introduced a series of case studies to participants. These were intended to help participants understand the different ways in which their health and social care data is used and explore some of the inherent trade-offs, building up understanding of the context ahead of discussions on the specific questions of governance, the value of data, and a data pact. The case studies were designed to cover different categories of use case: individual care, population health management, planning and improving services, and research and innovation. Tier 1 participants reviewed all ten, while a rotating selection was used in the shorter Tier 2 sessions, and in the Tier 3 deliberative survey participants answered a single question about the categories of use case. Full case studies can be found in the appendix of this report.

The themes discussed in each case study are complex. Each case study was designed to inform and engage discussion about different elements – e.g. anonymisation, deidentification, pseudonymisation, reidentification. Additional work to explore population health management specifically is being conducted by NHS England.

This chapter briefly summarises each case study, then gives an overview of what participants felt were the benefits, concerns, and impact on trust for each.

3.1 Key findings

To build participants' understanding of health and social care data use, ten case studies were explored, covering the four use cases for data sharing (individual care, population health management, planning and improving services, and research and innovation) in different contexts. Responses to these case studies show how these same principles underly trust in different context.

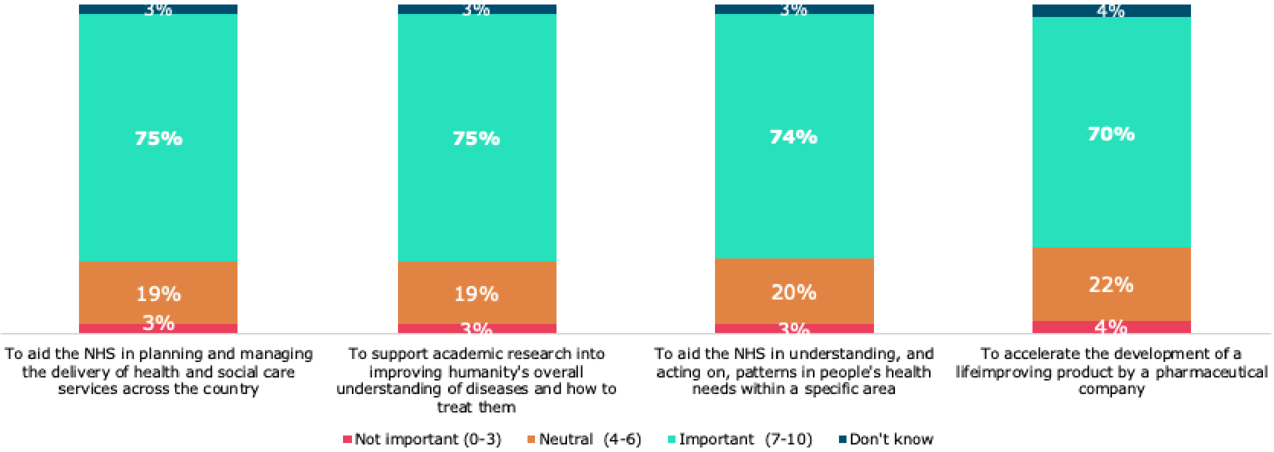
Participants were mostly positive where they could see a clear benefit for themselves or the 'greater good', by improving treatment and diagnosis. Participants could also see benefits of sharing their data with the NHS for commissioning and planning and to provide proactive clinical support.

Transparency, deidentification, and a clear opt-out mechanisms were key conditions for trust. However, concerns remained around data security, especially around data breaches, hacking and data sharing with third parties.

3.2 Feelings about data use and access in different scenarios

The Tier 3 quantitative findings demonstrated that the majority of the public are starting from a position that it is important to provide access to health and social care data in a range of different contexts to deliver benefits to patients and the public.

A majority (between 70-75%) said that each area tested is important. This compares to only a small minority (between 2-4%) say that providing access to health and social care data in each of these areas is not important. As we might expect based on the evidence review and initial reactions described in chapter 2, participants were less supportive when a pharmaceutical company was mentioned as part of the question.



Perceived importance of data sharing for activities

Q. To what extent do you think it is important or unimportant for the health and social care system to be able to provide secure access to health and social care data for the following purposes? Please answer on a scale from 0 to 10, where 0 is very unimportant and 10 is very important. Base: All respondents (n= 2,001)

Figure 9 - Perceived importance of use cases

The table below summarises the ten cases studies explored across the four categories:

Case studies		
Topic	**Summary**	**Rationale**
Population health management	Case study 1: How anonymised patient data can be combined with local area deprivation and ethnicity data to inform service design and resourcing for enhanced patient care.	To understand the public's comfort with health and social care data being combined with data sources from outside the NHS
Personalisation	Case study 3: How the NHS app could be used to track patients' recent health searches and provide suggestions for	To understand the public's comfort with their data

	tailored services e.g. alerts when entering an area with a high pollen count.	being used across multiple NHS platforms
	Case study 4: How demographic and health data could be combined to identify those at risk of certain conditions and provide tailored services, reminders, information, and guidance.	To understand the public's comfort with receiving tailored communications and services based on their health data
The Federated Data Platform	Case study 5: Introduction to the NHS Federated Data Platform (FDP).	To understand the public's response to the NHS employing a third party to manage the FDP
Research and Innovation	Case study 2: How genomic data can be used to improve research and diagnosis into hereditary diseases.	To bring to life a data for research case study through hearing first-hand experience
	Case study 6: How the social care records of people living in care homes can be combined with health records in a research study about the extent of infection and its consequences.	To understand the public's response to social care data being used in combination with health data
Type of organisation	Case study 7: How an AI tool developed by a medical research charity could be used to improve diagnosis and treatment for breast cancer. Participants were then asked to consider the scenario again, but where the company developing the AI tool is a start-up pharmaceutical company.	To understand the public's response to their health data being used to train AI tools, and how their views differed depending on the type if organisation doing the research
International vs UK	Case study 8: A UK-based academic pharmaceutical company is conducting research into the cause of heart arrythmia with the aim of developing new treatments. Participants were then asked to consider the scenario again, with the company being a start-up pharmaceutical company based in Canada.	To understand how the public's views of data use and access differ between UK vs international uses

Type of product	Case study 9: An academic research agency has put in a request for patient data on Alzheimer's disease, to produce a research paper to better understand causes, early signs, and treatments. Participants were then asked to consider the scenario again, with the company aiming to produce a new drug or device.	To understand how the type of output of the data used influences the public's perceptions
Scale of product	Case study 10: How patient data could be used to explore cures or treatments for a widespread condition that affects hundreds of thousands of people every year. Participants were then asked to consider the scenario again, for a very rare condition, which affects less than 10 people a year.	To understand how the scale of a product – or the number of people it could benefit – impacts the public's perceptions

3.3 Population health management

Case Study 1

Benefits: This example felt familiar to participants. They described benefits related to better public health and cost savings to the NHS through proactive identification of patients in need.

> *"I would be very happy [for my data to be used this way] as it will prevent future suffering and help to prevent diseases like diabetes, saving lives and money."*
>
> *Plymouth, male, Workshop 1*

Concerns*:* Participants were worried about the "invasive" nature of being contacted unexpectedly and without explicit consent. Other concerns focused on the security of data, the risk of data breaches and hacking, data being sold to third parties or shared with charities without their knowledge or consent. It was felt that more detail on deidentification and anonymisation needed.

Impact on trust*:* A concrete example of deidentification provided reassurance. As there are high levels of trust for data sharing within the NHS, this was considered an adequate measure to protect patient identifies, however there were concerns about even anonymised data being shared with third parties outside of the NHS.

> *"Again, it's cost benefit, its being proactive, but at the same time some people might find it invasive. It's toeing the line."*
>
> *North London, female, Workshop 1*

3.4 Personalisation

Case study 3

***Benefits**:* Better public health through improved prevention and improved individual health outcomes. There was a level of familiarity among participants as to how they could 'opt-out' of sharing their location with the app, which was felt to be reassuring.

> *"My son has ADHD so remembering to use his meds is very important. For somebody like him having this reminder to take them would work really well. It's very positive."*
>
> *Canterbury, female, Workshop 1*

***Concerns**:* The benefits are not generally felt to be significant enough to justify the collection of location data. Worries that a more tech-reliant NHS might reduce access to in-person services needed for those not comfortable with technology and concerns that constant reminders could become annoying or feel intrusive. Those managing health conditions or disabilities worried the constant reminders of their condition via an app could be triggering.

> *"It does seem a bit like nannying. Why does he need the NHS app to tell him this?"*
>
> *Sheffield, male, Workshop 1*

***Impact on trust**:* Overall this was not felt to be a particularly compelling use of data. The benign nature of the data (e.g. searches within the NHS app) and explicit need for consent before location data is accessed, were felt to be adequate protection measures, though not adequate enough to make the use case compelling.

> *"As long as you've opted in for it because you deem it beneficial for you, I think it's ok for data to be used like this. But it's also important to be able to specify that it's ok to use my location data only when the app is being used."*
>
> *Canterbury, female, Workshop 1*

Those most opposed to their data being collected raised concerns about being 'tracked'; they wanted to understand more about what data would be collected, how else it could be used, who else it might be shared with, and if there would be a way to opt-out of this service.

> *"I would question why my search history is being monitored. If I'm just randomly searching for hay fever, fine, but if I'm searching something more personal, I wouldn't want to be contacted."*
>
> *Canterbury, male, Workshop 1*

Case Study 4

Benefits: Participants could see how this may benefit personal health outcomes. Reminders were felt to be good for those who might suffer serious health complications from missed medications. Those in a carer or support role felt this would help navigate the appointments, medications, and needs of the person they care for.

> *"This is brilliant, I am diabetic, they told me to take medicine, but I didn't take it much, but I did a lot of exercise, and now my diabetes is under control. This health data is a really good thing."*
>
> *North London, male, Workshop 1*

Participants also identified how this use case could have public health benefits. Aggregate data could be used to identify patterns in health across the country, improve NHS care and be used for cost saving preventative healthcare.

> *"I trust it more because there's a positive outcome and it's being used for the greater good, not just the individual."*
>
> *Plymouth, male, Workshop 1*

Concerns: Concerns were raised about the accessibility of a digital service, and how this could exclude the demographics it would be most helpful for i.e. the elderly. Amongst those concerned, a wider worry was expressed about the NHS developing an over-reliance on technology for health were also raised.

> *"There needs to be alternatives for those who are less tech savvy. Older people might not be able to cope with digital aspect of it."*
>
> *Plymouth, female, Workshop 1*

Impact on trust: It was felt that explicit consent to collect, use and send notifications would need to be obtained proactively e.g. when the app is first downloaded. A small proportion of participants, more likely to be sceptical of data use, wondered if this is just a way to gather additional patient data.

> *"Basically, if it's an app and you need to be confident that it's got brilliant security."*
>
> *Plymouth, male, Workshop 1*

3.5 The Federated Data Platform

Benefits*:* Participants listed a number of important benefits, including more joined up services; improved patient care; time savings for NHS staff; improved communication between NHS systems; a streamlined patient experience; using a third-party supplier would save the NHS money; and allowing the NHS to focus their funding on healthcare rather than on IT services.

> *"You get the expertise getting it from the private sector, it means that they get the skills they need. You need people who are clued up in this sort of work, unless the NHS has their own high-tech team that can do it."*
>
> *North London, female, Workshop 1*

These benefits are especially important for Tier 2 participants with frequent interaction with the NHS due to health conditions and/or disabilities.

> *"I like the idea of things being connected from an accessibility point of view, so I don't have to keep repeating myself. They used to lose my file all the time."*
>
> *Registered Blind, Depth interview, Seldom heard audience*

There was a hope that the NHS could learn from the new system, either to make improvements themselves or to create the opportunity for the NHS to develop their own system in the future.

> *"Sometimes improving on something is better than making it. Even if there are flaws, you think they'd get identified quickly and they can make it better."*
>
> *North London, female, Workshop 1*

Concerns*:* Storing all NHS data together could, participants felt, make it vulnerable to hacking. They felt it important to inform patients of the plan and of the safeguarding measures put in place to prevent hacking and data breaches.

> *"Being in the same system is a big risk of a data breach. It seems like a bigger risk being in one place. The reason people should know is that it shows they are not trying to hide something or go behind their backs."*
>
> *Canterbury, male, Workshop 1*

Among the more sceptical participants, there were concerns that privacy may be affected by using a third-party supplier; questioned if the third-party software may be liable to data breaches or system crashes; worried that data may be accessed or 'stolen' by the supplier and sold on to further parties. As such, participants felt it was essential that the NHS 'own' the data and have full control over who can access it.

> *"I feel like it's the dream, but I don't see it currently working. I would feel better if it was government controlled, not the private sector. I don't trust the private sector enough to deal with the security, just look at the post office scandal."*
>
> *North London, female, Workshop 1*

Certain Tier 2 audiences – especially those with prior justice system involvement, care experienced adults and those from ethnic minority backgrounds – were particularly concerned about third-party suppliers 'stealing' data and selling it on. These audiences had all experienced discrimination and stigmatisation due to sharing of their personal data previously and felt they could not trust a third-party supplier to keep their data safe.

Impact on trust*:* There was a feeling that use of third-party suppliers ‘happens all the time’ in other sectors, and so the purchasing of software felt reassuringly familiar; that responsibility could be easily attributed to the supplier in the instance of a data leak or breach also felt reassuring.

> *“I don’t see an issue, if a third party wants to try something, for example if they want to leak information, the NHS will know its them. There would be fines or prison time, so it’s still something safe.”*
>
> *North London, male, Workshop 1*

However, participants felt that transparency about who is providing the software would be key. As would the ability to switch suppliers in the future and that the supplier be a ‘reputable’ firm, ideally known to the public.

> *“Probably how reputable the private sector client they're buying from is, if it's well established and has a good record, that's good to know, otherwise people hear private sector firm, they'll be like 'what does that mean'. If we know who it is, it will reduce those anxieties.”*
>
> *North London, female, Workshop 1*

Participants felt it was key that patient data stay within the UK’s data protection regime and not be stored or shared internationally; they also felt more comfortable with the idea of using a UK based third-party supplier, with the more wary individuals saying they would be more likely to opt-out if they knew the supplier was international.

> *“We should know if it’s a foreign company that owns the data, it should be owned by a UK company. I might have to rethink my consent after seeing who owns the company.”*
>
> *Plymouth, female, Workshop 1*

Both the NHS and the supplier would need to be transparent about how data will be used, who it will be shared with, and why. Participants want patients to be informed of the safeguards in place and the reassurance that all procedure is compliant with UK data law. They also suggested that the system go through a trial or that a regulatory authority or ombudsman should oversee procedures.

> *“The NHS should tell people they are using third party if it is trustworthy why not tell them. I trust the NHS to use a trustworthy organisation. I think it should be transparent.”*
>
> *Canterbury, female, Workshop 1*

3.6 Research and Innovation

Case Study 2

Benefits: The main benefit identified within this consented research example was better health outcomes for minority, previously overlooked, or at-risk groups. This example felt like an 'altruistic' use of health data that would benefit the 'greater good' of the nation's health.

> *"I'd be okay with my data being used for beneficial research. Stuff like this can really affect people, if they have disorders which aren't really understood or can't be treated."*
>
> *North London, female, Workshop 1*

Concerns: These focused on the security of the data, the risk of data leaks or breaches, and hacking. Participants were comfortable sharing genomic data within the NHS but raised concerns about it being sold to third parties.

Impact on trust*:* A concrete example of deidentification provided reassurance. Genomic data felt safer than other health data as it's harder to re-identify individuals. Conditions of trust were keeping genomic data secure, obtaining consent for use, and ensuring that data is destroyed after.

> *"This is one of the best examples, consent is clearly given, there is a good outcome with future benefits and is used for a specific outcome."*
>
> *Canterbury, male, Workshop 1*

Case Study 6

Description*:* Case study 6 outlined how the social care records of people living in care homes can be combined with health records in a research study about the extent of infection and its consequences.

Benefits: Those with personal experience of infections within care homes were quick to identify benefits; they felt protecting the elderly in care was a justifiable use of data.

> *"A lot of the identifying data has been taken out of this, it's not like a central database. This is talking about health in care homes and learning how to minimise the spread of infection, not gaining information about any one person."*
>
> *Sheffield, female, Workshop 1*

Concerns*:* Not all could see the value of putting patients at risk of their data being leaked, especially those without first-hand experience of social care; concerns were raised around collecting informed consent from the elderly. Participants would want there to be a clear, accessible, and easy to understand opt-out system.

> *"My dad doesn't have the capacity to understand. He wouldn't even know what a data breach is, even if you explained it to him. You have a duty of care, so you have to take responsibility."*
>
> *Plymouth, female, Workshop 1*

Impact on trust: There was a high level of trust in data sharing between the NHS and social care systems. Indeed, there were participants who assumed health data is already shared with care homes. The use of NHS numbers rather than names was felt to be reassuring.

> *"No concerns at all, it states that having access to NHS so if it is all for the good of the people, benefits far outweigh the risks. Combining data that is already there with the care home."*
>
> *Plymouth, male, Workshop 1*

But the possibility that data can be reidentified if there was a data leak was worrying. Participants wanted to know who would be held responsible in the case of a data leak and thought care workers should receive training in data protection.

> *"It's a red flag that the researchers can access information leading back to individuals. The research is necessary, but why link it back to an individual? I would prefer it if the patient stayed un-identified."*
>
> *Canterbury, female, Workshop 1*

Overall participants would feel more trusting if the aims of the research study were made clearer; wanted reassurances about who would be able to access the data, whether it would be shared outside the UK or sold to other research organisations; also want full transparency surrounding who commissioned the research and where funding is coming from.

> *"You got to gain the public's trust, by publicising what you're doing and why, not keeping it behind closed doors. Because when it goes wrong, because it will go wrong at some point, people won't be dubious of what was going on with their data in the first place."*
>
> *Plymouth, male, Workshop 1*

3.7 Type of organisation

Medical research charity: This was considered a beneficial use of patient data. Participants liked that research is being conducted by a medical research charity, and any profit would be funnelled back into that charity. They generally felt positively towards AI use for this purpose.

> *"I think if it advances technology than that's a good thing, if it makes it more precise in terms of screening."*
>
> *North London, female, Workshop 1*

Impact on trust: There were high levels of trust in the NHS and academic charitable institutions. Participants felt that the NHS requires funding, and this could be a beneficial way for them to generate funds. It was felt to be unlikely individuals could be identified from this data but felt that it would be necessary to gain consent. Those participants who raised consent here highlighted how this issue was not always clearly understood by all participants – and it is important to note that there were other participants who did recognise this was not a consented study.

> *"It's definitely the correct set of data to use for the benefit of the general public. But the concern is that the mammogram scan of breasts are sensitive to individuals, so there needs to be some consent involved in the use of those images."*
>
> *North London, female, Workshop 1*

Start-up pharmaceutical company*:* Participants felt less trusting of a pharmaceutical company, and worried that results would be manipulated to sell more of the company's products. Concerns were also raised the results would only benefit certain demographics that could afford the service. Whereas if the research was conducted by a charity, the outcome would be more likely to be universally accessible and beneficial.

> *"I worry [with it being a pharmaceutical company] because it's about lining someone's pockets."*
>
> *North London, female, Workshop 1*

Impact on trust*:* Concerns were raised about the data security standards of a 'start-up'; participants felt that more safeguards would need to be put in place to protect patient data and ensure it is used for the intended purpose.

> *"I'm okay with them making a profit that's what they exist to do. So long as it is for the greater good and the correct processes in place. I am okay with it, but there has to be a lot of safeguards in place."*
>
> *North London, male, Workshop 1*

Participant preference: Overall, participants felt significantly less comfortable with their data being shared with a private pharmaceutical company, than with an academic research charity. This feeling stemmed from a belief that a pharmaceutical company would be more financially motivated, with profits ultimately going to shareholders, whereas a charity would be more focused on improving health outcomes for patients.

> *"It makes me question it a bit, how much of it is for the greater good. If they find something more accurate and more precise but is it accessible to everyone or is it for their greed."*
>
> *North London, female, Workshop 1*

3.8 International vs UK

UK based pharmaceutical company*:* Participants believed this could save lives, provide a source of income to the NHS, give a boost to UK academia, and generate greater learnings for the medical community.

> *"I would comfortably sell my data if it meant developing better meds and treatments to health issues."*
>
> *Canterbury, female, Workshop 1*

Impact on trust*:* Concerns that pharmaceutical companies are ultimately financially motivated, rather than patient focused. Participant were keen to understand how the profit generated from selling patient data would be used to benefit the NHS.

> *"I am presuming the NHS can sell that data without names, all anonymised and general. Only problem is that they might then end up making lots of money, while the NHS can barely afford those treatments."*
>
> *Plymouth, female, Workshop 1*

Canadian, rather than UK, pharmaceutical company*:* Benefits identified included the potential for countries to learn from each other. However, it was felt that certain countries would be more trusted than others e.g. Canada would be more trusted than China. There was a sense that some countries have data protection regimes largely similar to the UK and so are considered more trustworthy than those countries which participants assume have different approaches.

> *"If you say it's a Canadian company, I trust that because I feel like they have standards that are similar to ours, whereas if you say Chinese company I have much less trust, because there is so much more state control."*
>
> *North London, male, Workshop 1*

Impact on trust*:* Data sharing with an international pharmaceutical company raised additional concerns, including the potential of weaker data protection laws outside of the UK, that could increase the risk of hacking or data breaches. Worries that data may be sold on by another country or to an additional third party deepened this sense of mistrust.

> *"Data protection laws are different in different countries there are different standards in different countries, and there are different levels of corruption."*
>
> *North London, female, Workshop 1*

Participant preference: Ultimately, there were higher levels of trust for a UK pharmaceutical company than for an internationally based one. Participants felt most trusting of their data being shared within the UK where data protection law (GDPR) is known and less trusting of international data sharing where responsibility for a data leak was less clear.

3.9 Type of product

Research paper*:* Those managing health conditions or caring for those with health conditions were particularly supportive of this use case. There was recognition that a research paper is an important stepping stone to finding a cure; the use of data for this purpose is felt to 'benefit everyone'. The nature of the data was felt to be adequately depersonalised so as not to present a risk to patients' identities; and a research agency was generally felt to be trustworthy to handle the data safely.

> *"They do research papers at academic research institutions all the time, it's their bread and butter, and the researchers have to go through a lot of training and certification to access that data, and there are protocols for disposing of it afterwards too."*
>
> *Sheffield, female, Workshop 1*

Impact on trust*:* Concerns that data can never truly be anonymous.

To develop a new drug or device*:* It felt acceptable for the NHS to ask for payment for access to the data, but there were also concerns that drug development may be motivated by profit.

> *"I think if this drug is going to be sold, where the data is being used to create a new product, I think the NHS should be able to charge for data access."*
>
> *Sheffield, male, Workshop 1*

Impact on trust*:* Although participants were keen to see new drugs and treatments developed, the introduction of the chance of generating a profit reduced trust, despite the drug being produced by a charity. Tier 2 participants were more likely to recognise the necessity of drug development as could have concrete benefits with the appropriate precautions in place.

> *"The drug is a treatment, so that seems more favourable, it helps more. But if they're not a member of an academic body then they don't have that scrutiny or accountability. There's a question of safeguarding."*
>
> *Sheffield, male, Workshop 1*

Participant preference: Ultimately, academic research is trusted more than drug development. In addition, academia researchers were felt to be more trustworthy than those working in drug development, as there is an assumption they will be better trained in handling sensitive information.

3.10 Scale of product

High-prevalence condition*:* Key benefit for participants was the potential to improve public health; the opportunity to improve diagnosis and treatment for previously overlooked groups and improve NHS efficiency. It was felt that the NHS is uniquely positioned to provide data sets of this size.

> *“I think to understand these things, you need a lot of data. Either you have to have that quantity of data, or you won't be able to understand it. That's why the NHS data set is so important, because a dataset on that scale doesn't exist in many other places."*
>
> *Sheffield, male, Workshop 1*

However, there were concerns about consent and how easy it would be to opt-out. The mention of lifestyle factors was felt to border on ‘invasive’ and more sceptical participants wondered what the benefit of assessing environmental factors would be, as health agencies such as the NHS and social care system are unlikely to be able to make changes to these areas.

> *“Using my data to look at the bigger picture is fine, but my data is not going to help people's environments, what's the point, it could just be lifestyle factors.”*
>
> *North London, female, Workshop 1*

Impact on trust*:* Overall, participants had high levels of trust for the NHS to use their data in this way as long as there is clarity on anonymity, transparency about what data is being used for, as well as clear instructions of how to opt-out.

> *“I'd be a lot more comfortable with a medical charity doing it [than a pharmaceutical company], because they're not doing it for a profit, and with the NHS it feels like the right way to approach it.”*
>
> *Sheffield, female, Workshop 1*

Low-prevalence condition*:* Those from smaller incidence populations in Tier 2 felt it was more critical their data be used for research. In particular, transgender audiences saw the case for their data being used to help smaller numbers of people.

> *“I had a very rare procedure done and I want researchers to know about it because it’s such a rare operation. It would benefit the NHS for them to know about it.”*
>
> *Participant with learning difficulties, Depth interview, Seldom heard audience*

Among the general population audiences, it was felt that research to save lives is worthwhile. But while many participants saw this as admirable, it did not necessarily aid their trust in sharing their data.

> *“If it is for the benefit of all, it is good to share data as one can be part of the few people who have rare conditions.”*
>
> *Plymouth, male, Workshop 1*

Impact on trust*:* The scale of the product had little impact on participants’ trust. Although there was an assumption among a few participants that the rarer the disease the more likely they would be to be identified by their data, for most the conditions of trust remained the same; they would want to be informed what their data would be used for and wanted reassured that data would be anonymised.

> *"The smaller the group, the less anonymous you are. But I think your vested interest in finding an answer is going to be higher so you will be more willing to help more. In that position, I would accept I would not remain anonymous."*
>
> *Plymouth, female, Workshop 1*

Participant preference: Overall, participants felt that research wherever possible should be focused on the most prevalent conditions, for the widest impact. The severity of the condition was weighed up against this, however ultimately proportionality was felt to be the superior factor.

> *"If there is a million pounds to be invested that should be shared out based on some sort of framework, and severity should come into that, but also proportionality and some sort of rational decision maker."*
>
> *North London, male, Workshop 1*

What reactions to the case studies tell us

These case studies introduced participants to some of the complexities and trade-offs around data use in health and social care, outside of individual care.

Participants' reactions made it clear that various factors influence trust how health and social care data is used, with a consistent demand for transparency and security – concerns were raised repeatedly about potential data misuse.

Trust was influenced by the familiarity of using third-party suppliers, with a preference for UK-based companies due to worries about varying international data protection laws.

Participants felt reassured by examples of data deidentification, with the genomic data case study showing data security that provided reassurance. They trusted data sharing within the NHS and social care systems, appreciating the use of NHS numbers to anonymize data.

Transparency about the research, including who can access the data and how it is funded, was crucial for trust. There were concerns about the security standards of start-ups and the motivations of pharmaceutical companies, especially regarding profit from health and social care data.

Participants worried about the challenges of obtaining permission from vulnerable patients and the potential for data breaches. Despite these concerns, there was overall trust in the NHS, provided there was clarity on anonymity, permission, and opt-out options. Trust remained consistent across different scales of data use.

4. Governance and Data Access Committees

Introduction and context

DHSC and NHSE are moving to a system whereby if researchers want to access NHS data in England they must apply to one of 12 Secure Data Environments (SDEs). Each SDE holds data on around 5 million people, and they provide secure access only to the data needed for a particular research project. This means that only the findings of any analysis can be withdrawn from the SDE, rather than any raw data. Each SDE has a Data Access Committee (DAC) in place to assess applications from researchers and to decide whether or not to grant access to the data. We introduced SDEs to participants and explored their expectations of governance and DACs.

A proposed set of principles, based on the Five Safes framework and tailored to DACs, was shared with participants. The way in which DACs manage data use and access was also demonstrated. Tier 1 participants were introduced to these topics in the second workshop, where we asked participants to weigh up the respective merits of three hypothetical approaches to managing a request for data from multiple SDEs. This chapter explores participants' expectations for the DAC decision-making process and outlines the implications for policymakers.

4.1 Key findings

Previous local engagement had led to findings that all SDEs involved in a project had to be equally involved in decision-making, leading to a very decentralised approach. The Tier 1 **participants were split on this preference**, with roughly as many supporting greater central coordination, consistency, and shared decision-making, as that supported a model where each SDE was involved in every decision.

There were four clear priorities for policy makers to balance in deciding the rules that govern data access to an SDE:

Transparency of process: Participants in the data deliberation were shown principles for data management rooted in the Five Safes model[6]. Openly demonstrating the principles that govern data use and access reassured participants, mitigating concerns that this might be kept hidden from the public. A lack of transparency about the principles would undermine trust in how data is used by raising fears about why these principles were not being shared.

Consistent application of principles: Ensuring that all organisations involved in decisions about data use and access are acting according to the principles was

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[6] https://digital.nhs.uk/services/secure-data-environment-service/introduction/five-safes-framework

crucial for participants. They wanted principles to be enforced, with clear sanctions for any breaches. Participants also wanted decisions about who has access to data to be consistent and felt this would be a good test of whether principles were clear enough about appropriate use.

An inclusive process: Ensuring inclusion of a relevant diverse set of views in the decision-making process was also important, especially to those who felt at most risk of discrimination. More localised decision-making was seen as important to fairness, but only if decision-making panels included lay people, from diverse backgrounds, as well as specialists with the right expertise and knowledge.

Efficient decision-making: An efficient process, led by specialists and including public voices, which minimised bureaucracy and resulted in swift decision-making, instilled confidence. Participants generally rejected the most complex decision-making systems for researcher applications.

The tension between an efficient process (with fewer people involved in decision-making) and an inclusive one (which included all relevant and diverse voices) echoed in the Tier 3 survey findings. There we saw a preference for consistency over local decision-making, but also for local decision-making over efficiency.

Policy makers therefore need to consider how they deliver an efficient, consistent process for DACs – for instance, formalising the standards discussed and creating central oversight and escalation routes to drive consistently. They need to balance this with keeping enough local autonomy to reflect the diverse nature of any regions that are represented.

4.2 The context

The NHS is moving from a system of data sharing to a more controlled one of data use and access. Rather than transferring data to external parties, data is instead hosted on platforms known as Secure Data Environments. The public have been supportive of this move, with a 2023 survey finding that 86% of respondents expressed feeling more comfortable with data access than data sharing[7]. The process of managing these data access requests from researchers – through Data Access Committees (DACs) attached to each SDE – was a key topic for this data deliberation. Our evidence review showed that previous local engagement on the topic had indicated that the public want any decisions made about local data to be via their local DAC specifically. This has implications for when data from multiple regions is needed.

The evidence review told us several other things about existing attitudes towards the governance of data use and access. As we have already seen,

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[7] https://www.bcg.com/united-kingdom/centre-for-growth/insights/towards-a-healthier-wealthier-uk-unlocking-the-value-of-healthcare-data

security and unauthorised access are consistent worries for the public. And those from ethnic minority backgrounds and other socially disadvantaged communities also have additional concerns centred around fairness and equality.

Given these concerns, the existing evidence suggests that the public believes in the need for clear governance for any data use and access model. They feel that this should be led by subject experts, that these experts can be trusted, and that the public can exert meaningful scrutiny on this process – specifically by having public representatives involved in any decision-making process.

Lastly, the evidence review suggests that transparency is important for the public in all aspects of data use and access. Even if this has not been expressed in relation to DACs, it has been a critical and non-negotiable factor in building the public's trust around data use and access.

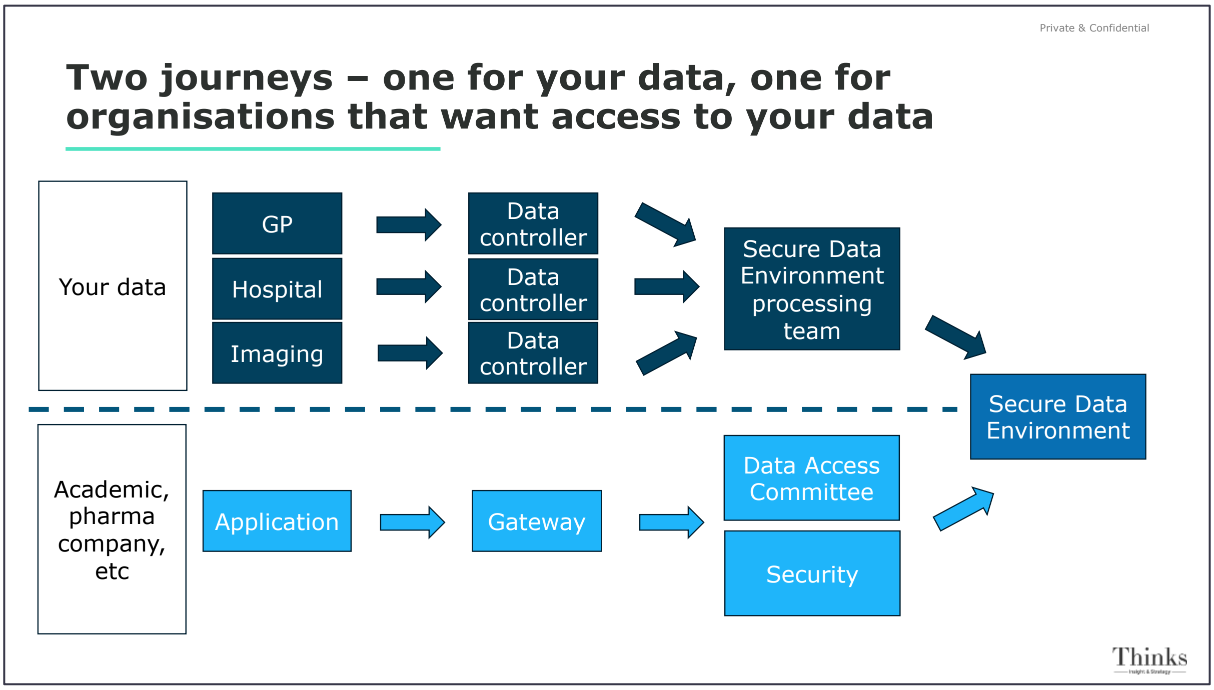
4.3 Introducing the participants to the principles and DACs

By the end of Workshop 1, participants had learnt about a range of use cases and started to explore what these meant for their trust in how health and social care data is used.

In Workshop 2, they were introduced to different aspects of the way use and access can be governed. First, they were introduced to a set of proposed principles, based on the Five Safes framework and tailored to DACs. These principles pertain to how decisions are made about who gets access to data and for what uses. The principles presented were (full details can be found in the appendix of this report):

1. Safe Projects.
2. Safe People.
3. Safe Setting.
4. Safe Data.
5. Safe Outputs.

Secure Data Environments (SDEs) and the DACs process were then explained and explored through a mix of stimulus material, specialist presentations, and case study discussions.



Private & Confidential

Two journeys – one for your data, one for organisations that want access to your data

Your data

GP

Hospital

Imaging

Data controller

Data controller

Data controller

Secure Data Environment processing team

Secure Data Environment

Academic, pharma company, etc

Application

Gateway

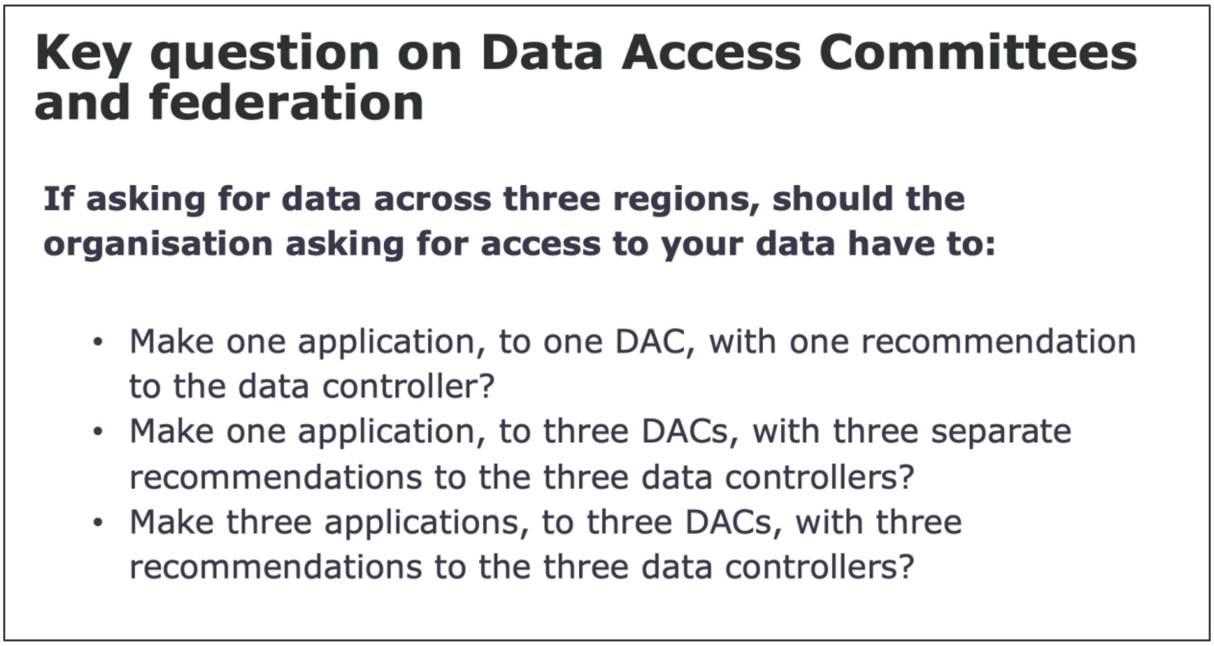
Data Access Committee

Security

Thinks

Figure 10 - The data journey

Finally, participants were presented with three different options for how applications to DACs could be processed and were asked to discuss which they would choose. This was a simplified example scenario designed to stimulate discussion about what mattered most to participants.



Key question on Data Access Committees and federation

If asking for data across three regions, should the organisation asking for access to your data have to:

- Make one application, to one DAC, with one recommendation to the data controller?
- Make one application, to three DACs, with three separate recommendations to the three data controllers?
- Make three applications, to three DACs, with three recommendations to the three data controllers?

Figure 11 - Application decision-making options

4.4 Expectations for governance

Tier 1 participants placed greater emphasis on consistency of decision-making and efficiency of process than expected based on indications from prior research. Inclusivity and local autonomy were also important. Participants' expectations for governance can be summarised as four distinct priorities:

- Transparency of process: Openly demonstrating the principles that govern data use and access, and presenting these principles in clear, simple language, reassured participants.
- Consistent application of principles: Ensuring that all organisations involved in decisions about data use and access are acting according to the principles, including enforcement and sanction if this is not the case.
- Efficient decision-making: Decisions should be made as quickly and as simply as possible.
- An inclusive process: Ensuring the process includes a diverse range of perspectives and voices, reflecting the regions where data is held.

Transparency of process

The draft principles for governance were widely supported by Tier 1 and Tier 2 participants. They comprehensively demonstrated what should be expected of decision-making, use, and access. The principles were clearly worded and easy to understand.

First and foremost, the sharing of the principles, worded in clear and understandable language, was reassuring to participants. This made it clear that data security – such a significant concern for participants – is being taken seriously in an open way.

> *"It really demystifies the concept of data security for me. It sounds like such an abstract thing (and) it's out there and you don't really know how it functions, but they seem to have thought of everything."*
>
> *Sheffield, female, Workshop 2*

Participants praised the principles for their clarity and use of plain English. This established trust as participants worried that jargon could be used to deliberately mislead or to hide bad intentions.

> *"They're easy to understand (as well), which I like. Sometimes you read this stuff and you need a dictionary. I like the simple language in this - so even if someone's not savvy, they can understand."*
>
> *Registered Blind, Depth interview, Seldom heard audience*

Consistent application of principles

Participants believed that good decision-making would be the result of application of the principles. Therefore, they wanted to see the principles applied consistently, no matter what the specific constitution of any individual DAC. That separate DACs might apply the principles in the same way but reach different decisions seemed unlikely to participants. If this did occur, they felt this would imply an unstable system prone to manipulation, raising fears of misuse.

> *"I think the principles are right, the question would be about how they are applied…"*
>
> *North London, male, Workshop 2*

The idea of inconsistent decision-making prompted concerns that some DACs could be seen as a 'soft touch' compared to others, and that it could lead to organisations targeting these for improper uses of data. Or that datasets could end up being unrepresentative – and the findings from research conducted using them, biased or incorrect – because of certain regions being avoided if they were more likely to reject applications for data access.

> *"I would be worried that if one region continually rejects me, maybe eventually that company chooses not to go to that region and then the dataset becomes unrepresentative."*
>
> *Sheffield, female, Workshop 3*

Consistency, for participants across Tier 1, required enforcement. This was instinctively seen as a valuable tool in ensuring consistency of decision-making in alignment with the guiding principles.

> *"Will there be real ramifications for breaching? Will it just be a fine or a slap on the wrist?"*
>
> *Migrant, Workshop, Seldom Heard Audience*

Efficient decision-making

Participants wanted decisions to be made as quickly as possible, given that lives could be saved by potential new treatments.

Therefore, simple structures are preferred, to minimise bureaucracy and waste. Complexity was equated with bureaucracy, which in turn signalled time-wasting. For participants, more bureaucracy also created an opportunity for misuse by any bad actors.

> *"There needs to be the absolute minimum bureaucracy there can be."*
>
> *North London, male, Workshop 3*

Ensuring DACs include well-qualified specialists was also felt to be crucial in arriving at informed decisions as logically and efficiently as possible.

> *"It does sound like the DAC has the broad distribution of profession required to know and to process how the data is relevant, whether it is actually needed, and the implications of using it."*
>
> *North London, male, Workshop 2*

When asked to choose between different ways decisions-making could happen (Figure 8, above), there was near-universal rejection of the most complex of the three – "Make three applications, to three DACs, with three recommendations to the three data controllers". This option was considered the slowest, most bureaucratic, and least efficient of the options put to participants.

> *"I feel the third option is completely disjointed and puts so much bureaucracy in the system. There are too many barriers in place to access the information they want to access."*
>
> *Canterbury, female, Workshop 2*

The first option – "Make one application, to one DAC, with one recommendation to the data controller" – was popular with those who prioritised efficiency and speed. Furthermore, those in favour of this approach also argued that England lacks the level of regional diversity that calls for local representation in all cases.

> *"I think it's about the size, like if you were talking about America, they have more regional health care whereas here we have some, like in the midlands and London, but in general we're quite a small country."*
>
> *Canterbury, female, Workshop 2*

Those living with a long-term health condition, or with characteristics which mean they have more frequent interaction with the health services, were also more likely to favour this option.

> *"The whole point really is to be making it come through faster."*
>
> *Sheffield, female, Workshop 2*

Participants spontaneously considered the priorities of actors in the process, including researchers and beneficiaries of data use. This served to further underline the importance of efficiency as a condition of trust and confidence in data use and access.

> *"Would the researcher pay for the three applications? Is this something they would consider? (You) have to think from the other side. Paperwork, isn't it?"*
>
> *Canterbury, female, Workshop 2*

An inclusive process

Participants wanted specialists to lead the decision-making process. But they also wanted to ensure that a diversity of perspectives is incorporated – including patients and lay people, as well as people who understand local or regional needs, alongside specialists.

This was particularly important to those who felt at risk of discrimination. This included LGBQ+, transgender people, migrants, and people from an ethnic minority background.

> *"I don't think it's a one-size-fits-all, each DAC knows their region best. There might be reasons why they don't want to share certain information."*

Migrant, Workshop, Seldom heard audiences

Those seldom heard audiences who had lower levels of trust in national institutions – included those with previous experience of the criminal justice system, care-experienced adults, and domestic abuse survivors – were also keen on a diverse range of voices being included in decision-making.

From this perspective, it was important to add in an extra layer of safety and security in ensuring local voices are heard. The second option – "Make one application, to three DACs, with three separate recommendations to the three data controllers" – was, in this view, not seen to overtly impact on the speed of applications. Especially, participants suggested, if DACs work in parallel.

"I don't see how going to different regions is going to slow it down."

Sheffield, female, Workshop 2

It should be noted that participants were largely unaware of some of the factors that might lead to hold ups and delays in reality – for example, they did not consider the time and resource costs of an application to ten DACs, rather than the three suggested in the example.

4.5 Balancing competing expectations

It was clear that participants perceived an inherent tension in striving for an efficient process while also retaining the autonomy to be inclusive. Tier 1 participants were evenly split – in total and across the four locations – on whether efficiency or inclusivity should be most important. That said, given participants almost universally rejected the third option, which could be considered the most inclusive and devolved approach, it could be implied that efficiency was the key priority.

These tensions between expectations were explored further in the Tier 3 deliberative survey.

We presented respondents with a short explanation of the application process and posed the question of how DACs should best work together. Specifically, we provided respondents with three choices, trading off efficiency, local participation, and consistency, as shown in the figure below.

Level of agreement with statement A or B

Q. For each, move the slider towards the side you agree with the most. The closer you move the slider towards a statement, the stronger you feel towards that statement. Base: All respondents (n=4,007)

Figure 12 - Tier 3, how should DACs work together?

As among Tier 1 participants, we did not see overwhelming support for any one option. That said, looking at the three choices in turn we see an ordering emerge, one that supports the central importance of consistency:

- Consistency is more important than local input to decisions.
- Local input is more important than efficiency, and so is involvement of local members of the public.

Looking in more detail, we see that for those who describe themselves as wanting the greatest control over their data, a proxy group for those most concerned about data access, lean more strongly towards local involvement. For example, 53% of this group say that it is most important for local areas to get a say on who gets access to their data, compared to only 41% of the public overall.

4.6 The role of oversight

There was enthusiasm for some means to ensure transparency of process and consistent application of the principles. Participants felt this would bolster public trust and confidence in data use and access.

Participants in all locations spontaneously raised the potential need for oversight before being explicitly asked about it. The precise definition of oversight for participants varied according to individual understanding and prior experience. But participants were clear that, in order to have trust and confidence in governance and DACs, some oversight ensuring and enforcing adherence to the principles would be required.

> *"That [oversight] would make me feel more safe, to make sure there is another layer of protection."*
>
> *Care experienced adult, Depth interview, Seldom heard audiences*

For example, there were those who proposed national oversight to bolster simplicity and consistency of decision-making across DACs. The idea of establishing a single national DAC to maximise efficiency took hold in Sheffield – i.e. in place of regional DACs in the case of applications for cross-regional data.

> *"I think it should go to one national DAC. It takes away from data being centralised if you have to make different applications to different places - going forwards that's the aim, to make things less complicated."*
>
> *Sheffield, female, Workshop 3*

Yet discussions about what form oversight should take continually brought participants back to the need to balance efficiency and inclusivity. Participants wrestled with this, proposing various hybrid combinations of oversight structures and systems, and suggesting some trial and error may be required to get this right.

> *"You have to work on how to fine tune everything to work better together and more uniform."*
>
> *Plymouth, male, Workshop 2*

And opinions shifted over the workshops. Those who felt strongly either about minimising bureaucracy or maximising local input tended to sway others.

> *"I'm more in the middle now. I thought variety would be a good thing, but I also agree that if you can't trust one DAC then the system should be redesigned."*
>
> *North London, female, Workshop 3*

4.7 What this means for governance

More than any other topic discussed in this process, there are clear recommendations for both national and local policy on governance.

National policy recommendations

- The **quality and rigour of decision-making is the priority for the public**, not a particular structure. Policymakers should utilise whatever structures meet this end.
- **Consistency and safeguarding**, as expressed in the principles, were **prioritised over all other considerations**.
- There should be **some form of central oversight, including enforcement.**
- Policymakers should **focus on fulfilling and balancing public expectations rather than be committed to any one set mechanism** of oversight immediately.

Regional policy recommendations

- DACs must **reflect the diverse nature of regions**.
- Each SDE should **conduct its own engagement on who sits on a DAC**, as reflects the region.

National policy recommendations

Previous research had led policymakers to believe that a more streamlined system was not a viable path – that individual regions were not happy to delegate any decision-making about access to their data to other regions or nationally.

What we heard clearly in the workshops was that the quality and rigour of decision-making, using appropriate safeguards and appropriate decision makers, is the priority for the public, not a particular structure. Policymakers should utilise whatever structures meet these ends.

Participants in Tier 1 especially indicated a willingness to deprioritise decision-making being wholly local to favour efficiency and consistency. This should give policymakers more flexibility to put in place proportionate solutions. They need to consider how to deliver this expected efficiency and consistency of process and outcome. This should include formalising the principles and creating some form of central oversight, including enforcement.

Oversight will be key to mitigating trade-offs between consistency of decision-making and maximising efficiency of process on one hand and ensuring adequate local representation and inclusivity on the other. The fact that participants struggled to identify and agree on a preferred form of oversight and indicated their permission to use their judgement to decide an appropriate approach to oversight, means that policymakers should focus on fulfilling and balancing the broader public expectations rather than be committed to any one set mechanism of oversight immediately.

Regional policy recommendations

Policymakers must not neglect the importance of local autonomy, and DACs must reflect the diverse nature of the SDE network regions.

Certain Tier 2 audiences were especially keen to ensure DACs reflect their voices and needs. This means that individual DACs will have to consider the needs of their own communities carefully when deciding how to structure themselves. This need will be heightened in SDE regions with higher concentrations of minority and seldom heard audiences. Therefore, the expectation is that each SDE conduct its own engagement on who sits on a DAC, as reflects the region.

Of course, delivering representation for all is challenging while simultaneously avoiding bureaucracy. While everyone cannot be represented, ensuring good range and diversity of experience and perspective is an important goal for policy makers to strive for – and it’s clear that the public are willing to accept some experimentation in governance structures when attempting to resolve this tension.

5. The value of data for research

Introduction and context

Providing researchers with secure access to health and social care data costs the NHS money, which is offset from researchers via fees. However, there are further means through which the NHS could gain additional value from this data use. It could make a financial surplus by charging researchers more money, it could negotiate deals with researchers for other benefits like early access to medicines or a share of profits, or it could keep costs low and attract more researchers to the UK. We introduced the concept of data for research to participants and then asked them about how important each of these options was to them.

This chapter explores attitudes towards generating value from health and social care data. It looks at initial reactions to this concept and the interests and concerns driving the responses – as well as situating the discussions in the context of the preceding topic, especially the governance of data access. We then look at participants' feelings about different ways of generating value.

5.1 Key findings

While noting the small minority who remained opposed throughout the deliberations, **participants were broadly supportive of the NHS charging for access** to data to cover its costs. They recognised the value of the health and social care data that is collected, and supported it being used for research that benefits patients and the public. They wanted to see the value of data being shared fairly with the health and social care system.

However, it was important to participants that realising value from data should not detract from or conflict with the basic purpose of the health and social care system: to improve health outcomes. This principle then informed participants' views on how to realise value from data. They told us that:

- Generating **wider benefits** (for example, early access to or discounts on treatments developed from health and social care data; more clinical trials for patients to participate in; ownership of Intellectual Property from new treatments) should be the **highest priority** as this is most closely aligned with the mission of the NHS to improve health. Participants brought different values and assumptions to this part of the discussion and further exploration of "wider benefits" will be required, as well as consideration as to which benefits should be prioritised.
- **A surplus should be sought, participants were keen that this happen, and it should be reinvested in the NHS**. But care must be taken to **avoid negative consequences** like cuts in overall funding, or charging large sums for access that might discourage research that could lead to loss of wider benefits, particularly from charity and academic partners that may find high access charges a barrier. Exactly where the balance is between surplus sought and discouraging certain types of

research was unclear, and therefore requires further exploration. Importantly, participants did not feel that seeking a surplus was akin to "selling" their data.
- **Encouraging research in England is valued by the public.** This was especially the case if there are clear benefits patients and the public, either through surplus or wider benefits.

Importantly, all three of these ways of generating value from data were broadly supported by Tier 1 participants. However, in this area we heard some important differences between the audiences:

- Our **seldom heard Tier 2 audiences were sometimes more cautious**. Despite recognising the value of research in achieving health benefits, some had negative experiences of research benefits being promised but not arriving. Or, for transgender people and migrants, experiences of research being harmful to their interests. Therefore, these groups wanted reassurances that the wider benefits would, at the very least, not be actively harmful to people like them.
- **In the Tier 3 survey,** where participants had only basic information – and thus arguably better represented the views of the wider public – about why and how the NHS shares data for research, **there was greater reticence about the NHS making money from charging for access** – around 1 in 3 in this Tier told us that it is wrong for the NHS to make money from charging for access. They preferred a smaller surplus to a larger one and were more supportive when reassured that the surplus would be retained by the NHS. Therefore, generating value still carries some risk if the public are not informed on how and why data is being used.
- Thus, it seems clear that **more information and time to discuss the implications of charging for access – as the Tier 1 participants had – lead to greater support** for and trust in this concept.

5.2 The context

The evidence review highlighted that there has been limited discussion around value re-distribution and how the NHS should utilise any profits that are accrued from data. What evidence there is suggests that equitable distribution is a key priority for the public.

The NHS's existing commercial principles[8] have however been tested with the public and found to be both clear and acceptable. This suggests that charging for data access is broadly accepted. The public believes the NHS should be more

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[8] https://transform.england.nhs.uk/key-tools-and-info/centre-improving-data-collaboration/guide-to-effective-nhs-data-partnerships/

commercially savvy and that NHS bodies will need continuous support and guidance to help negotiate fair terms for access to data[9][10].

It seems that the public recognises the value that commercial partnerships can offer the NHS. However, there is some discomfort around these agreements, in part driven by misgivings about making profit from patient data. These misgivings are somewhat allayed when assurances are provided around reinvestment of the surplus – thus implying that public benefit is being realised by reinvesting surplus in services.

5.3 Introducing participants to the value of data for research

As described above, participants in Tiers 1 and 2 started with broad discussions of data (chapter 2), before exploring range of case studies illustrating how data could be used in health and social care (chapter 3), focusing on the direct benefits e.g. research impacts. Discussions then focused on the use of data for research, as facilitated by the SDEs (chapter 4). We then moved on to a discussion of how the use of data can generate value, and the approach the NHS should take to this.

In Workshop 2, participants were introduced to the costs of managing and maintaining health and social care data for research, how this data is valuable in different ways to different types of organisations, and how the NHS can recover these costs. Presentations from NHS specialists covered:

- The current costs of managing and maintaining health and social care data, regardless of who has access.
- The potential value this data has to the public, the NHS, and the outside organisations.
- How the NHS might realise that value, highlighting the three ways NHS could think about returning data value.
- The risks and benefits of these options and how much value is placed on NHS data.
- Three ways the NHS could recover value from data:
    - Generating surplus beyond covering the cost of managing access to your data.
    - Seeking wider benefits to the NHS (for example, new treatments and diagnostics developed through health data analysis; Research and analysis that leads to better planning and delivery of health services).

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[9] https://understandingpatientdata.org.uk/sites/default/files/2020-03/Foundations%20of%20Fairness%20-%20Full%20Research%20Report.pdf

[10] https://www.onelondon.online/citizens-advisory-group/#:~:text=The%20Citizen%20Advisory%20Group%20was,from%20any%20innovations%20that%20result.

  - Encouraging more researchers to carry out their research in England.

During the design phase prior to the workshops, there was uncertainty about whether tiered pricing would be a feasible option for generating value in all contexts. This specifically focused on whether Treasury guidelines laid out in "Managing Public Money"[11] allow for different amounts to be charged to different organisations of customers for the same service. Consequently, tiered pricing was actively excluded as a topic for discussion.

It is also important to note that these discussions about the value of data used for research purposes took place after the discussions about governance. This means that participants had explored the key principles for data use and access – the 5 Safes. As the previous chapter on governance demonstrates, they were also largely reassured by what they had seen and discussed with the 5 Safes Principles helping to mitigate the concerns about data security expressed at the start of Workshop 1.

5.4 Initial attitudes to generating value from data

Having already explored a range of examples of research in Workshop 1, participants agreed that their health and social care data represented a valuable resource. They also tended to agree that the NHS should seek some value from this resource and were receptive to the idea of the NHS allowing outside organisations to access health and social care data.

Tier 2 participants also believed that their data has value and could be more valuable than that of the general population. That is, having certain protected characteristics – such as a disability, long-term health condition, or sexuality/gender identity – makes their data more useful for targeted research.

The Tier 3 survey findings indicated the wider public are broadly happy with this – 62% of respondents were comfortable with the NHS charging for data access.

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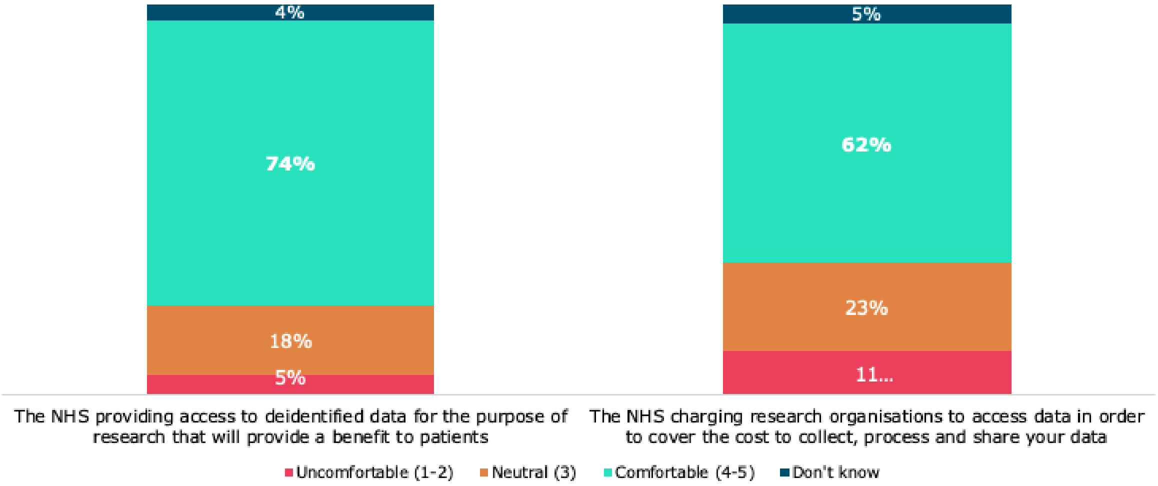
[11] https://assets.publishing.service.gov.uk/media/65c4a3773f634b001242c6b7/Managing_Public_Money_-_May_2023_2.pdf



Comfort with charging for and generating benefits from access to health and social care data

Q. Thinking about how the NHS approaches providing access to de-identified health and social care data, how comfortable or uncomfortable are you with each of the following? Base: All respondents (n=4007)

Figure 13 - Tier 3 comfort with charging and generating benefit

Several benefits of charging for access were spontaneously mentioned, often in the context of participants feeling that the NHS is underfunded and struggling, particularly after COVID-19. There were participants who felt that extracting value from health and social care data might help ease some of these pressures.

A small number of participants felt that when considering the commercialisation of NHS data, the NHS should look to behave more like a business.

> *"Much of the NHS is quietly a business so it's hard to imagine why you would not generate surplus. The data is of great value so why would you not? One part of the health service finances another part of the health service, it is already a business."*
>
> *Plymouth, male, Workshop 2*

Typically, the idea of the NHS making a surplus from its data was received positively, but only if this surplus could be channelled back into the NHS. The acknowledged funding pressures and the ethos of the NHS to put patients first mitigated concerns about the NHS making a profit.

> *"We have a national health system, big country, probably really unique and we are very diverse. Where else would you have a data set like this? It's very valuable, should not undersell it."*
>
> *Plymouth, male, Workshop 2*

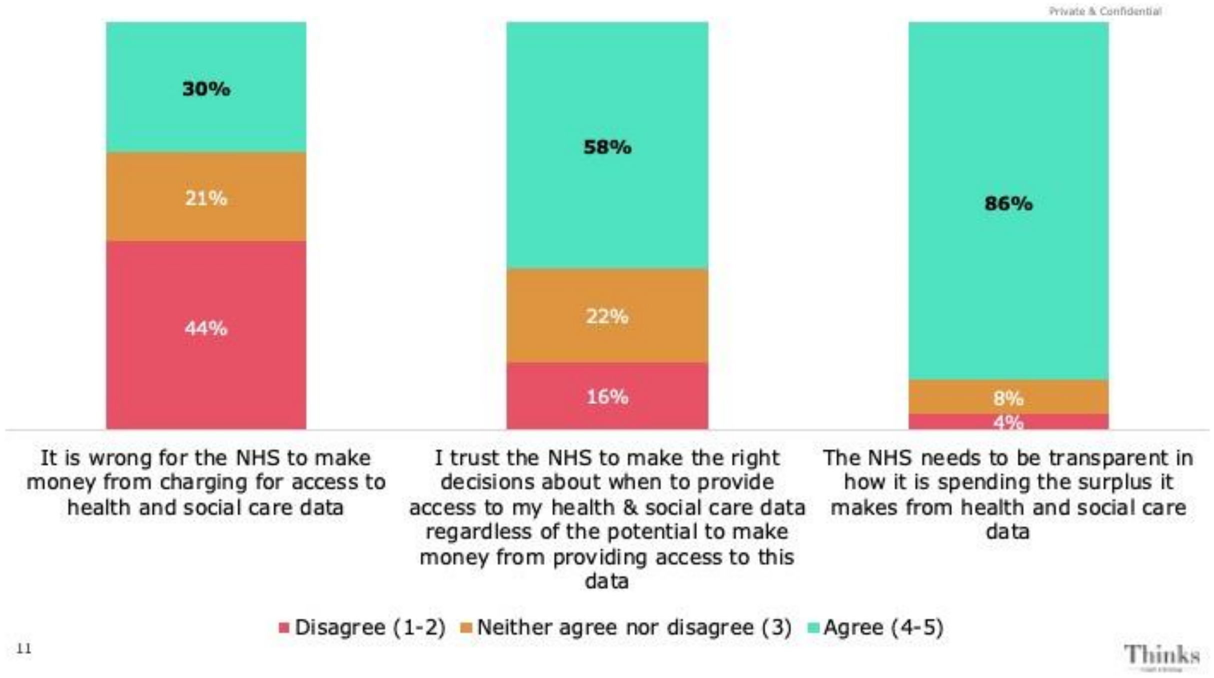
Yet there were those for whom the idea of charging for access to data was, initially at least, uncomfortable. However, as the discussions evolved, these participants tended to become more comfortable with the idea. Ultimately, there was broad agreement among participants that charging for access did not equate to “selling” their data. Participants specifically mentioned the benefits to patients that making a surplus could provide. They described how the notion of data being “sold” ignores the other potential value that could be generated by allowing access to health and social care data.

> *“If you say selling data, that’s like give it to marketing companies who have no legitimate interest, ‘selling’ implies a more unethical implication. But it’s for the greater good, and that’s what the DAC is there for.”*
>
> *Canterbury, male, Workshop 2*

It’s important to note that this specific discussion took place after the participants had explored in detail the safeguarding that is in place around who gets access to data. Therefore, the widespread the support for the NHS charging for access was apparent after safeguarding had been discussed. And, as we have seen, safeguarding and fear of data breaches were key concerns at the start of Workshop 1.

The impact of this is illustrated in the findings of the survey. Here respondents had not had the same opportunity to learn about and discuss the potential benefits and existing safeguards. And 30% of these respondents felt that it was wrong for the NHS to make money from access charges. That said, even among the Tier 3 survey respondents, 44% disagreed that this was wrong, even without the deliberating and learning more about the subject.

Public agreement with the Value of Data statements



Q. Thinking about how the NHS provides access to health and social care data, to what extent do you agree or disagree with each of the following statements? Please answer on a scale from 1 to 5, where 1 is strongly disagree and 5 is strongly agree. Base: All respondents (n= 4,007)

Figure 14 - Tier 3 agreement with Value of Data statements

These survey findings should sound a note of caution, when communicating about how the NHS realised value from data – close to one in three (30%) of the wider public, having not been part of the deliberations, agree with the statement "it is wrong for the NHS to make money from charging for access to health and social care data". Both Tier 1 and survey findings show that participants value transparency about charging, as well as safeguards to ensure data is used in ways that benefit human health. This is supported further by the evidence review, which found that in general the public are keen that commercial partnerships should be both fair and beneficial, meeting key criteria for both transparency and security.

5.5 Different ways to generate value from data

Three different approaches to generating value from data were presented for discussion:

- Generating a surplus through charging for access – e.g. providing direct financial returns for the NHS;
- Seeking wider benefits - e.g. new treatments and diagnostics developed through health data analysis; research and analysis that leads to better planning and delivery of health services; and
- Improving attractiveness of England as a research hub - i.e. the quality of research data leads to an increase in research in England, foreign investment, and/or job creation.

Seeking wider benefits

While all three approaches to generating value were viewed favourably across the participants collectively, seeking wider benefits was the most positively received across the whole of Tier 1 and within each of the four locations. It remained the most positively received when participants were reconvened for Workshop 3. It was the option that participants considered as having the greatest benefit for everyone, and they could begin see how it would work in practice. Case studies and examples used were helpful in showing how wider benefits could support NHS patients.

Participants were presented with three examples of the benefits the NHS could achieve:

- Early access to medicines.
- More clinical trials for patients to participate in.
- Ownership of Intellectual Property (for the NHS) from new treatments developed from accessing your data.

They were also shown an example of a cancer treatment that the NHS would be given early access to, as well as the potential to be given a discount on the drug and/or a small percentage of the profits.

It is important to note that, taken together, this category represents a diverse array of "wider benefits". Participants may have placed greater emphasis on some of these benefits over others. However, it is impossible to disaggregate the impact of any individual "wider benefit" as they were presented together as examples and discussed in general among participants. Equally, the challenges of obtaining some of these wider benefits in reality was not discussed in depth. Further work will be required to explore and distil exactly how the public feel about specific wider benefits, and to check that an appropriate breadth of wider benefit options are considered.

Support for seeking wider benefits

No matter the type of wider benefit discussed, each was broadly considered an acceptable way to generate value, especially as participants felt they all ensure value is directed back into the health and social care system. This served to mitigate the fears of those participants who were uncomfortable with the NHS as a profit-making organisation.

> *"I think this is a good idea. I think it's best for the NHS to charge less for data if it meant having access to the treatments at a discount, it feels more in sync with the ethos of the NHS"*
>
> *Canterbury, female, Workshop 2*

This idea that generating value should be aligned with participants' perceptions of the NHS' ethos surfaced repeatedly in these discussions. The NHS was widely described as an institution that puts patients first, and seeking wider benefits is considered the most 'moral' and ethical option.

> *"The NHS is ultimately for patients, so I'd prioritise developing new treatments and using the data to help services and not focusing on generating revenue."*
>
> *Sheffield, male, Workshop 2*

A key finding of previous research in the evidence review was that the public are more positive about data use and access when they can see a tangible benefit[12]. The examples of some "wider benefits" shared with participants served to make this option tangible.

Concerns about seeking wider benefits

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[12] https://understandingpatientdata.org.uk/analysis-uk-media-reporting-health-data-stories#:~:text=Reporting%20on%20health%20data%20is,health%20data%20in%20getting%20there.

However, certain Tier 2 audiences were hesitant. They felt that research into wider benefits hadn't always benefitted them. Transgender and sex worker participants in particular were sceptical about the use of their data for research purposes – which, in turn, made them sceptical about the benefits of generating value from data. They talked about research informing policies which have discriminated against them in the past. As the previous chapter discussed, these groups were particularly keen on actively anti-discrimination rules being built into decision-making around data use and access.

As the discussion continued, participants raised several questions related to the examples they were presented with. When discussing early access to cheaper treatments, participants had some ethical concerns relating to getting these treatments before other countries. There was a particular concern that poorer, less developed countries wouldn't be able to do this and therefore their population will suffer.

> *"It feels unfair to get access to drugs before other countries. It feels a geographical lottery of treatment."*
>
> *North London, male, Workshop 2*

Participants also wanted to know how long discounts on drugs developed through data access would last – and how much of a discount the NHS would receive. Participants are far more accepting of this as a benefit if the discount lasts longer and is greater. However, discussion around this was somewhat limited – information on the detail and complexity of potential commercial arrangements was not part of the data deliberation.

Generating surplus

Tier 1 participants were broadly keen on generating surplus, largely in response to a widespread sense that the NHS is underfunded and needs the money. But participants had two definitive red lines – all surplus must be directed straight back into the NHS, and this surplus should not replace existing funding streams for the health service, or allow the Government to cut funding to the NHS.

> *"We need all the money we can get for the NHS. We could generate surplus with data and put it back into patient services and wages and primary care. NHS needs money, and it sounds like we can get it, so why wouldn't we sell it?"*
>
> *Plymouth, male, Workshop 3*

Support for generating surplus

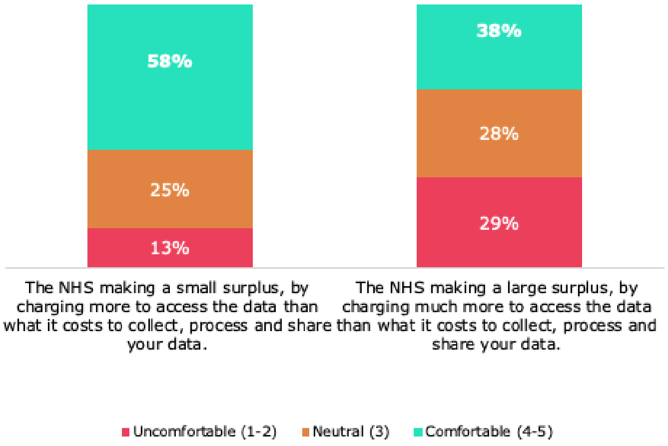
Support for generating surplus was rooted in the assumption that surplus would be redirected back into the NHS. The NHS's popularity meant discussions on generating a surplus centred on the benefits this could bring to the NHS. Participants often mentioned the surplus being "for the greater good [of the

NHS]", especially as an institution with strains on its resources. Retaining the surplus within the NHS, with the funds used directly to the benefits of patients, was commonly suggested as a condition for any surplus. And this surplus should not be focused on funding any particular service – there was a fear that this might make a particular service reliant on revenue from data, thus risking the viability of that service if wider funding was then withdrawn or the value of data declined.

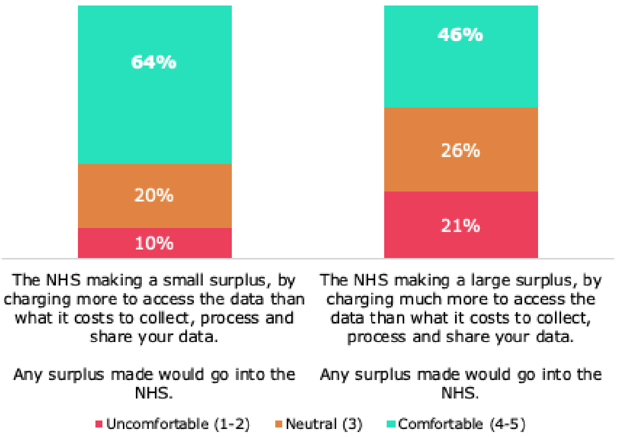
When asked whether the NHS should aim for a larger or smaller surplus, there was greater acceptance of a smaller surplus. A smaller surplus was associated with charging less for access to the data, making the data more accessible to a wider range of organisations. If more people can access the data, participants stated that this can lead to greater, wider benefits – e.g. new drug development. Participants felt care should be taken not to discourage research that could lead to wider benefits, particularly from charity and academic partners who should be charged less. Though it is important to recall that tiered pricing was not explicitly part of the data deliberation.

Both of these points (preference for a surplus to be retained, and a preference for a lower level of surplus) were confirmed in the Tier 3 survey findings. The bars on the left of Figure 12 shows the proportion of respondents supporting the NHS making a small surplus (58%) vs a large surplus (38%). On the right, the two bars show the same question, but where the respondents were told that any surplus would go into the NHS. With this framing of the question, we see support for a small surplus increase by 6% and support for a large surplus increase by 10%.

*Public opinions towards how the NHS approaches providing access to de-identified health and social care data – **no reference** to retaining surplus*



*Public opinions towards how the NHS approaches providing access to de-identified health and social care data – **with reference** to retaining surplus*



Q. Thinking about how the NHS approaches providing access to de-identified health and social care data, how comfortable or uncomfortable are you with each of the following? Base: Split sample C (n=2007), Split sample D (n=2000)

Figure 15 - Tier 3 opinion on access to de-identified data

Across the discussions of who can access the data, there was a stronger support for charities or other research bodies to access it as opposed pharmaceutical companies. When charging a smaller fee, participants mostly focussed on charities and academic research bodies as they were expected to have lower budgets. They were far more accepting of charging pharmaceutical companies more for access.

This also stemmed from a general acceptance of allowing charities and other research bodies access to NHS data, rather than pharmaceutical companies. This was common throughout Tier 1. Conversely, among Tier 2 audiences, people with long term health conditions and disabilities were more comfortable with their data being used for research purposes, including by pharmaceutical companies, especially if it could benefit people with similar conditions.

Concerns about generating surplus

While generating surplus had broad support, there were initially some strongly held concerns among a small number of participants. For this group, the NHS is a publicly funded body that should put patients at the heart of what they do, not profit. Generating a surplus was immediately compared by participants with private companies who have an assumed profit-driven goal, which is at odds with how this group believe the NHS should be run.

However, when this was discussed further within breakout groups, these concerns lessened. In large part, this appeared to be influenced by the views of their fellow participants, who articulated the benefits of a surplus that could help the NHS achieve these patient-centred goals. With time to discuss their concerns, some of these more sceptical participants moved to the position that the benefits of NHS data outweighed their concerns. For all participants however, that this surplus should be reinvested into the NHS was non-negotiable.

> *“We should take advantage of the fact that we have a valuable pool of data. We should incentivise and make the information more accessible … The money that is generated should only benefit the NHS.”*
>
> *Sheffield, male, Workshop 2*

There was also a view that the NHS needs to be more commercially aware as to not be taken advantage of by more commercially-focused companies – specifically, pharmaceutical companies. This is supported by previous research highlighted in the evidence review about commercial principles.

There was also a worry that the surplus will be used as a form of primary funding for frontline NHS services. This could cause the NHS to prioritise becoming more profit driven, rather than patient focussed and may impact who they allow to access NHS data. Participants wanted transparency on how the surplus is spent, and that any surplus does not displace regular funding. Participants stressed that this shouldn't be used as an excuse by future governments to reduce NHS funding and should be in addition to any other core funding.

> *"My big worry with any surplus … I have worked for government bodies, who say we are cutting back on the funding you can use that surplus to plug the gap … All areas crying for money, if they see the NHS has more money they could take other funding away."*
>
> *Canterbury, female, Workshop 3*

Encouraging research

Encouraging research conducted using English data and infrastructure was framed within the context of needing to keep the cost of accessing data low. This, in turn, would encourage more research can happen in England and the UK and it encourages further investment in life sciences here overall. Participants were made aware that more research can lead to more patient benefits, e.g. new drugs or treatments being developed. This option was roughly as popular with Tier 1 participants as generating surplus, further highlighting the broad support for the diverse ways of generating value from data.

Support for encouraging research

Among Tier 2 participants, those with long term health conditions and disabilities were more likely than other audiences to prioritise 'making England an attractive place to do research.' This is also true for participants in other audiences with experience of rare conditions, either personally or impacting someone they care for. There was a sense that these kinds of conditions do not receive the same investment in a research context as more well-known conditions such as cancer, and they see the potential for research to help future generations.

> *"I'm happy for my data to be used for research - no issue with that. It can help other people going forward. Endometriosis is not a curable condition."*
>
> *Person with a long-term health condition, Depth interview, Seldom heard audiences*

Participants highlighted the overall economic impact that attracting more research to England could have on the country. The main impact highlighted was the boosting of the economy through the growth of the research sector. Encouraging research to be done in England will attract new talent and businesses to move to the UK.

> *"We would benefit a lot in the UK from number 3 [attracting research] - more jobs, better administration and more researchers."*

North London, male, Workshop 2

Participants also acknowledged the impact of Brexit, and how this could encourage research that Brexit may have impacted. Collaboration with other countries was seen a positive which can lead to more, and quicker developed, patient benefits.

Concerns about encouraging research

Data security and legitimate use cases or purpose should always be prioritised over making money. Participants' concerns centred on how secure NHS data would be if being accessed from outside the UK. Participants queried whether, if a company outside the UK wants access to NHS data, the NHS can ensure the data is protected and subject to UK regulations. It was highlighted in the evidence review, that data security is top-of-mind for the public and they require transparency on data use and access.

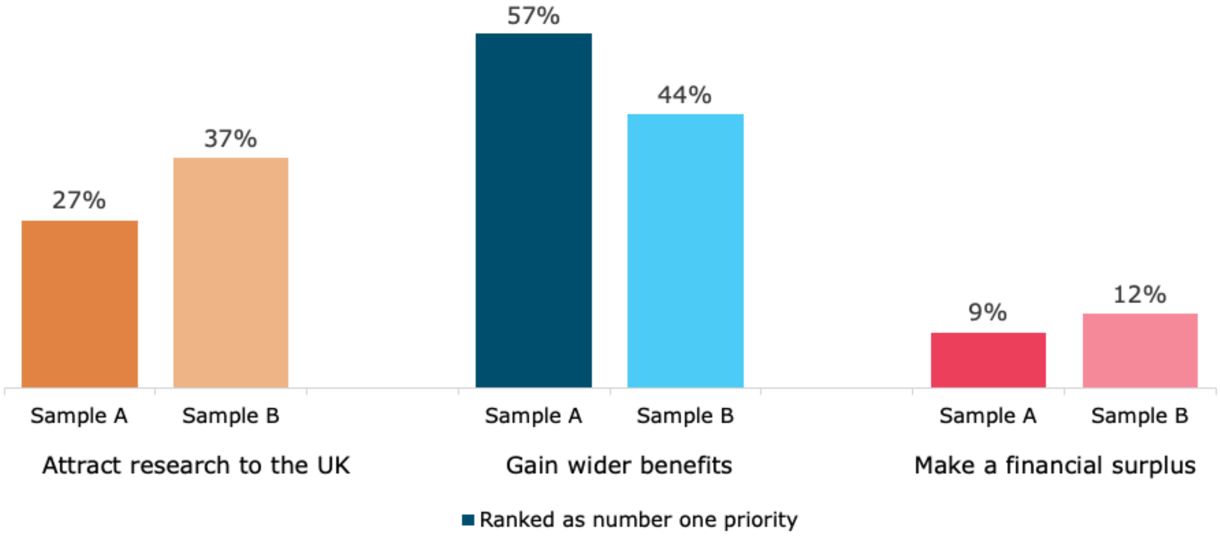
Tier 2 participants were also less comfortable with companies outside the UK being part of this process of generating value from data – with China, Russia, and the United States in particular triggering concerns – due to having unfamiliar policies and legislation in place. Being presented with information demonstrating the processes in place for a research organisation to be granted access to healthcare data goes a long way in reassuring participants their data won't be used for nefarious reasons.

5.6 Comparing approaches to realising value

It is important to note that, overall, all three approaches were popular and Tier 1 participants were comfortable for all three to be pursued. In these Tier 1 workshops, on balance most participants prioritised seeking wider benefits, with generating a surplus and encouraging research in England given similar, and lower, levels of priority.

However, for respondents to the survey, who had less chance to deliberate on the questions and less information about how data is used for research, generating a surplus was a lower priority. Figure 13 shows two things: firstly, it shows the percentage of respondents selecting each benefit type as their priority, with gaining wider benefits the clear frontrunner, followed by attracting research, and generating a surplus much lower.

Perceived priority of how the NHS should best get value from the data



Q8b. Earlier we described the engagement that we undertook with 120 members of the public. In these discussions, the members of the public discussed which of the following ways were most important to get the best value out of the health and social care data. During these discussions, people said that all three options were important. But, of the three, they felt that it would be most important for the NHS to seek wider benefits, for example get early access to new approved treatments. Which do you feel would be most important for the NHS to prioritise? Base: Split sample A (n= 2004) Split sample B (n=2003)

Figure 16 - Tier 3 perceived priority of NHS value from data

Secondly this figure shows the impact of sharing with survey respondents the findings of the deliberation. For each benefit type, the left-hand bar (sample A) shows the responses of participants who were told that a group of their peers had discussed this question and prioritised wider benefits. The right-hand bar (sample B) represents respondents who did not receive this prompt. As you can see, survey respondents are more supportive of wider benefits when they hear that their peers have reached this conclusion. This suggests that providing information to citizens about the results of deliberative engagement like this can influence their preferences, an important factor in thinking about how to communicate complex topics.

5.7 What this means for the value of data for research

Across all three strands of engagement, we see that there are participants who believe there is value to be generated from health and social care data and wanted the NHS to realise a fair share of this. There are those who felt it is not appropriate for the NHS to generate value from data – that is, the NHS is not and should not be a commercial organisation. Yet this view was lessened for Tier 1 participants by exposure to information both about the purposes of research, and the safeguards in place to protect data and data subjects. Recommendations for the value of data for research focus largely on national policy.

National policy recommendations

- Communicating clearly about **what safeguards are in place to protect individuals’ data is essential for public trust in realising the value of health and care data.**
- **Providing appropriate safeguards are in place**, the public are **happy for the NHS to generate value from data for** research, whether that is value from wider benefits, generating a surplus, or encouraging research within the UK.
- The purpose for access to be given to data must always be for public benefit. Arrangements for **access should never be purely for the creation of value or benefit for third parties.**
- When generating value through encouraging research, all organisations involved must **demonstrate that the benefits would be realised in England** or the UK, not just that the research would take place using English health and care data.
- **All surplus must demonstrably be returned to the NHS** and must not be used as a replacement for existing NHS funding.

Recommendations for future engagement

- **Support needs to be fostered** through public engagement and information sharing.
- Clear **rules around enforcement of commercial principles must be communicated with the public.**
- **Codesign of wider benefits and nuance of surplus charging** to be further explored through deliberation.

National policy recommendations

Participants expected data security to be the key priority when data access arrangements are considered and revisited this topic regularly, although earlier workshop discussions on the SDEs and the DAC process were reassuring in this regard. When participants were shown how companies can access data and the procedures in place, they worried less about data leaks, for example. Therefore, communicating clearly about what safeguarding is in place is essential for public trust in realising the value of data. Indeed, it is important to demonstrate that data security is a higher priority than realising value.

In practice, this could mean transparency around and openness about the ways in which SDEs vet applications and the function of Data Access Committees. Additionally, having additional checks in place once access has been granted – to ensure researchers and companies have stayed faithful to the agreed terms – is felt to be important. Knowing that companies’ access is time-limited may well provide further reassurance for participants.

Participants were generally most comfortable with the NHS seeking value through wider benefits like early access to treatments, profit sharing, or other in-kind contributions. The goal for the NHS should be to improve health, and wider benefits should contribute to this, as should the research itself. Therefore, when charging for access, each use case must demonstrate a direct or indirect public benefit, and arrangements for access should never be purely value-based or entirely for third-party interests.

Attracting research to England was valued for similar reasons. Therefore, generating value must demonstrate that the benefits and not just that the research would be realised here.

Regarding realising surplus, the central recommendation is that all surplus should demonstrably be returned to the NHS and must not be used as a replacement for existing NHS funding.

Recommendations for future engagement

When communicating about realising value from health and social care data we found that information and time to deliberate did change views, surfacing requirements like surplus being retained within the NHS. We also found a small change in preferences when survey respondents heard about the conclusions of their peers in Tiers 1 and 2, suggesting support can be fostered through public engagement and information sharing.

As we have seen in discussions around governance and as is also apparent in the following chapter, there was a strongly held desire for enforcement of rules and repercussions when the safeguarding is ignored or broken. This was felt to be highly relevant to any commercial arrangements. Therefore, clear rules around enforcement must be in place and communicated with the public.

This discussion focused on value of data as it related to the SDE network. There is scope for a broader discussion with the public about the value of NHS data in a broader context.

6. A Data Pact

Introduction and context

DHSC and NHS England are drafting a 'Data Pact', a document aimed at giving people confidence in how the health and social care system uses their data. The pact will try to do this by setting out clearly, in simple terms and in one place commitments related to:

- *Keeping your data secure;*
- *The steps involved in an organisation getting access to your data;*
- *How you and the wider public will be involved in decision-making about how data is used;*
- *What data you have access to;*
- *How your data will be used; and*
- *The choices you have about how your data is used.*

The pact would not introduce any new laws but would set out existing laws and protections. We introduced a draft of the pact to Tier 1 participants in the third workshop. This early draft was intended to support discussion and deliberation. We asked participants about the impact they thought it might have, how likely they would be to read it, and how they felt about the language used in the draft.

This chapter begins by detailing initial views on the concept of a data pact, before detailing views on a draft of a data pact – the draft was created for the third workshop to help participants get a sense of what it might contain and help frame discussions about what they wanted from a data pact. It then outlines how participants think a data pact could function in practice, before concluding with implications for a data pact moving forwards.

6.1 Key findings

Across the previous two days of discussions, Tier 1 participants showed a **clear appetite for more information to be shared** with the public about how their health and social care data is used. They recognised that their own views had changed as they learned more, with most becoming more confident about how health and social care data is used. Many Tier 1 participants told us that the fact officials were taking the time to make this information widely available was in itself a sign that data security and public trust were being taken seriously and showed the good intentions of the health and social care system. Without having been part of the deliberative process, 62% of Tier 3 respondents felt the pact would increase confidence.

Despite their support in principle, Tier 1 participants felt that the pact could be made more effective. For these Tier 1 participants, the word "pact" implied action, not just information. This meant that participants expected the document to be legally binding, rather than providing information about the legal framework that is currently in place. Participants were therefore confused about why the pact was not legally binding, and ultimately felt the draft **data pact lacked authority.** Some cited examples like the Post Office scandal to emphasise the importance of accountability in building trust. As well as binding conditions, they wanted the pact to have more information about recourse – i.e. how the pact would enable people to take action if it has been broken.

6.2 The context

A data pact is a strand of work originating in the Data Saves Lives strategy. The purpose of the pact is to set out clearly, in simple terms and in one place, how the NHS and social care uses data and what the public has the right to expect.

It aims to provide clarity and certainty about what does – and does not – happen to health and social care data and give the public confidence that the health and social care system is a trustworthy custodian of data. From the evidence review we know that, for a data pact to be a successful in building public trust, it must be tailored to public needs in order to encourage buy-in.

In 2023, DHSC and NHS England funded the Patients Association[13] to give patients the chance to share their views on the development of a data pact via a series of focus groups. This research found that while a data pact would not completely relieve scepticism around data use and access, it could be a first step to addressing mistrust. This was particularly true among patients with little to no knowledge of how the system works.

Participants from the Patients Association recommended that DHSC and NHSE take a draft version of the pact to a larger scale deliberative engagement.

6.3 Introducing a draft data pact to participants

Tier 1 participants were introduced to a draft data pact in Workshop 3. They explored the draft data pact, providing feedback on how it can be most effective both at ensuring data is used well, and at building public confidence.

Speakers from DHSC introduced participants to the concept of a data pact and provided an overview of a mock-up version of a data pact that had been drafted to simulate discussion and provide an example of what it could look like in practice. Representatives from the Patients Association described the impact this could have on individual care and their previous engagement on it.

The Head of Data Strategy at NHS England then provided an overview of the introductory pages of the draft, plus an overview of the thematic sections

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[13] https://www.patients-association.org.uk/blog/new-report-on-the-relationship-between-the-public-their-data-and-the-health-and-care-system

including transparency and governance. Each table in the workshops was then allocated two other chapters to review and discuss.

All Tier 2 participants were introduced to the concept of a data pact through a summarised overview presented by the moderator. Due to time constraints, this was the only information that those who took part in interviews saw. Tier 2 participants who took part in workshops were also provided with the overarching principles, a summary slide of the structure, and detail on transparency and involvement. The differences between findings from Tier 1 participants and Tier 2 participants should be considered with this in mind.

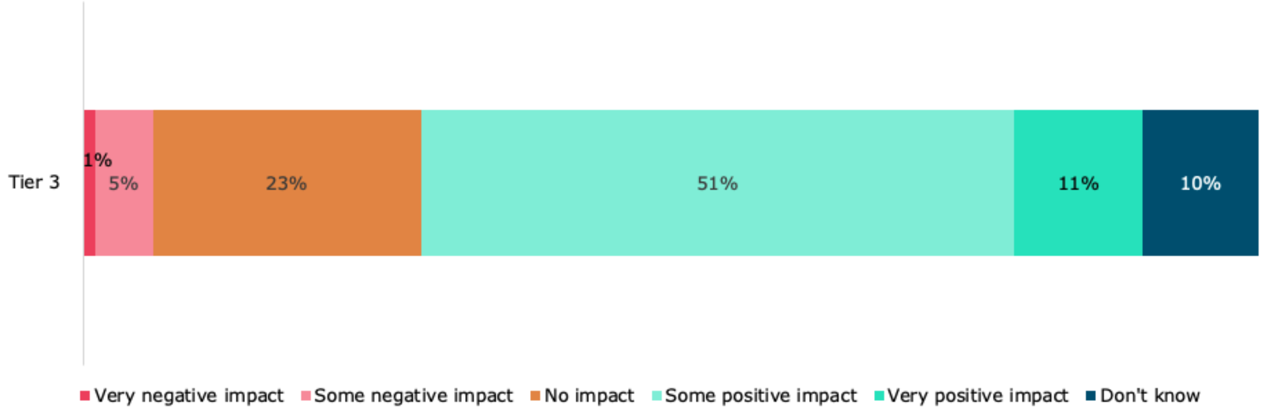
6.4 Views on the concept of a data pact

Tier 1 participants began the first workshop with a general lack of trust in how data is used, with specific concerns about data breaches. However, across the three Tier 1 workshops and the Tier 2 engagement, positive views were driven by learning about NHS reassurances of consent being sought (which is how they tended to describe things like the opt-out), depersonalisation, regulations and guidelines, and a belief that this will deliver positive health impacts to individuals and society as a whole.

Following preceding discussions around initial views on data, informed discussion on governance, and the value of data, there was an appetite among participants for a document that clearly sets out how data is used and accessed in the health and social care system in one place. Participants were positive about the idea of a document that explains the system, processes and regulations, and offers reassurance about the safety of their data.

Participants saw potential for a data pact to build the public’s confidence in how their data is used by clearly setting out how the NHS and social care uses health and social care data and what the public has the right to expect. Participants in both Tier 1 and Tier 2 were pleased to see that NHSE and DHSC have taken the time to develop this resource, feeling that it demonstrates good intentions around data use and access.

This was reflected in the Tier 3 deliberative survey, where 63% said that a data pact would have a positive impact on building confidence in data use, as shown in figure 14 below. Even within those most concerned about their data, 47% thought a data pact would have an impact.



The impact of a data pact on building confidence in NHS use of patient data

Q. As mentioned, a data pact aims to give people confidence in how the health and social care system will collect and use the public's data. Base: All respondents (n = 4007)

Figure 17 - Impact of a data pact on confidence

Given that this discussion about a data pact came at the end of our engagement, these findings corroborate with the Patients Association findings that as conversations developed throughout their research, numerous themes and areas emerged where a pact (or similar document) could provide the starting point for improving the public's trust and confidence.

6.5 Initial views on the title 'data pact'

There was however an initial concern, particularly among participants in Tier 1, that a data 'pact' lacks a clear purpose. Participants felt the phrase 'pact' suggests something beyond an information document. Instead, that it implies an agreement between the public and the health and social care system. This raised questions about whether it needed to be formally signed by both parties, and whether there will be repercussions if either party break the agreement.

This aligns with the research from the Patients Association, which found that the term 'pact' was inappropriate as it suggests that it has been developed by both sides. Rather, the way this data pact has been developed led participants to feel that they were being told what to expect.

> *"Is it a two-way contract? Are they signing something before they get the data? Is it a pact with the public? Who is the pact between?"*
>
> *Sheffield, female, Workshop 3*

When the concept of a data pact was initially introduced to participants, it was explained that the pact itself will not introduce any new laws but set out existing laws and protections. This raised concerns among participants in both Tiers 1 and 2. Participants were worried that without repercussions for misusing data, those who are responsible will not take sufficient care of patients' data. Outlining a process for what happens when the pact is 'broken' by the health and social care system was felt to build confidence among the public. While the pact does set out the legislation that currently exists, the fact participants were raising these concerns suggests that this information was not clear enough in the pact, and this led participants to think that the pact *is* the legislation.

> *"In a company if you know the repercussions are going to be bad then people will always double check. So, they should say in the guidelines what would happen if it wasn't followed. That would help people trust them."*
>
> *Young person with long-term health condition, Workshop, Seldom heard audiences*

Changes to data use and access

There was also confusion among participants about whether the information in the pact reflects changes to data use, or whether it reflects the current system. The pact needs to be clearer that it is a representation of the current system and doesn't introduce any new laws or policy changes. Participants were more likely to feel comfortable with an agreement that is already in place and can evidence what is working well, and the pact should be positioned more clearly as a communication of the current system to instil this confidence.

> *"I don't really understand on how it differs from the way things are done at the moment. Can anyone explain a bit more about this?"*
>
> *Canterbury, male, Workshop 3*

6.6 The components of a data pact

Following discussion around the concept of a data pact, The Head of Data Strategy at NHS England provided an overview of the current draft. This included the first few pages of the draft data pact plus an overview of the thematic sections including transparency and governance. Each table was then allocated two other chapters to review and discuss. Tier 2 participants who participated in workshops were shown a summary slide on the structure of the draft data pact and detail on transparency and involvement (again, the full draft data pact and these sections can be found in the appendix).

Explaining data use and access

As previously mentioned, participants felt they had learnt a lot about how data is used and accessed in the health and social care system by the time they were introduced to the draft data pact. As we shall see in the next chapter, this made them feel more confident and trusting in how their data can be used and accessed than they had been at the outset. As a result, participants felt that increasing the public's knowledge and awareness around data use and access will build trust between them and the health and social care system.

> *"I think it goes back to what I said last Saturday, that information is key."*

Plymouth, male, Workshop 3

Participants felt very positive about the way the draft data pact explains elements of data use and access in the health and social care system. They pointed to explanations of opt-out and the information about the involvement of other agencies as helping them understand how data is used. Educating the public on data use and access was seen to be crucial for building trust between patients and the health and social care system. Participants felt a data pact can be a useful resource in facilitating this education by providing clear and accessible information for the public in one place.

> *"I'm already more confident now. All I needed was the proper information."*

Older person with long-term health condition, Workshop, Seldom heard audiences

Purpose & accountability

Participants' main concern around a data pact centred on its purpose. Given that a data pact is not legally binding, and did not mean any change in policy, participants struggled to understand what a data pact is trying to achieve aside from providing general information about data use and access.

> *"Nobody's going to read it all. Junk mail. It needs to be legally binding before it's taken seriously."*

Canterbury, female, Workshop 3

More specifically, participants had concerns and questions about accountability. This view was shared across locations but was felt most strongly in Canterbury, with participants feeling the pact lacked detail on accountability. Given the title 'pact', participants felt the document lacked detail on who is responsible for acting on misuses of data, and what the punishment will be for the misuse of their data. These participants found it hard to understand the purpose of a pact if there are not details about accountability.

> *"What is the point of it? If no one can be held accountable what is the point?"*

Canterbury, female, workshop 3

Data breaches

Concerns throughout the data deliberation around data breaches were reflected in discussions about the draft data pact. 'Data breaches' were referred to very broadly in this context, and participants were not referring to specific types of data being leaked.

Participants felt there must be information in a data pact about what happens if there is a data breach, and who will be held accountable. Indeed, in the Tier 3 survey, those most concerned about their data (41%) were more likely than those overall (38%) to say that they would read the pact. There were discussions in Canterbury about the implications of a leak: they asked whether the NHS would be penalised, what damage it might do to its reputation, and whether a fine would be funded by taxpayer money.

> *"A question to consider is that of breaches. If there is a breach, who would that fine go to? People wouldn't want the NHS to be fined. Would a third-party security firm take that fine?"*
>
> *Canterbury, male, Workshop 3*

Across locations, including information in a data pact about data breaches was felt to be necessary to build trust among the public. This aligns with research from the Patients Association that found participants expressed the importance of clarity on the consequences for any breaches.

Tier 2 participants pointed to the British Post Office scandal as an example of a lack of accountability damaging the public's trust in something widely regarded as a public service. Participants felt a data pact may be avoiding detail around accountability to protect itself from scrutiny in the future. This made participants question the integrity and effectiveness of a data pact. This was a particular issue for Tier 2 audiences who had very low trust in public services, such as those with prior justice involvement and care experienced adults.

> *"Just thinking about the British Post Office scandal which was covered up and not acted upon. Maybe they don't want to damage the reputation of the NHS… how would we manage recompense for damages and stuff like that?"*
>
> *Care experienced adult, Depth interview, Seldom heard audiences*

The role of the public

As with concerns about the use of the word 'pact', participants in Sheffield and North London were concerned about the sections titled 'we ask of you'. While participants understood that this was a pact that included responsibilities from patients as well as the health service, there was concern about asking the public to take responsibility for something. They felt it is unfair to place responsibility on the public who may feel at fault if something goes wrong.

> *"It feels like if there is a data breach then it's your fault because you didn't contact the national cyber security centre."*
>
> *North London, female, Workshop 3*

There was a fear that some people may be alarmed by this phrase, and feel they need to take action, or their data might be used and/or accessed in ways they don't agree with.

> *"Is this going out to people directly? My mum would read this and think it's a call to action every time it says "we ask of you". They might think they need to do something."*
>
> *Sheffield, male, Workshop 3*

Recourse

Given the importance placed on transparency throughout the research, participants wanted more information in the pact about who to contact if patients have queries about how their data is used. While there was information about who to contact in the Governance section of the pact (including the local organisation or the Information Commissioner's Office) the fact participants were suggesting this demonstrates the need for a data pact to be clearer about what is available to the public.

> *"There needs to be communication between patient and NHS, you should be able to contact them and ask to see what data they have used and given out."*
>
> *Canterbury, male, Workshop 3*

Not only did participants want to be able to enquire about how their data is used, they also wanted to be able to complain if they feel their data has been mishandled. Participants felt a data pact could be referred to retrospectively if they felt their data had been misused by the health and social care system. If they feel the pact has been 'broken' by the NHS, they want to be able to speak to an independent advisor. Participants in Plymouth pointed to the Patient Advice and Liaison Service (PALS) as an example of a service that offers confidential advice, support, and information on health-related matters.

> *"PALS is an anonymous service and they back you 100% if something goes wrong for you as a patient. It was excellent because their sole focus is helping you. A similar sort of system for your data in case anything goes wrong would be great."*
>
> *Plymouth, female, Workshop 3*

To maximise transparency and increase confidence, participants felt this kind of interaction needs to be available face-to-face. Participants were sceptical of the use of chat bots or formal emails, for example, saying this wouldn't make them feel confident contacting someone. There was also a desire for such a service to be visible – for example, having a presence at hospitals and GP practices. Participants in Plymouth explained how PALS often has desks in hospitals, which makes patients aware that this service is available, as well as making it accessible for those who are not confident online.

> *"I don't want someone at the end of the line saying 'blah blah blah', I need to talk to someone face to face."*
>
> *Sheffield, male, Workshop 3*

However, participants in Sheffield recognised that this would require extra resource, and they were conscious about balancing this against putting more strain on public services.

> *"Could it be incorporated into Citizen's Advice? Sadly, it's adding to someone's workload."*
>
> *Sheffield, male, Workshop 3*

Discrimination

There were concerns among the transgender audience in Tier 2 about the lack of detail in the pact around proactively preventing discrimination. Participants pointed to the line '*Ensure everyone's data is treated equally and is protected regardless of their background or where they live'* as a good starting point but felt it could go further.

Transgender participants were looking for additional reassurance. They wanted a data pact to prevent the health and social care system from discriminating against them in the use of their data. But they also wanted to prevent outputs from research using their data from furthering stereotypes and discriminatory practices against them.

> *"Where it says 'regardless of background', I assume that includes the quality of us being trans. That would worry me because is our data going to be treated differently? So with segregation in wards for example, if I am down as trans on the data then will I be treated the same or different even if I have transitioned?"*
>
> *Transgender participant, Workshop, Seldom heard audience*

Sex workers and those from ethnic minority backgrounds were also concerned about this and looked for further reassurances that outputs would be non-discriminatory.

Decisions made by power of attorney

With the misconception that the public will be required to consent to or sign the pact, participants across audiences in Tier 2 also raised concerns about individuals who are unable to understand a data pact, and therefore unable to consent to their data being used in this way. They referred to those with learning difficulties or for whom English is a second language. There were similar concerns about making decisions by power of attorney. Participants wanted to see information about how others can make decisions on their behalf.

> *"You have to think about those with English as a second language and/or learning difficulties who may not have the capacity to understand [a data pact]. Who is going to make decisions on their part?"*
>
> *Carer, Depth interview, Seldom heard audiences*

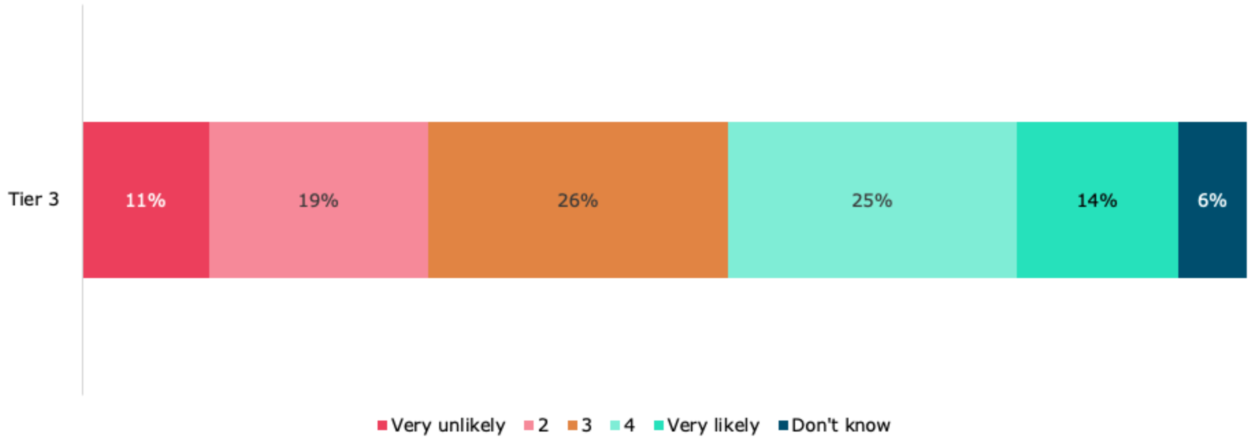
6.7 The functioning of a data pact

While participants across Tier 1 and Tier 2 supported educating the public about data use and access, views about how this might work in practice were mixed.

Tier 1 participants were optimistic about the public taking time to review a data pact and understand how their data is used and accessed – perhaps reflecting their positive experience of deliberating in depth about these issues. There were admissions among Tier 1 participants that they had become more interested in and curious about data because of their involvement in the deliberative process. And they felt this might mean they are more likely to engage with a data pact than those who have not taken part in the research.

Tier 2 participants, on the other hand, were less sure the public would read through a data pact. This is likely due to the lower level of engagement in this cohort, but it gives an indication that those who are coming to this topic with less background or knowledge would be less likely to engage with a data pact.

Tier 3 respondents were the least convinced that people would read a data pact, as shown in figure 16 below. While 38%, said they are likely to read it, nearly a third (30%) said they would be unlikely to do so. Older respondents (41%), those from higher socio-economic groups (SEG) (40%), and those who want more control over their data were most likely to say they would be likely to read it than the youngest segment (35%) and those from a lower SEG (36%).



Likelihood of reading a data pact

Q9. The Data Pact will be made publicly available online. How likely or unlikely do you think you would be to read the Data Pact?
Base: All respondents (n= 4007)

Figure 18 - Tier 3 likelihood of reading a data pact

That said, nearly two thirds (63%) said it will have a positive impact on building confidence in data use, chiming with positive views from Tier 1.

Accessibility

With this in mind there was a concern, particularly among Tier 2 participants, that a data pact could be more accessible. It was described as similar to terms and conditions or information about cookies that the public regularly see when visiting websites. They explained that they often ignore this kind of text and simply tick a box to say they have read it.

> *"It sounds like terms and conditions that no one reads on websites. Or if you were downloading the NHS app for the first time it would tell you this is how your data is used."*
>
> *Migrant, Workshop, Seldom heard audience*

Those with sensory impairments and learning disabilities were particularly concerned about important information being presented as a large body of text. These audiences stressed the importance of providing information in a variety of formats to ensure people aren't excluded from learning about how their data is used in the health and social care system.

> *"It needs to come out in accessible formats, such as large print, audio described, in braille, different coloured paper and online channels too."*
>
> *Sensory impairment, Depth interview, Seldom heard audience*

Participants across Tier 1 and Tier 2 suggested that a data pact should also be available in a video format. This, they felt, would allow members of the public who are unable to read large bodies of text to understand how their data is being used. Videos were also felt to be more engaging, and participants felt that the information is more likely to resonate with the public in this format.

The research from the Patients Association found that participants felt it would be appropriate for a data pact to be shown on the NHS app. In contrast, our participants were concerned about 'burying' a data pact on the NHS website or app in the same way terms and conditions are. Participants suggested using television adverts and social media to share the information. This, they felt, might reach those less confident in reading English, and those who don't use the NHS App or visit the NHS website. They felt this would ensure as many people as possible can see the information.

> *"Maybe some type of national press campaign which advertises it with a website you can visit. I think you need to provide a text version, an audio version and a video version – everyone's different."*
>
> *Sex worker, Depth interview, Seldom heard audiences*

Language and phrasing

Participants could see that the draft data pact had attempted to present information in a public facing way, and appreciated the efforts made by NHSE and DHSC to make the document accessible. However, a number of participants across both Tiers 1 and 2 felt there is still work to be done to ensure everyone can understand it.

> *"You'd get bored reading this. I don't think you would really understand this. I feel that even now and we've been sat through this for however many hours."*
>
> *Sheffield, female, Workshop 3*

Participants felt that there was still too much technical jargon in this draft that the public won't understand. Participants pointed to 'horizon scan', and the 'Caldicott principles' as examples of terms they don't understand. Ultimately, the majority of the public want to see the key points on what this means for them and their data, without what they see as unnecessary detail. If these phrases are included, they need to be explained so people aren't put off engaging with a data pact.

> *"It's not written for the general public, is it? Lots of things in there where you just think what does that mean? 'Horizon scanning', 'emerging technologies', what does that mean to me and my data?"*
>
> *North London, female, Workshop 3*

Participants across Tier 1 and Tier 2 felt there should be two versions of the pact. The majority wanted one version that is shorter than the draft they reviewed which clearly outlines the key points in plain English, and they feel this is the version the vast majority of the public would prefer to read. A small minority, generally older participants, felt the pact was too vague and did not explain some phrases and concepts in enough detail. Acknowledging criticisms from both sides about the level of detail, Tier 1 participants concluded that it would be best to have two versions of the pact: one more concise than the mock-up draft, and one longer.

> *"I'm just thinking about this pact. It needs to be accessible, for everyone to understand it, but also contain the details. You need to have both."*
>
> *Sheffield, male, Workshop 3*

Concerns about the language were particularly pronounced among migrants in Tier 2, who felt those with English as a second language would especially struggle to understand the current draft.

> *"Can they use non-medical terminology? People who aren't in that field or have English as their second language could be alienated."*
>
> *Migrant, Workshop, Seldom heard audiences*

Research from the Patients Association advised that future engagement refines the balance needed between keeping a data pact short and simple enough to be accessible, but substantive enough to be insightful. Our participants suggested creating a simplified version of the pact that covers the key points and avoids medical jargon but recognised that this may omit important details. They suggested an extended version is made available for those who want extra clarity. Ultimately, participants felt it is most important for as many people as possible to know the key points, rather than a minority understand the full detail through the current draft.

> *"If it could be relatively short for each area, with a high-level overview, that would be great. Offer a summary of each area with the option to read the detail with a 'click here' button and subheadings. That would cover most people's requirements."*
>
> *Person with a sensory impairment, Depth interview, Seldom heard audiences*

6.8 What this means for a data pact

There is great potential in a data pact to improve public confidence in how their data is used and access by the health and social care system by providing accessible information in one place.

Nation policy recommendations

- A data pact needs to **clearly outline what happens when data users break the rules**.
- The **purpose of a data pact must be made clear** to the public.

Recommendations for future engagement

- The **language used in a data pact needs to be refined and simplified** further.
- Policy makers should **consider having multiple versions with different levels of detail** for different audiences.

National policy recommendations

The framing of a data pact also raised questions about accountability. Given that it is not legally binding, the current draft was felt to lack authority. This undermined confidence that the pact will be closely adhered to by the health and social care system or by those seeking access to health and social care data. To reassure the public, a data pact needs to clearly outline what legislation is in place around enforcement.

The purpose of a data pact must be made clear to the public. At present, the title 'pact' created confusion among participants, who understood the pact to provide new rules on data use and access, which led to confusion about why it is not legally binding.

Recommendations for future engagement

The name ‘data pact’ needs to be reconsidered to make it clear to the public that it is communicating how data is used and access in the health and social care system, including what legislation is currently in place, rather than being a piece of legislation itself.

The language used in a data pact needs to be simplified further. Participants emphasised the importance of making sure as many people as possible are able to understand the pact, even if this means sacrificing some of the detail. A data pact should come in a simplified version that contains key points, and an extended version that covers all the detail for the smaller number of people who need it.

7. The impact of deliberation on participants' trust and confidence in data use and access

This chapter explores where participants ended up and what influenced trust – or otherwise – in how their data is used. It will look at how their thinking about the topics discussed (governance, the value of data, and a data pact) informed their trust and confidence in how their health and social care data is used. We will then summarise what this means for trust and confidence, including participants' red lines.

7.1 Key findings

At the outset of the deliberative workshops, Tier 1 participants typically had misgivings about data use in general. While they were supportive and trusting of the NHS, they felt that they lacked sufficient information to feel confident. By the end, most Tier 1 participants felt more confident about how their health and social care data was being used.

We identified three main factors driving this change:

- **Understanding the benefits of data for research** and seeing how these aligned with the goal of the NHS helped many participants have greater confidence in the purpose of data access. Sharing case studies and hearing from researchers and patients all contributed to this understanding.
- Developing a **greater understanding of the safeguards, principles, and processes** in place was critical to building confidence. Secure Data Environments, Data Access Committees, and a data pact were important parts of the infrastructure that participants wanted to know was in place to protect their data.
- For many participants **the engagement process itself** also contributed to greater confidence. The time and care invested in the data deliberation events, along with the level of detailed information and scope for influence that were included, all contributed to a sense that the NHS and DHSC are taking public views seriously and that trust in good intentions is well founded.

However, we should not read outputs as providing blanket permission for use of health and social care data. First, there were **participants across all Tiers who remained critical throughout**. These participants feared that safeguarding measures would not be sufficient to prevent the misuse of data and are sceptical of the intentions of actors like pharmaceutical and tech companies. For domestic abuse survivors, unhoused people, and those with prior justice system involvement, this mistrust was grounded in previous negative experiences with public institutions. They worried that their individual experiences will be replicated on a grand scale when it comes to data. Those who believed that the system remained too complex and opaque for them (or others) to have confidence in were a small but vocal cohort.

We also heard very clearly from participants about their expectations for a system of health and social care data use. They expected to see **data used for public benefit,** with no exceptions, and for this to be actively safeguarded by those granting access. They expected that the **benefits of research should be shared** among NHS patients and the public, not just private interests, and challenged the NHS to establish commercial arrangements to ensure this. And, above all, participants expect the security of this intensely personal data to be protected through **appropriate safeguards, with meaningful and visible sanctions for failure**.

7.2 A reminder of where we started

From the evidence review, we knew some important contextual information on how the public feel about the use of their health and social care data.

The evidence review told us that the public are generally positive about data use and access having a direct impact on patient outcomes. They are most positive when they can see a tangible benefit, especially for individuals, but also that the perception of benefits can differ across demographic groups and communities.

Awareness of how the NHS handles data use and access is low, and the NHS is a highly trusted organisation. Yet it is less trusted for its competence in keeping data safe and secure. And the public's concerns typically focus on data breaches. Furthermore, the public demand transparency around data use and access, making this vital to fostering trust and confidence as well.

At the outset of the data deliberation, therefore, there was a widespread lack of trust among our participants about how their personal data is used. This was primarily driven by a perceived lack of transparency and information about who has access to their personal data. This fostered concerns ranging from frustration with unwanted communications through to fears of scams and data breaches.

Those with fewer concerns were characterised by higher levels of trust in how their data is used – or, more crucially, the effectiveness of data protection regulations in keeping their data secure and safe. Trust in data use was also characterised by believing in the benefits for others or improved services. But not all trust was driven by positive beliefs in security or benefits – there were those simply resigned to sharing data in order to access services, including among those with frequent interaction with NHS services.

Therefore, early in the process, we saw how a perception of good intentions and tangible benefits have a positive impact on trust. Concerns about the motivations of those wanting access to data and fear of personal data being hacked and of data breaches more generally served to undermine trust.

7.3 What does trust look like after 15 hours of deliberation?

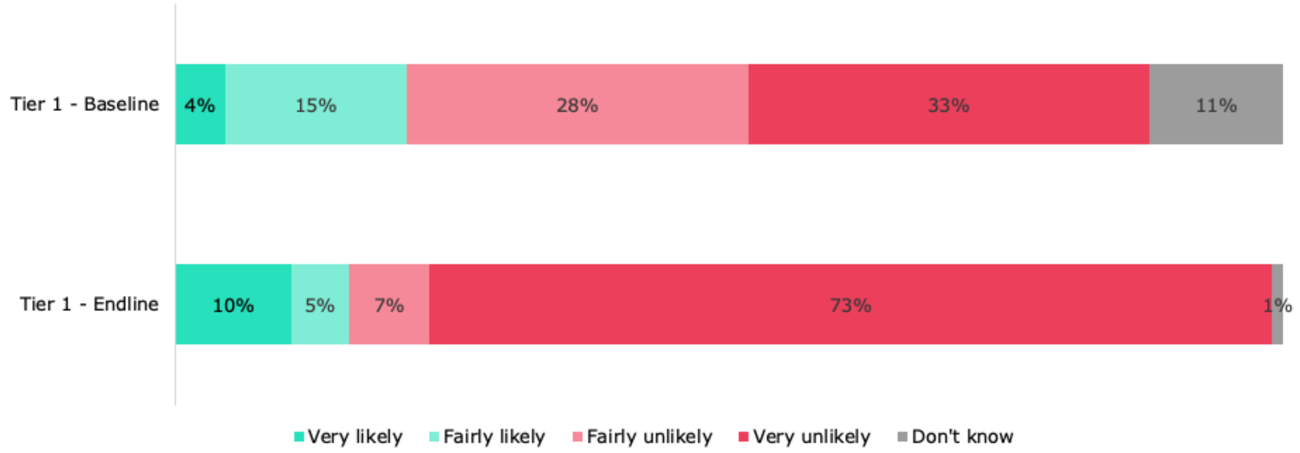
As Workshop 3 drew to a close, participants were asked to reflect on what they had heard across the workshops. In particular, they were asked about their levels of trust and confidence in how their data could be used, how that had changed, and what influenced their views.

By far the most common reaction across the participants was becoming more trusting in how their data is used. Yet there were also those who had mixed views, and those who were less trusting.

> *"My journey has been a rollercoaster, because at the first session I was very worried but now I'm feeling more confident."*
>
> *Sheffield, female, Workshop 3*

This is reflected in the baseline and endline questions we asked of Tier 1 participants at the start of Workshop 1 and the end of Workshop 3, respectively.

At the baseline 33% (from 97 giving a response) of Tier 1 participants said they would be very unlikely to opt-out. By the end of the process, this had increased to 73% (of 84 giving a response) saying they would be very unlikely to opt-out. And it is also notable that, while remaining a small minority, the number of participants saying they would be very likely to opt out doubled – from 4% (4 participants) to 10% (8 participants).



Likelihood of requesting to opt out of data being shared by the NHS

Q. How likely or unlikely would you be to request to opt out of your data being shared in this way?. Base: All respondents (n=97, n=83)

Figure 19 - Tier 1 likelihood to opt out

7.4 Increased trust

The process of learning and deliberating with specialists and one another led to increased trust and confidence in how data is used and accessed for most participants. There were several drivers of this:

- The potential benefits of greater data use.
- The processes and guidance around data use, best exemplified by the principles and the draft data pact.
- The wider system and the data security processes it has in place.
- The transparency and public engagement being demonstrated within and by the data deliberation.

Potential benefits

The impact of data use and access was an important factor driving greater trust. Participants talked about their data being used as a "social good". They referenced the case studies from Workshop 1 as an important factor in demonstrating what could be achieved. In particular, they felt that their data to be used could directly help others through improving research.

> *"The usage of examples does help put it in perspective. You can agree on a theoretical level, but you won't feel it on a personal level until you hear examples. It's helped put it into a real-life context, and now I know what the NHS is using my data for, and it being beneficial, I trust it more."*
>
> *North London, female, Workshop 3*

Discussions about the value of data for research highlighted how tangible benefits influenced trust.

Participants generally reached a point where they were comfortable with the Data for R&D programme charging to cover costs and with making some surplus. This was not considered "selling" data – participants felt that such a description undermined the importance of their data and the admirable objectives of the programme.

> *"Selling sounds cheap and inconsiderate without going into the deeper cause and why they are doing it."*
>
> *North London, female, Workshop 2*

Consideration of the wider benefits from generating value suggested to participants a welcome focus on longer term thinking. It was also felt to be closely aligned with their expectations of the NHS ethos. That is, putting patient care before profit.

> *"I think it's a thing of interest and conflict. The NHS has a very different ethos from a pharmaceutical company that just wants profit."*
>
> *Plymouth, male, Workshop 3*

Those with frequent interaction with the NHS due to health conditions, disabilities or being involved in care were particularly likely to support wider benefits as they could see how this could benefit those in a similar position to them in the future.

> *"The NHS needs as much help as it can get. Extra benefits would be great. I wouldn't mind if it's a monetary discount, I just want to see the NHS benefit."*
>
> *Learning difficulties, Depth interview, Seldom heard audience*

That said, there were some misgivings around seeking wider benefits. These misgivings primarily focused on the ethics of prioritising English patients over those in other countries. Participants who held this view were concerned about whether it is appropriate for the UK to have a monopoly, albeit only for a limited time, over treatments that could save lives elsewhere in the world.

Yet those with less common health conditions and/or disabilities did not share this concern, particularly among those who recognised other countries as leading in care for their condition. There was a desire among this audience to see the UK become that leader.

The principles and a data pact

Greater trust was closely linked to the principles and a data pact. The principles set out clear "rules" for how data will be used. This clarity provided reassurance, mitigating initial fears that data might be used in ways participants would be uncomfortable with. Similarly, despite the feedback on the need for clearer language, the draft data pact helped participants trust in the ways their data might be used.

> *"What they've set out, how it's going to be used and what's going to be used has all made me more trusting. I know that the rules around it now are quite strict. I thought it would be more about who is the highest bidder, with the pharmaceutical companies and knowing money comes into it but there are rules."*
>
> *Sheffield, female, Workshop 3*

The system and its processes

Control of data remaining with the NHS was a source of reassurance for participants. As is apparent from the discussions around the value of data, the NHS itself is a trusted system – trust which is rooted in it being non-profit-seeking. This provides reassurance for participants, especially where they have concerns about the potential motives of other organisations which may want access to this sensitive data.

> *"There is no question on trust. With what I know so far, I feel confident. Would I trust pharmaceuticals? No, because we're linking into pharmaceuticals, and there's a desire there to be more rigorous. But I trust the NHS."*
>
> *Plymouth, male, Workshop 3*

Beyond their faith in the NHS and its non-profit ethos, participants also talked about the reassurance provided by the information shared across the data deliberation. This, they felt, demonstrated that data security is being taken seriously. These 'good intentions' not only made participants more trusting, but they also made them more supportive of the ways in which their data might be used.

> *"I'm more reassured in the sense that I can tell things are moving in a direction... Challenging unhealthy narratives, such as paranoid conspiracy theories that too often stop people from doing good work with data and within healthcare."*
>
> *North London, male, Workshop 3*

Addressing their common concerns about data security remained a recurring issue for participants. They felt more confident in how their data could be used after hearing about the governance processes being put in place. Having been largely unaware of this at the outset, the 'vetting' of uses and organisations fostered greater trust – even among those who had been particularly sceptical at the start of the process.

> *"My point of view has massively changed. I would be more willing to share my data whereas, when I initially came, I was adamant I wouldn't want it. I didn't know where it would go, how safe it would be, whether it would be sold."*
>
> *Sheffield, female, Workshop 3*

One comparison that participants in Sheffield stressed was to online shopping. They initially discussed wider data uses in Workshop 1 and their uncertainty about how data is used by online retailers. What they learned through the course of the data deliberation created a belief that their health and social care data is in 'safer hands' than other sorts of data they might be sharing. This, they felt, could be a key argument for encouraging others to support greater use and access of health and social care data.

> *"If somebody asked me should I rely on it, should I trust it, I'd ask do you do online shopping? Then this is better than that by far."*
>
> *Sheffield, female, Workshop 3*

Public engagement and transparency

The most commonly reported factor in having greater trust and confidence was taking part in the Tier 1 deliberative process or the Tier 2 qualitative process. Learning about the benefits of data use and the measures in place to keep their data safe was a powerful influence on trust. Indeed, participants themselves suggested that the key to greater public acceptance is to demonstrate the potential benefits of data use and access.

> *"I will have more confidence. There is a need to find ways to emphasise benefits to the public… knowing more about this topic has increased my confidence."*

Sheffield, female, Workshop 3

Being invited to take part in the data deliberation demonstrated to participants that their views are being listened to – this sentiment was especially prominent in Plymouth. Sharing information in a transparent way and supporting the public to engage in open discussion about what they want fostered trust and confidence.

> *"Having been here for the past three days, I feel like I'm reassured that we are helping with the decision-making. I feel reassured that they care about our feedback. It's good too because you meet people with different perspectives you would never have thought of."*

Plymouth, female, Workshop 3

One other aspect of taking part helped improve trust and confidence in how health and social care data is used – the way the participants themselves engaged in the issue. The enthusiasm their peers showed for the subject reassured participants about how decisions around data use and access will be made.

> *"I was impressed not just by the NHS staff but how engaged the public are, and how much everyone clearly cares about this."*

North London, female, Workshop 3

Tier 2 participants shared similar reflections from their experience of taking part in the qualitative research. While many of these audiences are heavily researched in medical contexts, participants expressed that they do not often feel their opinions are asked. Being able to feed in and express how they feel their personal data should be handled gave participants a sense of control over the process and led to increased trust in the use of their data by the NHS.

> *"I feel more trusting now actually because now I understand the systems they have in place and I think the NHS is trying to be as sensitive as possible with my data."*

Sex worker, Depth interview, Seldom heard audience

There was a far more limited effect of participation on the Tier 3 respondents, where we saw limited change in the level of trust expressed by participants in the survey. For example, at the beginning of the survey, 60% of the sample said they trust the NHS to make balanced and informed decisions about who has access to their data. By the end of the survey this had risen to 65%.

7.5 Mixed views

Despite most of the participants feeling more confident in how their health and social care data is used, there were those who still felt uncomfortable with their data being used/still had concerns at the end of the process.

The primary factor for those with mixed feelings was an underlying sense of scepticism. These participants felt somewhat reassured but still had doubts about who might have access to their data and what might be done with it.

> *"I feel like they should feel more confident. I still think there's an element of things not being great. I'm certainly more confident but… there's still an element of scepticism."*
>
> *North London, female, Workshop 3*

For others, the ongoing concerns about data breaches lessened their trust in how their data is used. These participants had a strong belief that data breaches could never be entirely ruled out and, indeed, seem inevitable. This conviction underlay their scepticism about how safe their data could ever be. The enduring nature of concerns about data security is corroborated by much of the existing evidence, as outlined in the evidence review.

> *"I'm still sceptical, there's always a breach somewhere. With this conversation I'm maybe 70% there, it's opened my eyes, with your questions it's become a bit clearer but I'm still thinking."*
>
> *Sheffield, male, Workshop 3*

For Tier 2 participants with experience of discrimination via institutions, including those from ethnic minority backgrounds, care-experienced adults, LGBQ+ and transgender audiences, concerns around a data breach were paramount. A minority among these audiences did not feel they had seen enough information to feel reassured their shared data would be appropriately de-identified and could not be linked back to them in the event of a data breach. They also called for explicit acknowledgment that use of their data would not be used to reinforce discriminatory practices in the medical field.

> *"I want to know what will happen if there are breaches and to know who has accessed my data and what will be done about it."*
>
> *Care-experienced adult, Depth interview, Seldom heard audience*

There was also discomfort with what they learned about the Federated Data Platform – an uneasiness especially apparent in Plymouth. The use of a third-party supplier combined with the fear of data breaches tempered the trust built up across the data deliberation.

> *"They will keep data safe but there will be stuff going on behind the scenes with the tech storing company. I want to see the pact between (the provider of the) FDP and NHS."*
>
> *Plymouth, male, Workshop 3*

For the most part, mixed feelings and uncertainty about how far the data use proposed is trustworthy was, therefore, driven by balancing the potential positives with concerns about what might go wrong. However, for one North London participant, their mixed feelings were the result of a concern that the system as described might be too cautious and so fail to release the potential benefits.

> *"I would say it's safe. If anything, it's too safe. The risk here is not using the data for the benefits that it could be used for."*
>
> *North London, male, Workshop 3*

7.6 Decreased trust

Across the four locations there were a small number of participants who reached the end of the data deliberation and were less trusting than they had been going in. There were those who felt that the amount and complexity of the information shared made the situation more confusing, made them less certain about how they felt, and raised more doubts than it answered. For these people, there were also concerns about how people would react without the benefit of 15 hours of deliberation.

> *"I know my granny will look at this and not have a clue."*
>
> *Sheffield, male, Workshop 3*

In one case, the very fact of being asked to consider data use and access created suspicion.

> *"If you're having to tell me you're not going to share my data with people who shouldn't have it, that unsettles me. That feels like stating the obvious."*
>
> *North London, female, Workshop 3*

And there were those who were concerned about the motives of "Big Pharma". From this point of view, using health and social care data generated from NHS sources to help private companies make money felt inappropriate.

> *"My main opposition was selling to big pharma. I don't mind it going to universities for research or for that sort of thing. But when it came down to my data being sold to big pharma for them to make big profits that don't benefit the NHS, that I don't agree with".*
>
> *North London, female, Workshop 3*

Ultimately, those who had mixed feelings or less trust in how their data might be used were far outweighed by those who came away with greater trust and confidence.

7.7 What should be done to support greater trust and confidence?

Given all this, there are several ways in which greater trust and confidence can be fostered.

Changing perceptions

Bringing to life the intentions and impacts of data use and access through examples and case studies is important. Concrete examples of the benefits to patients and the security measures in place to keep data safe were especially effective in generating trust and confidence.

Yet positive views were – as we have seen throughout this first cohort of the data deliberation – not only linked to tangible individual benefits, as the existing evidence suggests. Wider societal benefits can also help build trust and confidence.

Continuing to develop and evolve a data pact is necessary to realise its potential. The concept of a data pact seems to have the potential to support greater trust, judging by the responses of the Tier 1 participants. A more concise and more direct version has the potential to assuage much of the doubt and uneasiness the public have about the ways their data can be used – though efforts will also need to be made to publicise any data pact, given less than two in five Tier 3 survey respondents said they would read it in the first place.

Tackling low awareness through publicising the work being done will help build trust. Little is known about how data use and access operates, and for what purposes – as identified in the evidence review. This lack of knowledge allows fears about data security and motivations behind seeking access to fester.

Demonstrating the guidelines and rules around how data can and cannot be used will also build trust and confidence. Fears about data breaches and subsequent misuse of health and social care data persisted throughout the deliberation and are a barrier to greater trust and confidence. Mitigating these fears is vital if trust is to be improved. It may also need honest dialogue with the public about the reality that some breaches will occur and explanation about how the impacts will be mitigated.

Transparency

Participants expressed concerns about the lack of transparency regarding data collection, use, and security, leading to mistrust. They desired clear information about how their health and social care data is used, who accesses it, and why, but without overwhelming legal details.

Transparency in demonstrating the principles governing data use helped alleviate concerns. Involvement in the deliberative process increased trust, with participants noting that understanding the benefits of data use and safety measures is crucial for public acceptance. Transparency about research funding and how surplus data is used was also important to them.

Increasing safeguarding of data, and awareness of what is already in place

Yet it is also important to further increase the safeguarding in place in order to foster greater trust. One key aspect of this is to incorporate explicit anti-discriminatory guidelines to ensure data is not used to further discrimination against any audience or group.

As stressed in the evidence review, there is a great deal of trust in the NHS to do the right thing and have the best intentions. The concern for the public – and this was reflected in the views of the participants – is that the NHS may not have the competence to keep data safe and secure.

Therefore, safeguarding around security and safety should include:

- Stressing what sanctions can be brought against those who do not adhere to the principles and who misuse data they are given access to.
- Giving a clear indication of what data protection regime access to health and social care data will be subject to.

This was especially important as those with mixed views or enduring scepticism focused on data breaches and misuse by either profit-motivated organisations or the third-party FDP provider.

Red lines and principles

Finally, there are three red lines that participants made clear across the course of deliberating on the use and access of health and social care data:

- NHS data should be used only for public benefit.
- These public benefits should be felt by, and shared among, NHS patients and the public at large, not just private interests.
- The security of individuals’ personal data should be the highest priority.

8. Sample profiles

Tier 1 workshops and deliberative pre-survey sample profile | March 2024

Sortition

Table 1: Sortition recruitment Tier 1 workshops sample profile (Total:79 participants)

Demographic	London	Sheffield	Canterbury	Plymouth
Age: 16-24	2	3	1	2
Age: 25-39	5	5	4	3
Age: 40-54	5	5	5	5
Age: 55-69	5	5	4	6
Age: 70-99	2	3	5	4
Gender: Male	8	10	9	9
Gender: Female	11	11	10	11
Gender: Other	0	0	0	0
Ethnicity: White British	7	15	17	17
Ethnicity: White Other	2	1	1	1
Ethnicity: Black or African or Caribbean or Black British	3	1	1	1
Ethnicity: Asian or Asian British	4	3	0	1
Ethnicity: Mixed or Multiple ethnic groups	1	1	0	0
Ethnicity: Other ethnic group	2	0	0	0
Segment: Confident	7	5	3	3
Segment: Sceptic	5	4	2	3
Segment: Unfamiliar	6	5	7	6
Segment: Apathetic	0	4	4	5
Segment: Disengaged	0	2	2	1
Segment: Cautious	0	1	0	2
Segment: Unassigned	0	0	1	0

Disability or LTHC: No	17	17	15	17
Disability or LTHC: Yes	2	4	4	3
Education: Level 3 or below	9	14	13	14
Education: Level 4 or above	10	7	6	6

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

Purposive

Table 2: Purposive recruitment Tier 1 workshops sample profile (Total: 33 participants)

Demographic	London	Sheffield	Canterbury	Plymouth
Age: 16-24	2	2	2	0
Age: 25-39	4	0	1	2
Age: 40-54	1	3	1	1
Age: 55-69	3	3	2	2
Age: 70-99	1	0	1	2
Gender: Male	5	5	3	3
Gender: Female	6	3	4	4
Gender: Other	0	0	0	0
Ethnicity: White British	2	5	2	5
Ethnicity: White Other	0	1	1	1
Ethnicity: Black or African or Caribbean or Black British	5	0	1	1
Ethnicity: Asian or Asian British	3	1	1	0
Ethnicity: Mixed or Multiple ethnic groups	1	1	2	0
Ethnicity: Other ethnic group	0	0	0	0
Segment: Confident	1	0	0	0
Segment: Sceptic	2	2	1	1
Segment: Unfamiliar	3	2	1	1
Segment: Apathetic	2	2	2	1
Segment: Disengaged	2	2	1	0

Segment: Cautious	1	0	2	3
Segment: Unassigned	0	0	0	1
Disability or LTHC: No	6	3	3	4
Disability or LTHC: Yes	5	5	4	3
Education: Level 3 or below	6	4	2	0
Education: Level 4 or above	5	4	5	6
Education: Undisclosed	0	0	0	1
Carer: Yes	3	3	3	2
Carer: No	8	5	4	5
LGBTQ+: Yes	2	1	1	0

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

Tier 2 depth interviews and workshops sample profile | March 2024

Table 3: Tier 2 depth interviews and workshops sample profile (Total: 73 participants)

Segment	**No. participant in In-depth interviews**	**No. of participants in workshops**	**Total**
Older person with LTHC	2	0	2
Domestic abuse survivors	4	0	4
Sex workers	4	0	4
LTHC / neurodiverse / mental health	9	0	9
Carers	6	0	6
Learning difficulties	5	0	5
Sensory impairments	4	0	4
Care experienced adults	3	0	3
Unhoused people	1	0	1
LGB(Q+)	0	7	7
Trans	0	8	8

Younger people with multiple LTHCs	0	8	8
Ethnic minorities	0	12	12
Total all segments	38	35	73

Tier 3 deliberative survey sample profile | March 2024

Table 4: Tier 3 quantitative survey profile – all data (Total: 4,007 respondents)

Demographic	Sample size
Age: 18-24	421
Age: 25-34	685
Age: 35-44	661
Age: 45-54	673
Age: 55-65	633
Age: 65+	934
North East	189
North West	525
Yorkshire and the Humber	389
West Midlands	417
East Midlands	349
East of England	449
London	618
South East	658
South West	413
Gender: Male	1934
Gender: Female	2061
Gender: Other	12
Ethnicity: White	3312
Ethnicity: Asian	411
Ethnicity: Black	112

Ethnicity: Mixed	109
Ethnicity: Other ethnic group	63
Segment: AB	1055
Segment: C1	1157
Segment: C2	840
Segment: DE	955
Likelihood to opt out: Already opted out	323
Likelihood to opt out: Likely to opt out	924
Likelihood to opt out: Unlikely to opt out	2202
Likelihood to opt out: Don’t know	558
Disability or LTHC: No	3110
Disability or LTHC: Yes	791

Table 5: Tier 3 quantitative survey profile – Base and endline sample (Total: 2,000 respondents)

Demographic	Sample size
Age: 18-24	210
Age: 25-34	342
Age: 35-44	330
Age: 45-54	336
Age: 55-65	316
Age: 65+	466
North East	94
North West	262
Yorkshire and the Humber	194
West Midlands	208
East Midlands	174
East of England	224
London	309
South East	328
South West	206

Gender: Male	967
Gender: Female	1030
Gender: Other	4
Ethnicity: White	1659
Ethnicity: Asian	205
Ethnicity: Black	58
Ethnicity: Mixed	57
Ethnicity: Other ethnic group	137
Segment: AB	527
Segment: C1	578
Segment: C2	419
Segment: DE	477
Likelihood to opt out: Already opted out	166
Likelihood to opt out: Likely to opt out	471
Likelihood to opt out: Unlikely to opt out	1097
Likelihood to opt out: Don’t know	267
Disability or LTHC: No	1569
Disability or LTHC: Yes	392