healthwatch
in Bath & North East Somerset, Swindon & Wiltshire

How should patient data be used?

Contents

Commission

This project was commissioned by the Bath and North East Somerset, Swindon and Wiltshire Integrated Care Board (ICB). The research was conducted between February and March 2026. The report was published in May 2026.

Acknowledgements

We would like to thank the following organisations for their support:

- Bemerton Heath Centre (Salisbury)
- Emmanuel's Yard (Trowbridge)
- MS Society (Devizes)
- Gorse Hill Community Church (Swindon)
- University students who volunteer with Healthwatch (Bath)
- Ks2 (Bath)
- St John's Foundation (Bath)

Summary

What this report is about

The NHS is looking at using people's health information in new ways to plan services and offer more proactive care. Healthwatch was asked to understand what the public think to ensure that any future use of patient information reflects their expectations. The findings highlight the conditions under which people feel comfortable sharing their data, and the risks that could undermine confidence.

What people think

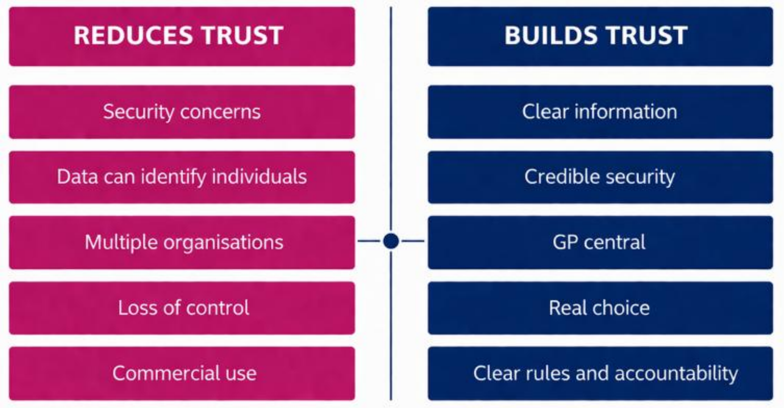
Most people are supportive of their data being used for the public good, but this support is conditional.

Trust reduces when:

- There are concerns about security
- Information identifies individuals
- Data is shared across multiple organisations
- People feel they don't have control
- Commercial organisations benefit

Trust increases when:

- Information is easy to understand
- Security is visible and credible
- The GP remains central to decisions and contact
- People have real choice and control
- There are clear rules



REDUCES TRUST	BUILDS TRUST
Security concerns	Clear information
Data can identify individuals	Credible security
Multiple organisations	GP central
Loss of control	Real choice
Commercial use	Clear rules and accountability

Key insight

Trust is highest when health information is closely controlled by the GP. Trust reduces when information moves from the GP into the wider health system. We call this The GP Distance Effect.

What this means

- Be transparent
- Keep the GP at the centre
- Make choices visible
- Show safeguards

It's emotional

This can be an emotional topic. One participant said: "This is sensitive stuff. Tread carefully."

About Healthwatch

Healthwatch is your independent, health and social care champion. We listen to people's experiences, amplify their voices, and make sure decision-makers understand what matters to communities. Our role is to ensure that the design and delivery of health and care reflects the needs of the people it serves.

About this report

Purpose

This report explores what people think about how patient information is used. It aims to:

- Identify when people feel the use of data is acceptable
- Provide evidence to inform the Integrated Care Board's future plans

Methodology

We used a mix of surveys and focus groups, involving a total of 146 people. See Appendix 1 for more detail.

Report terminology

Participants and respondents

Participants	People who took part in our focus groups
Respondents	People who completed our survey

Strength of opinion in focus groups

Significant majority	Most with few exceptions
Majority	More than half
Around half	Views were evenly split
Significant minority	Noticeable group, less than half
Minority	Small number

Commissioning Background

Why was this research commissioned?

The Integrated Care Board (ICB) for Bath and North East Somerset, Wiltshire and Swindon is responsible for planning the region's health services. It wants to use patient information in new ways to be more effective.

Because it is impractical to ask each resident for their consent, the ICB is applying to the Health Research Authority's Confidentiality Advisory Group (CAG) for permission to proceed. This process is known as applying for Section 251 approval under the NHS Act 2006. To make this application, the ICB must show that it is listening to public opinion – a task it has commissioned Healthwatch to lead.

Key terms

Confidential patient data

This health information includes the patient's name and NHS number, with details about their care and treatment. It is used by healthcare providers who are directly involved in the patient's care – usually the GP surgery and hospital.

Pseudonymised data

Confidential patient data can be 'pseudonymised'. This means replacing some identifying information, such as names or NHS numbers, with a code. For example, a name (Jane Smith) might be replaced with a reference number (1234).

Re-identifying patients

A reference tool (called a pseudo-key) can be used to link pseudonymised patient data back to a real person. For example, it would show that patient 1234 is Jane Smith. This key would only be used in specific, approved circumstances, by authorised staff.

What the ICB does now: The ICB uses national patient data to understand health needs and plan services.

What it wants to do in the future: The ICB wants to use local patient data and, in specific approved cases, re-identify patients to alert their GP.

Why? This will help the ICB to plan local services more effectively and target support to people who most need it

Example of how pseudonymised patient data could be used

Amina Rahman

Amina Rahman's health information is held in her GP practice record.

This includes **identifying** details such as her name, NHS number, date of birth and medical history.

1 Pseudonymisation

Amina's identifying details are removed and replaced with a code.

Amina Rahman → Patient 4721

2 ICB analysis

The ICB analyses coded data to identify patterns.

For example, **Patient 4721** appears in a group of patients who may benefit from a **blood pressure check.**

The ICB **cannot see the patient's identity.**

3 Strong governance

Under strict governance controls, a secure key allows the coded record to be matched back to the patient's identity.

Patient 4721 → Amina Rahman

4 ICB informs the GP practice

The ICB informs the GP practice that **Amina Rahman** appears in a group of patients who may benefit from a blood **pressure check.**

5 GP review

The GP practice reviews **Amina Rahman's** record and considers whether contacting her would be appropriate.

6 GP contacts the patient

If appropriate, the GP practice contacts **Amina Rahman** to offer a **blood pressure check.**

Context

What do we know already?

There is already a lot of research on what people think about the use of patient data. The main findings are:

What do we know already?

Trust in NHS
Most people trust the NHS to keep their data secure.

Trust in companies
People are more sceptical when private companies are involved.

Public benefit
There is support when using data clearly benefits the public.

Strong governance
Safeguards and transparency are important.

Cyber attacks
Cyber attacks on NHS IT systems are a common concern.

Artificial intelligence
AI use is raising questions about privacy, bias and governance.

High-profile data breaches
Past high-profile data breaches have caused alarm.

COVID-19 data programs
COVID-19 programs increased debate about patient data.

See Appendix 2 for more information.

A cautionary tale[1]

In 2013, the NHS launched the 'care.data' programme. It aimed to link GP and hospital records to better understand how services were used and improve planning.

However, the programme quickly became controversial. People were concerned about how it had been explained, what consent would involve, and whether data might be shared with commercial organisations.

Care.data: How did it go so wrong?

19 February 2014 · 354 Comments

After widespread criticism and a loss of public trust, the programme was cancelled in 2016. It shows how quickly public trust can be lost when transparency, clear communication and meaningful choice are not in place.

---

[1] https://www.bbc.co.uk/news/topics/c81zyn0888lt

Impact of today's patient data

Movement of data around health system

None of our participants reported a positive experience of patient data. The main concern was that it didn't follow them around the health system. When their patient journey took them between the GP and hospital, or from one region to another, or between countries, their medical data didn't move with them. As a result, patients can face delays in appointments and medication, as well as incomplete diagnosis.

Patient as data carrier

The majority felt they have to be their own 'data carriers'. This means making notes about their healthcare, and bringing copies of doctors' letters and test results to appointments. Three problems were identified with this approach:

- Patients are not medically trained and may not bring accurate or complete notes
- Some doctors "didn't believe" their medical histories, because they were not from an official source
- Some patients don't have the ability to be their own data carriers

We were told...

"I think my data should travel with me, but it doesn't."

"Medical professionals dismiss concerns when you go somewhere else. "

"You have to keep explaining the same thing over and over."

Delay in medication

A significant minority reported that their access to medication was interrupted because their patient data hadn't transferred to their new medical practice.

NHS app

We asked participants why they didn't use their NHS app to access their patient data. A significant minority (mostly older) participants reported that they had never used the NHS app, and didn't plan to do so. The three reasons were:

- They were not comfortable with technology in general, and don't regularly use apps
- They were concerned about the safety of using or storing their private data on an app
- New patient data (for example, a test result) had not been entered onto their NHS app notes

Impact on carers

People living with long-term conditions, such as multiple sclerosis (MS), and those who care for them, highlighted how inconsistently patient information is shared. Carers described situations where key information about a person's health was not shared with them, even when they were responsible for keeping that person safe.

For example, one carer was told an ambulance had been called for their suicidal partner but was given no further information due to "data protection". Others described patients being discharged without explanation. The carers were clear: sensitive personal details should remain confidential, but practical information must be shared where needed to support care.

Trust in the system

Participants did not distinguish between different parts of the NHS. From their perspective, the same system that is "failing" to manage patient data now is asking for greater access to it in the future.

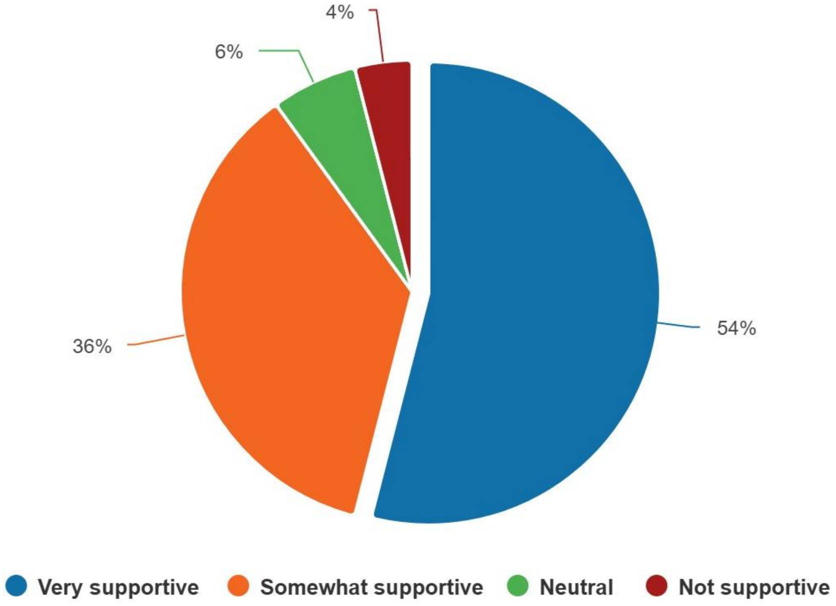
Support for public good

Instinctive support

A majority of respondents were comfortable with patient information being used to plan services and improve health. 54% were very supportive and 36% somewhat supportive. As one participant put it: "this is common sense."

Similar support was given for the NHS to improve services by linking non-identifiable patient data with information from other services, like councils or charities.

Comfortable with data being used to plan services and improve health

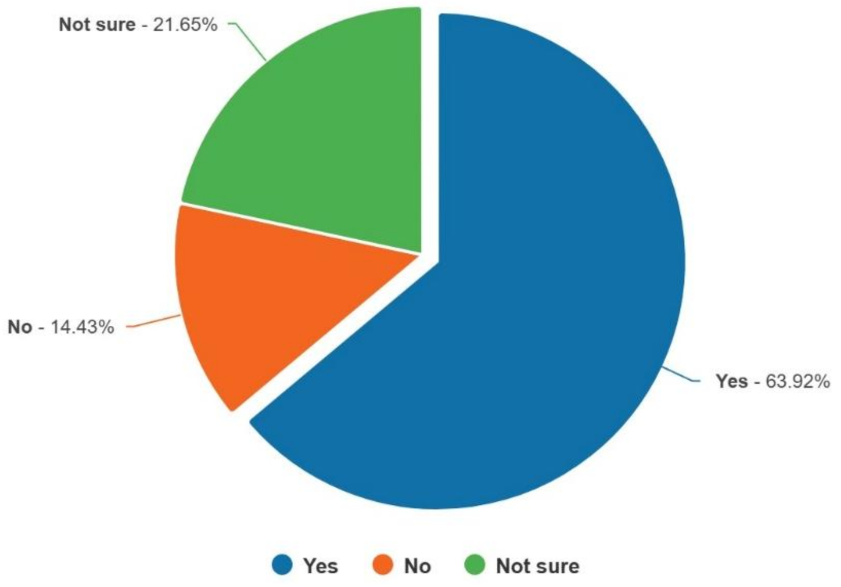


Public good

Support was driven by a desire to contribute to the 'public good'. 77% were happy for non-identifiable information to be used to understand issues like poor housing and health, and to share these insights with councils.

"If it's to improve the world and the system, then great, I'm all for it", said one participant.

Comfortable for data to be used to understand health issues and share with councils



Using data to understand care

Supporters recognised that data helps the NHS to spot trends, target support, address inequalities and improves the understanding of complex conditions.

.

Proactive direct care

A majority of respondents supported the NHS identifying patients who may benefit from preventative care. 66% were either ‘very’ or ‘somewhat’ comfortable - provided the contact comes from the GP.

“I like how I get contacted for health check-ups from my GP every few years when it is due.”

Falling through the cracks

There was strong support for using data to identify people who may have “fallen through the cracks” - people missing care, especially those unable to advocate for themselves.

Conditional support

Confidence in these uses of data was conditional. It fell if data was identifiable; commercial use was suspected; or when the GP had less control. (See Chapters 4 and 5).

Trusted GP Relationship

Participants consistently said: “You can trust your GP”.

The GP Distance Effect

Trust decreases as control moves further away from the GP

Trust is highest when the GP is seen to be in control. Most participants trusted their GP to manage their data.

As control moves away from the GP to the NHS as a whole (including the ICB), trust reduces. This is because patients don’t have a personal relationship with the NHS, or an understanding of how their data is used at this level. When data moves beyond the NHS to commercial organisations, trust drops further. This reflects people’s distaste of using patient data to make profit. 54% of respondents were ‘very sure’ or ‘sure’ that the NHS keeps their data safe and confidential.

Decision point

All our participants agreed that the GP should decide whether to contact them for preventative care – and should make that contact themselves. This is because the GP “knows the whole picture” about their health.

Declining trust in NHS

However, participants said that their trust in how GPs use patient information is shaped by their wider trust in the NHS - which is declining. This is supported by recent research by the King’s Fund and Nuffield Trust which indicates that trust in the NHS has fallen from 60% in 2019 to 21% in 2024.[2,3]

Postcode lottery

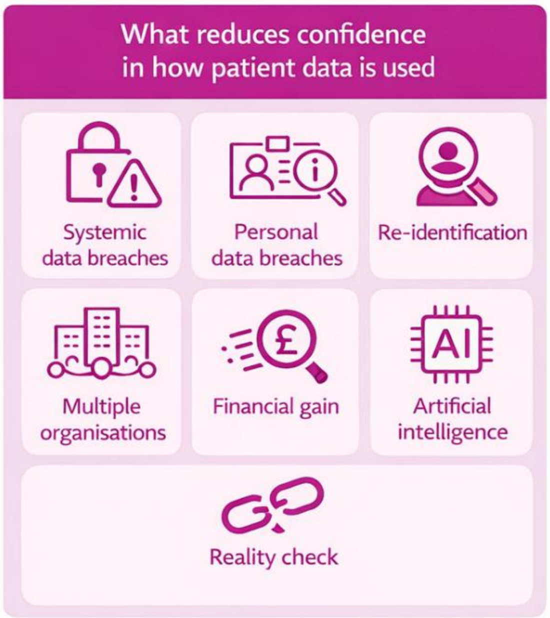
Participants were keen to hear each other’s GP stories. For some, their GP was “wonderful”; for others “awful”. This variation was described as a “postcode lottery”, where the quality of your care depends on where you live. Although trust in the GP was high overall, where participants experienced a poor experience, they were less likely to trust their GP with their data.

---

[2] https://www.kingsfund.org.uk/insight-and-analysis/reports/public-satisfaction-nhs-and-social-care-2022.html

[3] https://www.nuffieldtrust.org.uk/research/public-satisfaction-with-the-NHS-and-social-care-in-2024-Results-from-the-British-Social-Attitudes-survey

Undermining Trust



Systemic data breaches

Concerns about data security were common. Participants felt that no system is completely secure and breaches occur in all sectors. This created a sense of vulnerability because of the sensitivity of patient data.

“No system is completely safe”.

“There will always be staff willing to be manipulated to share data.”

Personal data breaches

As well as concerns about systemic breaches, a significant minority of participants were concerned about individual breaches. A typical story was told to us by a patient who was (incorrectly) treated according to someone else’s medical notes. This caused extreme distress.

Re-identification

While many were comfortable with non-dentifiable data being used, the idea that the data could be “unlocked” and linked back to them personally, created a big dip in confidence. A minority were very fearful of being re-identified. One participant described this as “kind of terrifying”.

Financial gain

Trust dropped sharply if there was any suggestion that data might be used for commercial gain. The idea that organisations could profit from personal health information was widely rejected.

“I trust my GP, but not the wider NHS as the service will inevitably be provided by a private company”.

“I want clear lines on what will never happen with my data, i.e. it will never be sold to a private company”.

Is commercial involvement good or bad?

Attitudes to commercial involvement depended on context. Where commercial involvement is clearly linked to public benefit - such as the development of vaccines or new treatments - public acceptability increases. When involvement is perceived as simply profit-driven or linked to wider concerns about the privatisation of the NHS, resistance becomes much stronger.

Artificial intelligence (AI)

While some participants saw the benefits of AI—such as analysing large volumes of patient information to identify risks — but this was offset by uncertainty about how those systems interpret health information. There were concerns about AI using incorrect or incomplete patient data to reach the wrong conclusions.

Reality check

Many questioned whether the health system has the capacity to respond to this new ICB, proactive approach . A typical comment was: “Is this really going to happen when people are not even attending their regular health checks?”

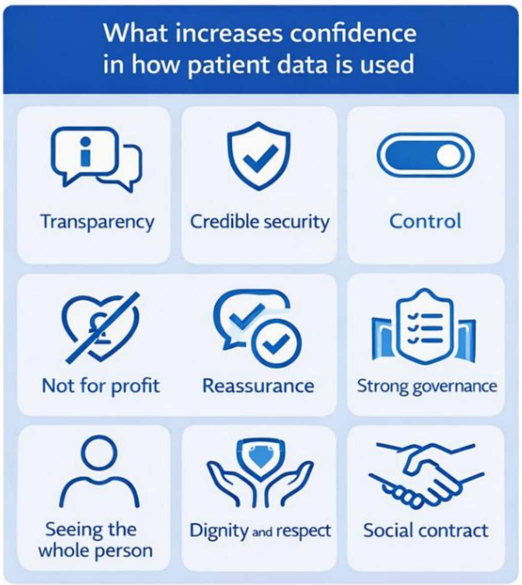
“The NHS doesn’t get the basics right, so how on earth are they going to manage this advanced approach?”

Building Trust

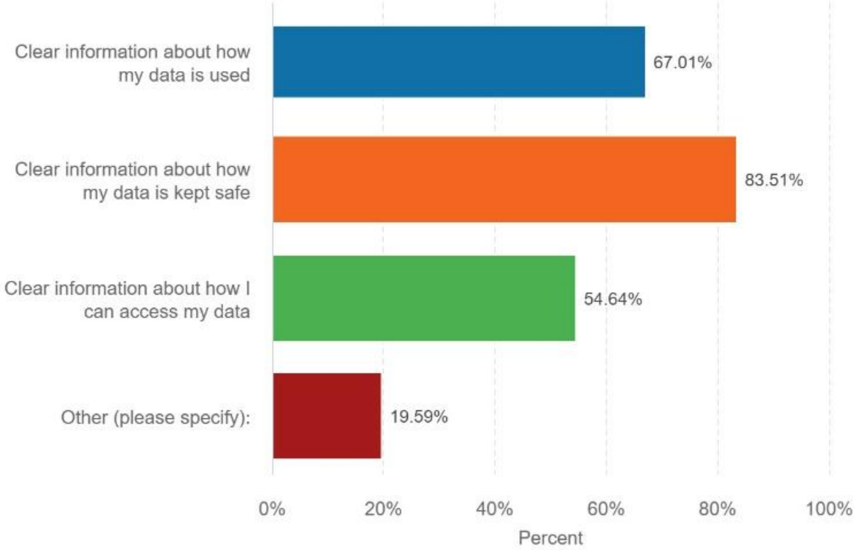
Transparency

Participants said they would feel more confidence if they knew what information is being used, who is using it, and why.

“The more transparent they are, the more trust we have in them.”



What would build your confidence?



Credible security

They need simple information about what data security protections are in place. If data is mishandled, they want NHS organisations to be open about it, take responsibility, and show how breaches will be prevented in future.

Control

Participants wanted control over how their information is used, including the ability to opt out or limit certain uses. (See next Chapter).

Not for profit

Participants want repeated reassurance that their data is for the benefit of patients, not profit.

Reassurance when contacted

Participants welcome their GP contacting them proactively to offer preventative care. But the reason must be clearly explained, otherwise this kind of contact can cause significant anxiety.

Strong governance

Participants want confidence that clear rules control how patient data is used. They also want staff to be properly trained in how to handle data properly. One respondent said that systems may be secure, but "people" are often where things go wrong.

Seeing the whole person

Participants expected that any use of data — particularly if it leads to patient contact — should take into account the full picture of a person's health.

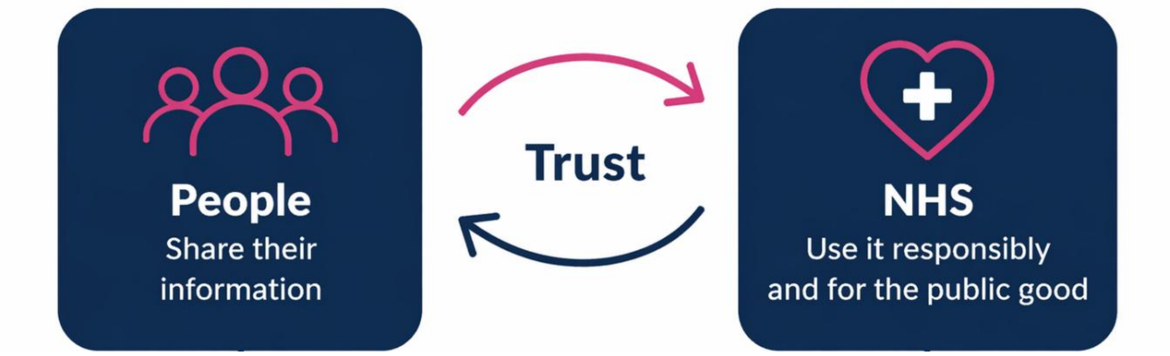
"If they don't know your full history it can mess up what is working."

Dignity & respect

Participants raised concerns about confidentiality not just at a system level, but in everyday settings — for example, conversations being overheard in GP surgeries. They want health information to be handled with dignity and respect.

Social contract

Some described all this reassurance as a 'social contract': the NHS uses people's information responsibility, and in return people are willing to share their data. If that trust is broken, support is lost.



Knowledge Gap

General lack of knowledge

68% of respondents said they knew the NHS uses patient information to plan services. However, this knowledge was shallow. Most participants had little or no understanding of how their information was used, beyond their direct care. For many, this was the first time they had considered the topic.

Terms and conditions

While there was interest in learning about how their data is used, participants acknowledged they would be unlikely to engage with detailed written information. They were "too busy" or just unable to absorb lots of text.

Knowledge of ICB

No participants had prior awareness of the ICB. This was not surprising, as it is not a public-facing organisation. Participants questioned why a system-level organisation would need access to information about their health, when their GP already has it.

National Data Opt-Out (England)

The National Data Opt-Out is a service that lets people choose whether their confidential patient information can be used for purposes beyond their own care, such as planning NHS services or medical research.

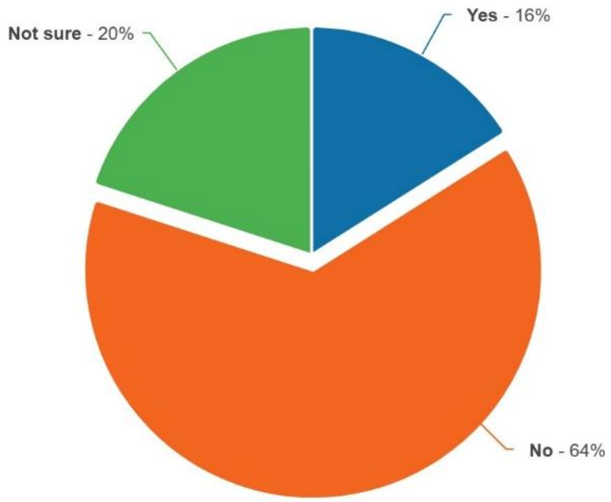
If someone opts out, their identifiable information should not be shared for these purposes (unless specific exceptions apply).

People can set or change their choice at any time, most commonly online via the NHS App or website, or by phone or post. As of November 2024, around 3.6 million people in England (about 5.4% of those registered with a GP) had chosen to opt out.

Knowledge of NHS Data Opt-Out

A significant majority of participants had not heard of the National Data Opt-Out, as well as 41% of respondents. Only 16% knew how to opt out. Participants felt that having control over their information was important, and some were surprised or upset that they had not been made aware of this option. One participant told us: “You can’t choose if you don’t know about it.” Respondents expected to find more information about the Opt-Out from their GP surgery (43%) and the NHS app (52%).

Do you know how to opt-out?



Lack of communication

Most participants did not recall receiving any clear communication about how their information is used, beyond the initial registration with their GP. There was a general sense that this topic had not been actively explained to them.

Lack of consent

Many participants were uncomfortable with the idea that their information could be used without them being explicitly asked for permission.

Key insight: explanation builds confidence

Confidence can quickly increase when people are given clear, credible explanations. In each group, there were one or two participants with a stronger understanding of how information is managed, often through experience in the NHS or other data-heavy sectors such as banking or telecommunications.

When these individuals explained governance, safeguards and training, confidence within the group increased noticeably. In one group, members initially rated their confidence in the safety of their data as 3 out of 5. After hearing a clinician explain the strict conditions used in a hospital, they re-rated their confidence as 4 out of 5. This shows how quickly confidence can shift when there are clear explanations.

Implications for ICB

1. Honesty

Acknowledge existing problems

Insight	People's views are shaped by frustration with how their health information does not follow them through the system, leading to delays in medication and diagnosis. Some participant felt they had to be their own 'data carier'.
Implication	Acknowledge these frustrations and explain how this approach will address them - recognising that trust is currently fragile and will need to be earned through actions that people can see, not just assurances.

2. Decision making

Test decisions against trust

Insight	The success of ICB's approach depends on public trust. Each of their decisions will either build confidence or undermine it. 
Implication	Decision makers should ask a simple question before proceeding: will this build or undermine trust? We call this the Trust Test.

3. Service Design

Keep the GP central

Insight	**The GP Distance Effect** Trust decreases as control is seen to move further away from the GP. 
Implication	Patient contact should come through GP practices, with the GP clearly acting as the decision-maker. Avoid approaches that feel automated or generated by the wider system rather than the GP. Where GP capacity is limited, practices may need support to ensure that proactive contact remains personal and trusted.

4. Ethics

Show this is not for profit

Insight	Support drops sharply when people believe their data may be used for financial gain or shared with commercial organisations.
Implication	Make clear that patient data is used to improve care, not for profit. Where private sector organisations are involved, their role should be clearly defined, including what they can and cannot do with it.

5. Control

Make choices visible

Insight	There are points where patients can influence how their data is used — such as decisions during care, GP record sharing preferences, and the National Data Opt-Out — but these are not widely understood. As a result, many people feel they have no say.
Implication	Information about the National Data Opt-Out should be clearly signposted in GP settings and digital services such as the NHS App. When decisions about sharing information arise during care, these should be made explicit so that patients recognise they have a choice.

6. Communication

Use plain language

Insight	People do not engage with technical or system-level language, but still expect to understand how their data is used.
Implication	Use plain, everyday language and avoid technical terms such as "pseudonymisation" and system terms such as 'ICB'. Explanations need to be provided in 'bite-sized chunks' so people's confidence can build over time. Information should focus on the benefits for the individual and the public good.

Consequences

These recommendations set out the minimum required for the ICB to maintain public trust. Experience from programmes such as care.data shows what happens when trust is not secured. The social contract breaks and the programme fails.

Last word

The views of many participants and respondents are conditional. For example, they support the use of patient data for the public good, but not where they suspect commercial benefit.

Their views are also emotional. For example, participants were angry that they did not know about the National Data Opt-Out.

As the ICB uses our insight to shape its approach, it should recognise that trust is not guaranteed and can be quickly lost. As one participant put it:

> **This is sensitive stuff.**
> **Tread carefully!**

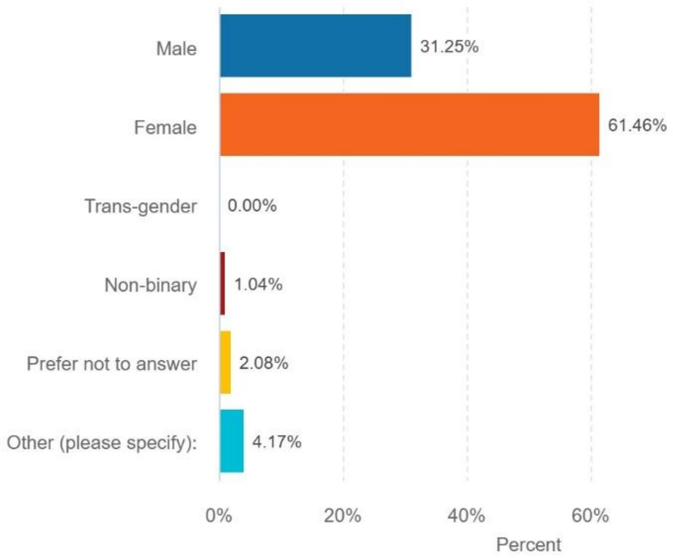
Appendix 1

Focus groups populations

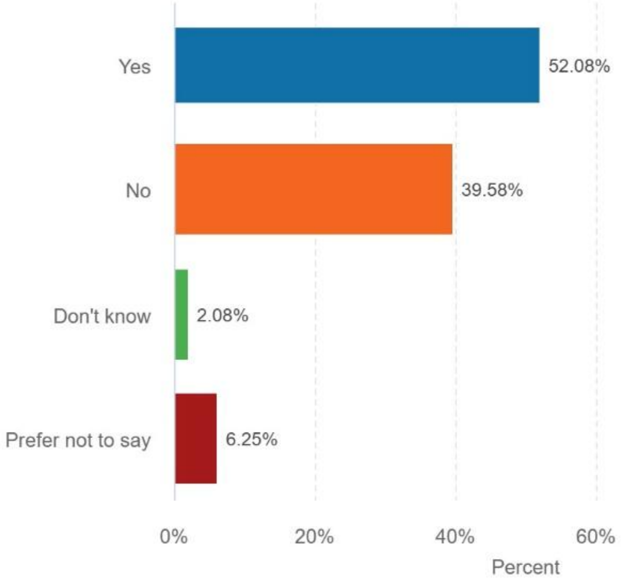
Venue	Location	Population
Gorse Hill Baptist Church	Swindon	Religious / deprived
MS support group	Devizes	Complex health conditions
Emmanuel's Yard	Trowbridge	Deprived
Bemerton Heath Centre	Salisbury	Deprived
University students	Bath	Young adults
Ks2	Bath	Carers (mental health)
St John's Foundation	Bath	Older adults

Characteristics of survey respondents

What gender do you identify as?



Do you have a disability or long-term health condition?



Ethnicity	%
White: British/English/Northern Irish/Scottish/Welsh	84
White: other	5
Prefer not to say	4
Other categories (each less than 1.5%)	7
Total	100

Sources for context

These sources provide insight into the context of how patient data is managed.

- BBC News, Facebook-Cambridge Analytica scandal, www.bbc.co.uk/news/topics/c81zyn0888lt
- Department for Science, Innovation and Technology (2023) Polling indicates growing public understanding about the importance of using health and care data. https://www.gov.uk/government/news/polling-indicates-growing-public-understanding-about-importance-of-using-health-and-care-data
- NHS England (2023) Public attitudes to data in the NHS and social care. https://www.england.nhs.uk/long-read/public-attitudes-to-data-in-the-nhs-and-social-care/
- Understanding Patient Data (2024) Public attitudes to patient data 2021–2024. https://understandingpatientdata.org.uk/sites/default/files/2024-09/Public%20Attitudes%202021-2024.pdf
- UK Government (2023) Public attitudes to data and AI Tracker Service: Wave 4 report. https://www.gov.uk/government/statistics/public-attitudes-to-data-and-ai-tracker-survey-wave-4

**The Vassall Centre
Gill Avenue
Fishponds
Bristol
BS16 2QQ**

**www.healthwatchwiltshire.co.uk
t: 01225 434218
e: info@healthwatchwiltshire.co.uk
𝕏 @HWWilts
f Facebook.com/HealthwatchWiltshire**

healthwatch
in Bath & North East Somerset, Swindon & Wiltshire