Involving people.
Transforming services.

olovus

Secure Data Environment

Engagement findings

October 2025

Contents

Executive summary

Introduction

The report provides an overview of the findings from an in-person/street survey conducted in September and October 2025, exploring the perception of the implementation of a regional Secure Data Environment (SDE). Specifically, the survey focused on understanding opinions about the sharing of health records for research and non-research purposes via the SDE.

The engagement was undertaken by industry independent experts, Olovus, who was commissioned by the Yorkshire and Humber SDE (YandH SDE).

Methodology

To ensure robustness of the sample, a target of 850 individuals was set with quotas for age, gender and ethnicity, with a split of respondents from all Yorkshire and the Humber sub-regions. To meet all quotas, surveys were conducted with a total sample of 901 individuals and weighted for population density of the region. Focus was made to engage with the population cohorts who have been shown to have stronger opinions on data sharing based on previous research carried out by Olovus for other SDE programmes.

Key findings

- **Two-thirds (66%) would be happy with an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details**, whilst 15% would not be happy.
- **Nearly three-quarters (72%) would be happy to share their health record via the SDE for research purposes**, whilst 14% would not be happy. Respondents feel happier about sharing their health record for research purposes with their doctor, hospital, or other medical professional looking after them and with NHS Teaching Hospitals (84% and 64% very happy or happy, respectively). They had the greatest concerns about sharing their health records with charities and local councils, with less than half happy to do this (41% and 39%, respectively).
- **Just over half (56%) would be happy to share their health record via the SDE for non-research purposes**, whilst 25% would not be happy. In terms of the organisations that could have access, respondents feel happier about sharing their health record with their doctor, hospital, or other medical professional and NHS Teaching Hospitals (69% and 58% happy, respectively). They had the greatest concerns about sharing with charities, local councils and pharmaceutical companies, with just a third happy to share their records for this purpose (32%, 35% and 42%, respectively).
- **Many could see the benefits that sharing their health records for research and non-research purposes could bring.** This included helping others and future generations, saving lives, supporting medicine/treatment developments, and improving the NHS more generally. However, there was a perception amongst many that sharing health records for non-research purposes is less important than sharing for research purposes, with comments about non-research purposes being

broad, undefined and unnecessary. This explains the results above and the lower satisfaction with data sharing for non-research purposes.

- **29% feel there are risks to people sharing their health record via a SDE for both research and non-research purposes, whilst 31% feel there are to some extent**. In contrast, 20% feel there are no risks.
- Key concerns relate to data security – specifically data 'leaks', 'hacks', 'breaches' – with concern about information getting into the wrong hands, which may have implications for individuals, as well as data access and use – specifically who will be accessing the data and for what purpose, with concerns about data misuse. Others expressed their personal preference of not wanting their personal information to be shared, even if anonymised, and/or lack of trust in general or more specifically for online systems, government and NHS organisations.
- **Half (49%) would prefer to approve the sharing of their health record themselves, whilst a third (37%) would be happy for their GP / other health service to share their health record directly into the SDE.** 9% do not want their health record to be shared at all.
- **Approximately two-thirds (60%) completely trust or trust that their anonymised health record would be used for the described reasons of the SDE only**. Furthermore, 18% neither trust nor don't trust, whilst 20% have little or no trust at all.
- Assurance was sought among many that their records would be anonymised, secure and used properly and for the right reasons, whilst others wanted more information to help them to make informed decisions.

Recommendations

The findings from this engagement provide a strong foundation for developing a more consistent, transparent and inclusive approach to communicating about the Secure Data Environment (SDE) across the Yorkshire and Humber region and the wider pan-North partnership. While there is broad support for data sharing for research purposes, public confidence remains conditional on reassurance that information will be used safely, ethically and for clearly defined purposes.

1. Strengthen public assurance around security and purpose

Clear, visible communication about how the SDE operates will be essential to build confidence. The SDE partners should:

- publish accessible explanations of how data is protected, including what happens if a breach occurs and who is accountable;
- share examples of approved projects that demonstrate tangible public benefit; and
- Continue to publish consistent regional narrative that explains how securely shared data supports better care, research and innovation.

2. Tailor engagement to varying levels of trust and understanding

Levels of trust and willingness to share data vary between population groups and areas.

- Target engagement in West Yorkshire and York, where trust and satisfaction were lowest.
- Use trusted community and NHS channels to reach older adults and people with lower financial security.
- Continue to work with ethnic-minority communities through established community and voluntary sector partners who already support research participation.

3. Clarify and co-design 'non-research purposes'

The term 'non-research purposes' is often viewed as too broad or undefined.

- Co-design clear, plain-English explanations and case studies of how data might be used for non-research purposes, such as improving emergency service planning.

- Carry out public member group activities to review proposed non-research uses, develop use cases, ensuring decisions are transparent and aligned with public values.

4. Strengthen ongoing public participation

- Strengthen public member group continuity to ensure public input into the design, governance and communication of the SDE.

- Offer training, mentoring and buddying to enable public contributors to engage confidently with technical and information-governance discussions.

- Sharelearning from this engagement within the wider DARE UK and TREvolution PPPIE programmes

5. Improve information feedback and transparency

- Produce a concise public summary of findings, accompanied by a one-page visual overview and a short narrated explainer to share results with participants and partners.

- Ensure outputs meet NHS accessibility standards and can be reused across partner organisations.

- Integrate these materials into regional campaigns to build public understanding of how health data is used safely and responsibly.

Next steps

Carry out cross-region comparison. Combine and compare findings from Yorkshire & Humber, North East and North West surveys to identify common and divergent attitudes.

Create a regional engagement framework which is a shared plan defining audiences, messages, and success measures for building long-term trust in data sharing.

Set up monitoring and review, using this report as a baseline to track changes in awareness, trust and willingness to share data over time.

These findings will be published on the Yorkshire & Humber Secure Data Environment website for transparency with the public.

This survey will shape and steer the public involvement work for 2026/27 within Yorkshire & Humber, focussing on areas that have less trust or knowledge around data being used for research and none research purposes.

This street survey will be repeated later in 2026 as a benchmark to provide ongoing monitoring of public views on the subject in Yorkshire & Humber (Y&H), capturing any development/change in opinion. It will be embedded as part of the Y&H public involvement strategy and steer communication and engagement focus in areas and demographics that are less sure about data being used for research and non-research purposes.

This report will be shared with Y&H decision makers and partners involved in the SDE programme.

Introduction

The report provides an overview of the findings from an in-person/street survey conducted in September and October 2025, exploring the perception of the implementation of a regional Secure Data Environment (SDE). Specifically, the survey focused on understanding opinions about the sharing of health records for research and non-research purposes via the SDE.

The engagement was undertaken by industry independent experts, Olovus, who were commissioned by Yorkshire and Humber SDE (YandH SDE).

Based on previous work conducted by Olovus regarding opinion on SDEs, specific focus was given to the following population cohorts who have been shown to have stronger opinions on data sharing via the SDE:

- Students, young couples, singles (i.e. those aged 16-24 years)
- Those aged 30 – 59 years, particularly women
- Those from ethnic minority communities
- Those living in rural and coastal areas
- Those who are well educated and affluent
- Those who struggle to make ends meet.

Methodology

Fieldwork was conducted over a five-week period spanning September to October 2025, engaging with 901 members of the public.

To ensure robustness of the sample, a target of 850 individuals was set with quotas for age, gender and ethnicity, with a split of respondents from all Yorkshire and the Humber sub-regions. This allowed for a 4% margin of error at the 95% confidence level.

To provide an explanation - if the research shows us that 52% of people would not be happy sharing their health record with a +/-4 percentage point margin of error at a confidence level of 95%, the actual percentage of people in the overall population who would not be happy is between 48% and 56%, 95 times out of 100.

To meet all quotas, surveys were conducted with a participant pool exceeding the target of 850. The subsequent tables show the quotas adhered to during the engagement and what was achieved based on age group, sex, ethnicity and sub-region.

	Approx. population size		Street survey participants	
	No.	**%**	**No.**	**%**
16 – 24	607,562	14	119	13%
25 – 34	718,232	16	135	15%
35 – 49	1,011,551	23	194	22%
50 – 64	1,081,966	24	202	22%
65 – 74	565,158	13	119	13%
75+	475,830	11	106	12%
Unknown	-	-	26	3%
Total			**901**	**100%**

Table 01: Quota by age group

	Approx. population size		Street survey participants	
	No.	**%**	**No.**	**%**
White	4,679,965	85.4	752	83%
Asian / Asian British Black / Black British Mixed or multiple ethnic groups Other ethnic group	800,809	14.6	126	14%
Unknown	-	-	23	3%
Total			**901**	**100%**

Table 02 : Quota by gender identity

	Approx. population size		Street survey participants	
	No.	%	No.	%
Male	2,689,092	49.1	445	49%
Female	2,791,685	50.9	438	49%
Other	-	-	1	<1%
Unknown	-	-	17	2%
Total			**901**	**100%**

Table 03 Quota by gender identity

Sub-region	Target sample	Street survey participants	
		No.	%
West Yorkshire Areas covered: Huddersfield, Leeds and Wakefield	175	209	23%
South Yorkshire Areas covered: Barnsley, Doncaster and Auckley	175	150	17%
East Riding of Yorkshire Areas covered: Bridlington and Hull	100	109	12%
City of York	100	108	12%
North Yorkshire Areas covered: Harrogate and Scarborough	100	103	11%
North Lincolnshire Areas covered: Epworth and Scunthorpe	100	114	13%
North East Lincolnshire Areas covered: Cleethorpes and Grimsby	100	108	12%
Total	**850**	**901**	**100%**

Table 04: Quota by sub-region

Financial status was not included within the quotas; however, it was included as a question in the equality monitoring section of the survey. Notably, compared to other questions asked as part of equality monitoring, a larger proportion did not disclose this information.

	Street survey participants	
	No.	**%**
I have more than enough money for basic necessities, and a lot of spare, that I can save or spend on extras or leisure	113	13%
I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure	262	29%
I have just enough money for basic necessities and little else	225	25%
I don't have enough money for basic necessities and sometimes or often run out of money	52	6%
Unknown	249	28%
Total	**901**	**100%**

Table 05: Sample breakdown – financial status

Additional equality monitoring information collected is available in the Appendix.

Survey findings

Notes on analysis

Percentages have been rounded to the nearest whole number; for this reason, responses to questions may not add up to 100% (i.e., 99 or 101%).

For all open questions in this survey, each response was assigned a code. In many cases, it was necessary to assign more than one code. These codes were then grouped to create themes, which are shown within the tables.

Further analysis was undertaken of closed questions by sex, age group, sub-region, ethnicity and financial status. Where differences were apparent, these are discussed.

Question responses

Question: How happy do you feel about an approved and authorised NHS organisation having access to your identifiable health record, including medical information, and then removing all your identifiable details, such as your name, address and NHS number?

Respondents were asked on a scale of 1 – 10[1], how they would feel about an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details, to which two thirds (66%) would be happy (40% very happy and 26% happy), whilst 15% would not be happy (5% not happy and 10% not happy at all).

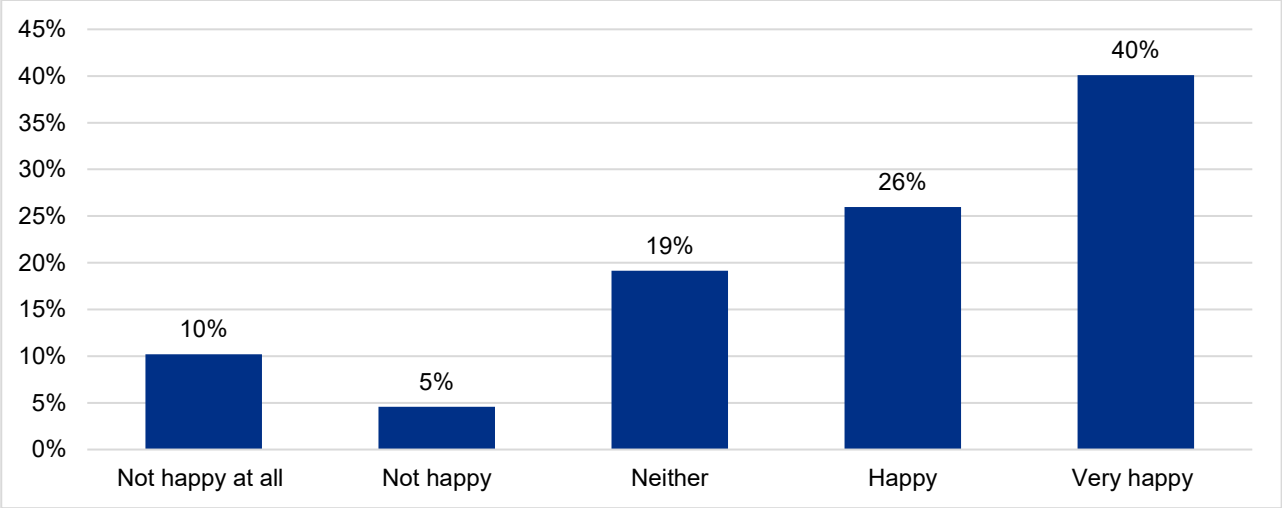


Figure 01: How respondents would feel about an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details (N=893)

Sub-group analysis revealed the following differences:

[1] Using a ten-point scale ranging from 1-10: Not at all happy: 1-2, Not happy 3-4, Neither happy nor not happy: 5-6, Happy: 7-8, Very happy: 9-10

- Those from ethnic minority groups were more likely to be happy, compared to those from White / other White backgrounds (74% vs 64%, respectively).
- Similar proportions stated being happy in all sub-regions (range 63-71%), with the exception being the City of York, where satisfaction was lowest (59%).

Question: Please tell us why you feel this way

Respondents were asked to provide a reason for their response; 530 individuals provided a response that was coded.

Many respondents were happy with what was being proposed and/or could see the benefit of doing so, and felt it was for a good reason. Benefits included helping others and future generations, saving lives, supporting medicine/treatment developments, and improving the NHS more generally.

"If it supports research and development for health care then it is a positive."

"Because that's how we get progress and drive things forward."

Whilst some felt confident that their personal records would be anonymised and/or were safe, others added a caveat, wanting additional assurance/guarantee that their records would be anonymised, secure, and used properly and for the right reasons.

"As long as no one gets hold of your information."

"As long as they are not sharing too much personal information like your full NHS record, then yes."

"I feel happy if we are guaranteed safety"

For those with concerns, these primarily related to data security - specifically hacking / data breaches and information getting into the wrong hands, privacy - with some not wanting their personal records to be shared, and data access and use – specifically concerns about who will be accessing the data and for what purpose. Others simply stated that they were not happy and/or did not trust or have confidence.

"I can never have 100% trust in anything with cyber attacks."

"Don't trust to be anonymous - breaches – hacking"

"A bit nervous when it's not my doctor and I don't know who they are."

Comments categorised as neutral included those who were unsure/unable to provide a reason, those who did not know enough and needed more information and those who were not bothered/interested.

"Having a bit more information about it"

"Don't really know much about it all"

Positive	No. of comments
Happy / no problem/trust	104
Beneficial / for a good reason	89
Caveat - as long as anonymous / used properly and for the right reasons / kept secure	53
Records are anonymous and safe	47
Positive comment about the NHS	10
Other positive comments	10
Happy with the way it is now / records already being shared	5
Negative	**No. of comments**
Concerns about data security	32
Privacy concerns / don't want to share personal records	31
Concern about data access and use	22
Other negative comments	21
No trust/confidence or not happy	17
Negative comment about the NHS	7
Not necessary	5
Scepticism	4
Lack of control / NHS already have data	4
Neutral	**No. of comments**
Not sure	49
Don't know enough / need more information	17
Not bothered or interested	20

Table 06: Please tell us why you feel this way - free text responses (N=530)

Sharing health records for research purposes

Question: How happy would you be to share your health record via the Secure Data Environment for research such as developing new treatments and drugs or improving local health services?

72% would be happy to share their health record via the SDE for research purposes (40% very happy and 32% happy), whilst 14% would not be happy (4% not happy and 10% not happy at all).

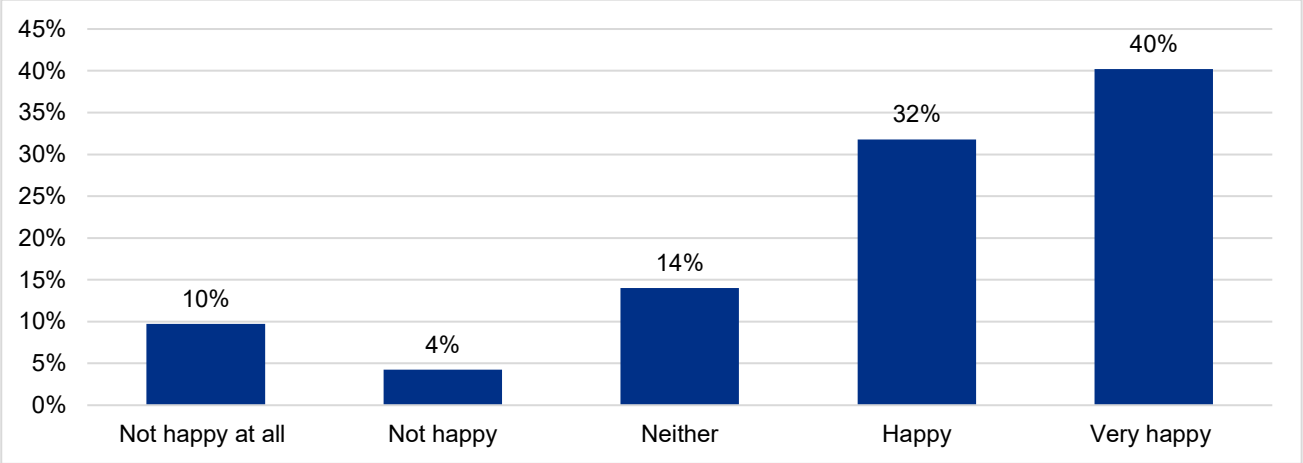


Figure 02: How respondents feel about sharing their health record via the SDE for research purposes (N=893)

Sub-group analysis revealed the following differences:

- Those aged 50-64 and 65-74 years had the greatest concerns about data sharing for this purpose (16% and 21% not happy, respectively) compared to all other age groups (range 8% - 13%).
- Satisfaction was greatest among those who are more financially stable, with the greatest proportion of those who 'struggle to make ends meet' saying that they are not happy at all (17%).
- Satisfaction was slightly higher amongst those residing within the East Riding of Yorkshire and North East Lincolnshire (75% and 77%, respectively), compared to all other sub-regions (range 69% - 70%). Satisfaction was lowest in the City of York, with 69% happy about data sharing for research purposes.

Question: Please tell us why you feel this way

Respondents were asked to give a reason for their choice; 494 individuals provided a response that was coded.

Most respondents indicated that they did not have a problem with their records being shared for research purposes and/or could see the benefit of doing so. Benefits identified included helping people and future generations, saving lives, supporting advancements in medication/treatment, and more generally, to help research.

"If it's not done, how will research be carried out?"

"I do research myself, so it's always helpful to get new information."

Again, whilst some felt confident that their personal records would be anonymised and/or were safe, others added a caveat wanting additional assurance/guarantee that their records would be anonymised, secure, and used properly and for the right reasons.

In terms of concerns, these primarily related to privacy, with some not wanting to share their personal records, data security – specifically concerns about hacking, breaches, and information getting into the wrong hands, data access and use, and more generally a lack of trust and confidence.

"Always have some reservations about where / why data is going"

Comments categorised as neutral included those who were unable to provide a reason, those who did not fully understand and required more information, and those who were not particularly bothered.

Positive	**No. of comments**
Beneficial / for a good reason	212
Happy / no problem/trust	97
Caveat - as long as anonymous / used properly and for the right reasons / kept secure	25
Other positive comments	15
Positive comment about the NHS	10
Records are anonymous and safe	10
Happy with the way it is now / records already being shared	2
Negative	**No. of comments**
Privacy concerns / don't want to share personal records	28
Concerns about data security	23
Concern about data access and use	17
Other negative comments	13
No trust/confidence or not happy	16
Not necessary / use what you already have	3
Scepticism	3
Lack of control / NHS already has data	2
Neutral	**No. of comments**
Not sure	19
Don't know enough / need more information	12
Not bothered or interested	2

Table 07: Please tell us why you feel this way - free text responses (N=494)

Question: How happy would you be to share your health record via the Secure Data Environment with the following organisations for research purposes[2]?

Respondents were happiest about sharing their health record for research purposes with their doctor, hospital or other medical professional looking after them (84% very happy/happy). High satisfaction was also found for NHS teaching hospitals (74%).

Similar satisfaction was found for universities, care agencies and pharmacies, with between a half and two-thirds happy to share their records for research purposes (66%, 60% and 53%, respectively).

Respondents were most concerned about sharing their health record for research purposes with charities and local councils, with less than half happy to do this (41% and 39%, respectively).

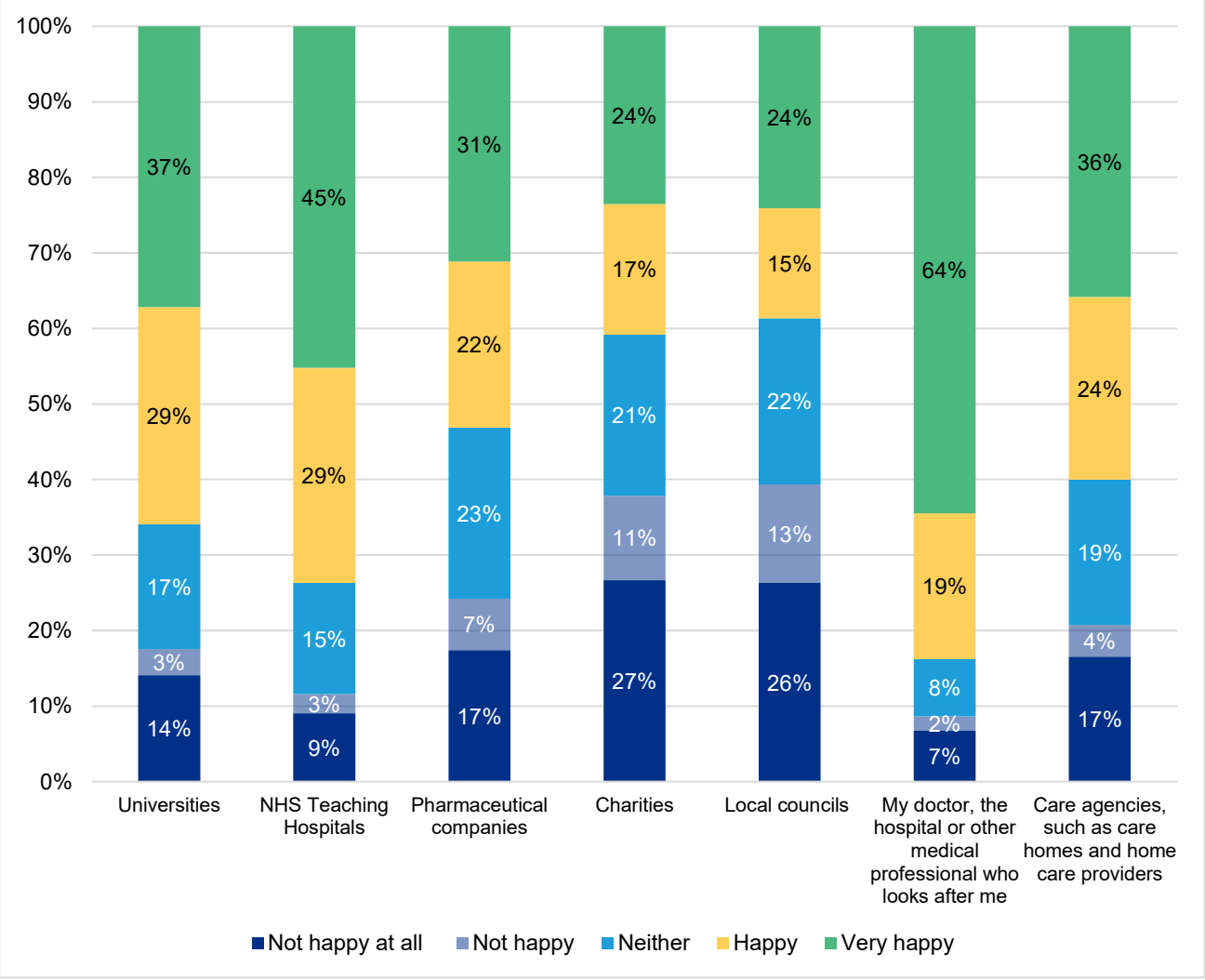


Figure 03: Sharing of health records with organisations for research purposes (N=901)

[2] Using a ten-point scale ranging from 1-10: Not at all happy: 1-2, Not happy 3-4, Neither happy nor not happy: 5-6, Happy: 7-8, Very happy: 9-10

Sharing health records for non-research purposes

Question: How happy would you be to share your health record via the Secure Data Environment for non-research purposes, such as understanding regional health trends to manage and improve services? This might include how it responds to an increase in flu or to help emergency services respond better when and where they are needed?[3]

56% would be happy (30% very happy and 26% happy) to share their health record via the SDE for non-research purposes. This is a lower proportion than those who would be happy to share their health record for research purposes (72%).

In contrast, 25% would not be happy (6% not happy and 19% not happy at all). Again, this is higher than those who would not be happy to share their health record for research purposes (14%).

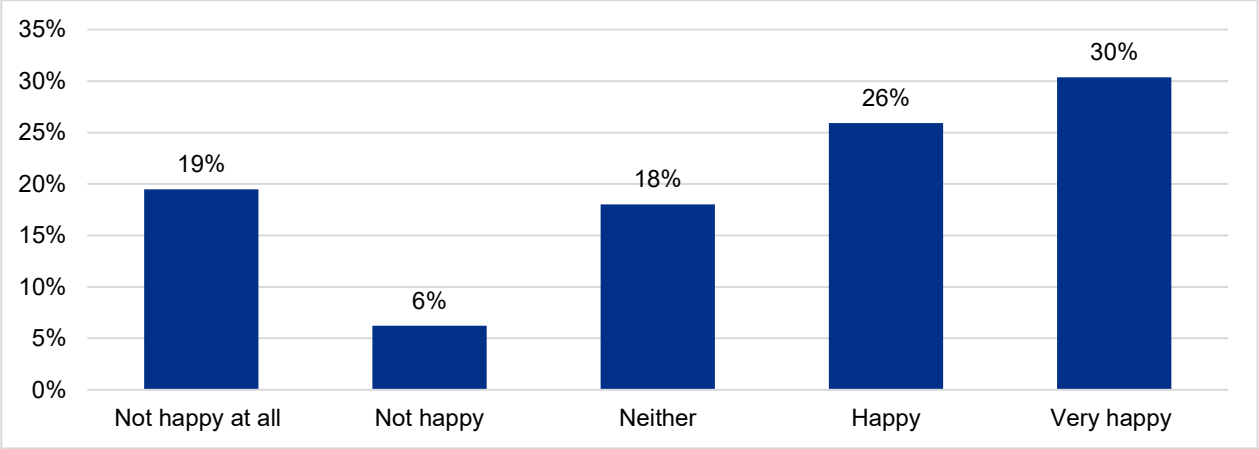


Figure 04: How respondents feel about sharing their health record via the SDE for non-research purposes (N=899)

Sub-group analysis revealed the following differences:

- Those aged 50-64 and 65-74 years had the greatest concerns about data sharing for this purpose (32% and 28% not happy, respectively) compared to all other age groups (range 20% - 25%).
- Those from ethnic minority groups were more likely to be happy, compared to those from White / White other backgrounds (67% vs 55%, respectively).
- Satisfaction was higher amongst those residing within North and North East Lincolnshire (67% and 66%, respectively), compared to all other sub-regions (range 50 - 57%). Satisfaction was lowest in West Yorkshire, with 50% happy about sharing their health records for non-research purposes.

[3] Using a ten-point scale ranging from 1-10: Not at all happy: 1-2, Not happy 3-4, Neither happy nor not happy: 5-6, Happy: 7-8, Very happy: 9-10

Question: Please tell us why you feel this way

Respondents were asked to give a reason for their choice; 469 individuals provided a response that was coded.

In support of health records being used for non-research purposes, respondents most frequently indicated that they did not have a problem and/or could see the benefit of doing so. However, the number commenting on each of these themes was lower than for research purposes.

"They need this information in order to roll out"

"Research is good and brings better treatments."

Compared to research purposes, similar concerns and objections were raised, including issues around privacy and reluctance to share personal records, lack of trust and confidence, and worries about how data is accessed, used, and secured.

The exception to this was feeling that data sharing for non-research purposes isn't as important as sharing for research purposes. Respondents felt the purpose was undefined/broad and deemed it to be unnecessary, with some sceptical about who would have access and for what purpose.

"Not a good enough reason, what else would they use it for?"

"If it isn't for better treatment, no need."

"No need for non-research purpose"

Positive	No. of comments
Beneficial / for a good reason	137
Happy / no problem/trust	43
Caveat - as long as anonymous / used properly and for the right reasons / kept secure	21
Other positive comments	6
Positive comment about the NHS	5
Records are anonymous and safe	9
Happy with the way it is now / records already being shared	2
Negative	**No. of comments**
Unnecessary/undefined / not as important as for research purposes	88
Privacy concerns / don't want to share personal records	37
No trust/confidence or not happy	32
Concern about data access and use	23
Concerns about data security	17
Other negative comments	8
Scepticism	4
Neutral	**No. of comments**
Not sure	31
Don't know enough / need more information	11
Not bothered or interested	8

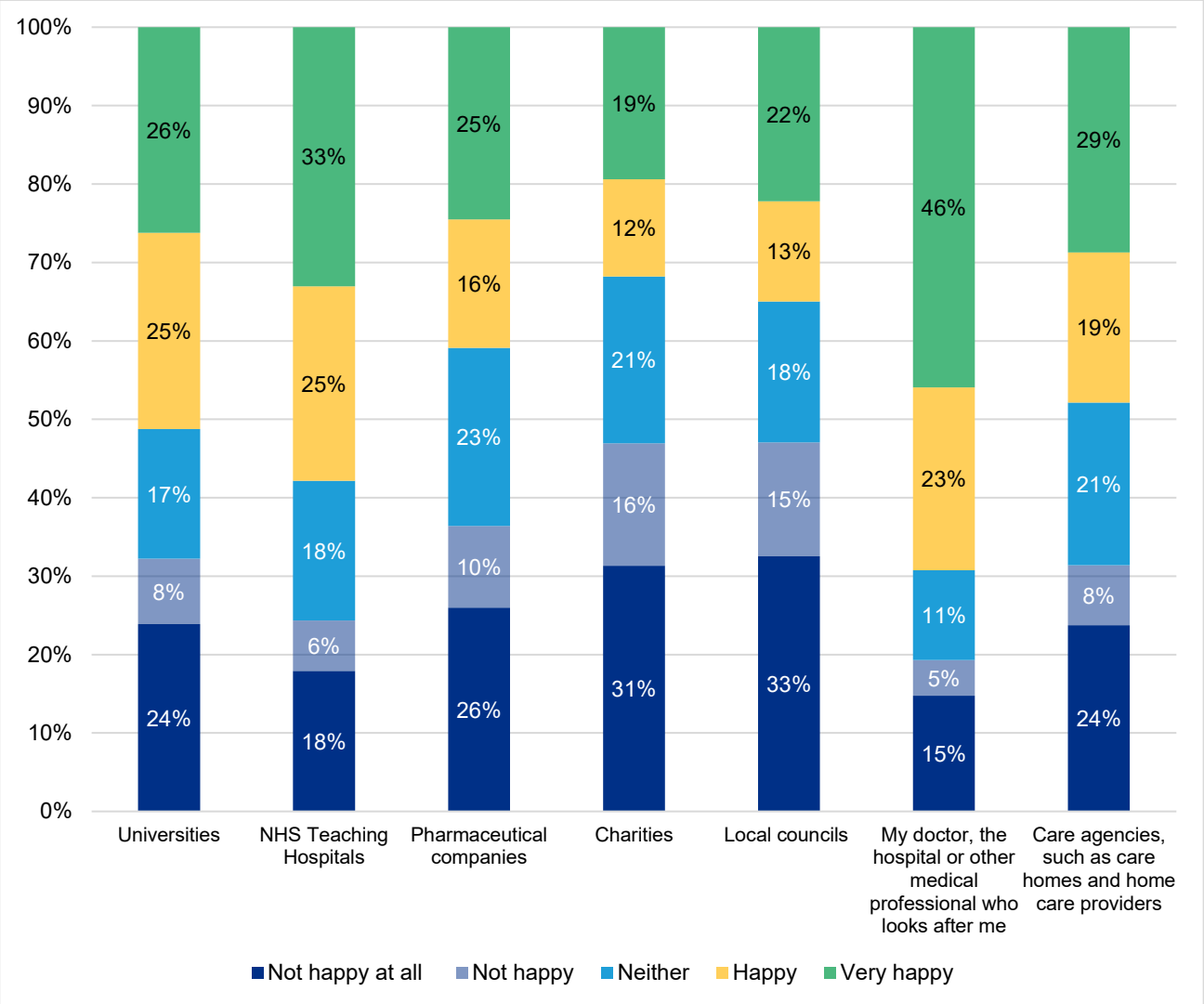
Table 08: Please tell us why you feel this way - free text responses (N=469)

Question: How happy would you be to share your health record via the Secure Data Environment with the following organisations for non-research purposes[4]?

For each of the organisations, respondents are less happy about sharing their health record for non-research purposes compared to research purposes. The biggest differences were observed for NHS Teaching hospitals, universities, and respondents' doctors, local hospitals, or other medical professionals who look after them, with approximately a 15% drop in satisfaction.

For non-research purposes, respondents are happiest about sharing their records with their doctor, hospital, or other medical professional (69%) and NHS Teaching Hospitals (58%).

Satisfaction was similar for sharing with universities and care agencies (51% and 48%, respectively) and lowest for charities, local councils, and pharmaceutical companies, with approximately a third happy to share their records for this purpose (32%, 35% and 42%, respectively).



[4] Using a ten-point scale ranging from 1-10: Not at all happy: 1-2, Not happy 3-4, Neither happy nor not happy: 5-6, Happy: 7-8, Very happy: 9-10

Figure 05: Sharing of health records with organisations for non-research purposes (N=901)

Risks of sharing health records

Question: Do you think there are risks to people sharing their health records via the Secure Data Environment for both research and non-research purposes[5]?

29% feel there are risks to people sharing their health record via the SDE for both research and non-research purposes, whilst 31% feel there are to some extent. In contrast, 20% feel there are no risks.

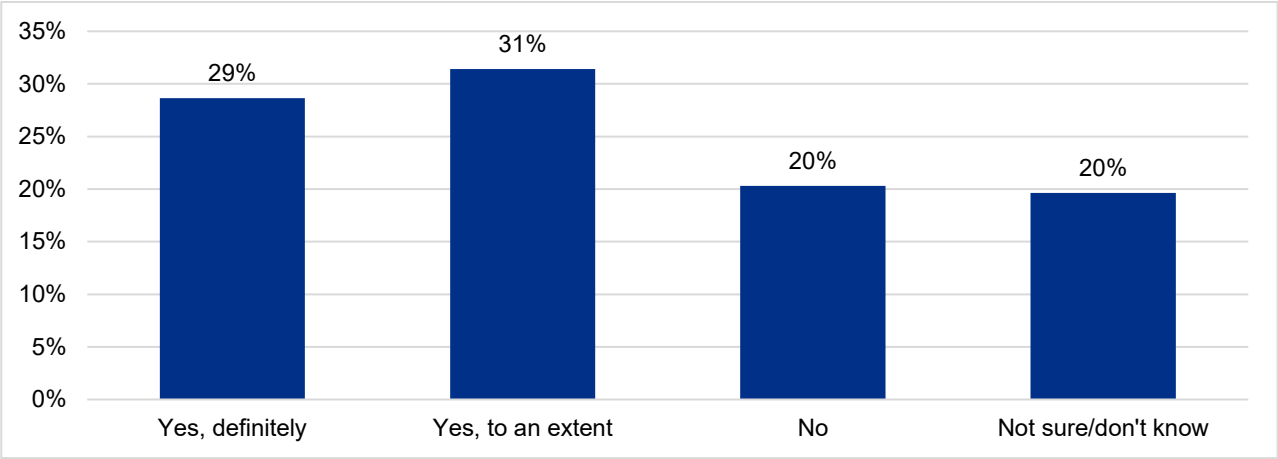


Figure 06: Whether respondents feel there are any risks to sharing their health record via the SDE for both research and non-research purposes (N=901)

Sub-group analysis revealed the following differences:

- Greater concerns amongst those aged 50-64 years (64%) compared to all other age groups (range 56 – 61%).
- Greater concerns among those who are more financially stable (70% vs 55-60% for all other groups).
- Similar level of concerns across all sub-regions (range 59-67%), with a slightly lower proportion of respondents from South Yorkshire perceiving that there is a risk (53%) and more respondents likely to be unsure.

[5] Using a ten-point scale ranging from 1-10: Not at all happy: 1-2, Not happy 3-4, Neither happy nor not happy: 5-6, Happy: 7-8, Very happy: 9-10

Question: If you have concerns, please tell us what they are…

Respondents were asked to tell us about their concerns; 442 individuals responded to the question.

Most revealed a concern relating to the security of their personal data and information getting into the wrong hands through data leaks/hacks/breaches. Some felt that this may lead to their personal information being identified.

Others perceive that there are always risks to data sharing and that mistakes can happen.

"Doesn't take a hacker to break into stuff"

"People could get into it, or students not using it right. Needs to be Confidential. People don't take their job seriously."

To a lesser extent, respondents talked about their concerns about their data being misused and/or exploited for profit, including uncertainty about who and how many people would be accessing their data, whilst others noted their lack of trust more generally in online systems and data sharing.

"Don't trust any more big companies anymore"

"It's making money off me."

A smaller number stressed how they do not want their health records to be shared at all and how this is a personal choice, and others stressed how they require more information to be able to make an informed decision.

"Don't like anything sharing other than with the doctor, private person"

"I'd need to know more about who it's going to"

Concerns	No. of comments
Security and information getting into the wrong hands through data hacks/leaks/breaches	170
Always a risk/mistakes can happen	80
None (as long as anonymous, secure and well managed)	54
Data access and misuse	44
Lack / no trust	27
Other concern or comment	26
Personal preference	23
Depends if monitored properly / it helps (caveat)	22
Don't know enough / need more information	10

Table 09: Concerns – free text responses (N=442)

Question: Which of the following statements applies to you…?

Respondents were asked if they would be happy for their GP / other health service to share their health record, or if they would prefer to manage this themselves.

Half (49%) would prefer to approve the sharing of their health record themselves, whilst a third (37%) would be happy for their GP / other health service to share their health record directly into the SDE. One in ten (9%) 9% do not want their health record to be shared at all.

	%
I would be happy for my GP / other health services to share my health record	37%
I would prefer to approve the sharing of my personal health record myself	49%
I would not be happy to share my health record at all	9%
Not sure / don't know	5%

Table 10: Whether respondents are happy for their GP / other health service to share their health record or whether they would prefer to manage this process themselves (N=901)

Sub-group analysis revealed the following differences:

- With increasing age, respondents would be happier for their GP / other health service to share their health record on their behalf (24% of those aged 16-24 years compared to 46% of those aged 75+ years).
- Respondents from ethnic minority groups would be happier for their GP / other health service to share their health record on their behalf, compared to White / other White respondents (48% and 36%, respectively).
- Those who are less financially stable were most likely to indicate that they did not want their health records to be shared at all (15%, compared to 5-6% of all other groups).
- There was a much greater preference for respondents from the City of York to share their health records themselves (61%), compared to all other sub-regions (range 38 – 55%).

Question: Do you trust that your anonymised health record would only be used for the reasons described in the Secure Data Environment only[6]?

Approximately two-thirds (60%) completely trust or trust that their anonymised health record would be used for the described reasons of the SDE only. Furthermore, 18% neither trust nor don't trust, whilst 20% have little or no trust at all.

[6] Using a ten-point scale ranging from 1-10: No trust at all: 1-2, Little trust: 3-4, Neither trust nor don't trust: 5-6, Trust: 7-8, Completely trust: 9-10

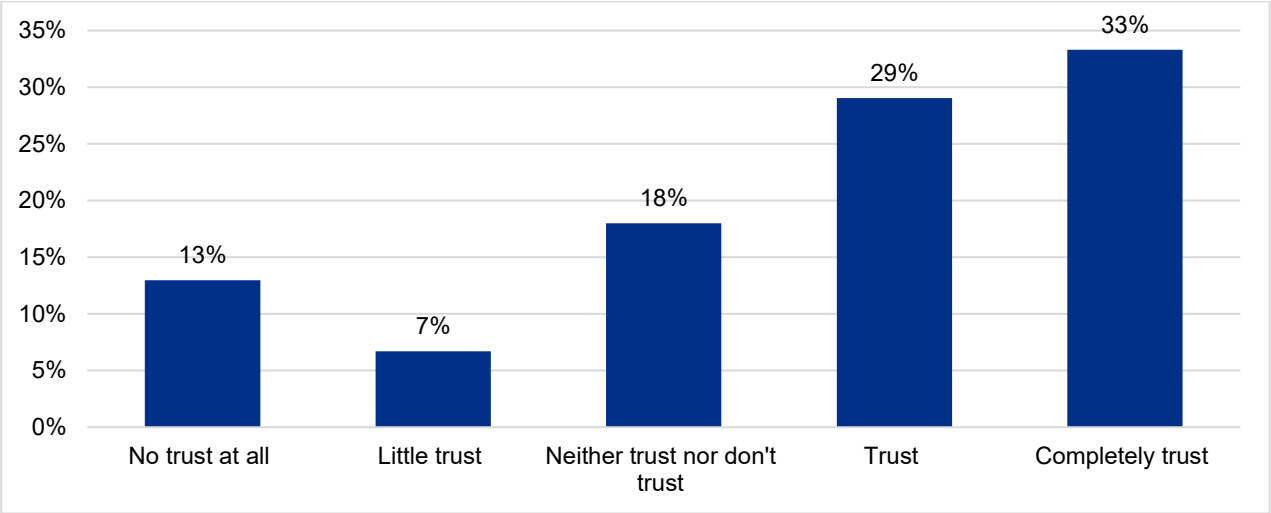


Figure 07: Whether respondents trust how their anonymised health record will be used in the SDE (N=895)

Sub-group analysis revealed the following differences:

- Trust was notably lower in West Yorkshire (54%), compared to all other sub-regions (range 62 – 70%).

Question: Is there anything else you would like to add?

Respondents were given the opportunity to provide any additional comments they had; 165 individuals provided a response.

Most were happy and/or recognised the benefits that sharing health records in the SDE would have.

Concerns or comments made by others related to:

- Concern about data security - specifically hacking, leaks and cyber attacks leading to information getting into the wrong hands and the implications this can have on individuals. There was a call for stringent data management principles to ensure the system is fully secure, that only trusted and approved users have access, and that it is used as it is supposed to be.
- Not sure / not interested – these individuals were unsure as to how they felt about the SDE, and/or were not bothered.
- Lack of, or no trust – where specified respondents expressed their distrust for online services and government and NHS organisations.
- Don’t know enough / want to know more – respondents wanted more transparency, wanting to know who will have access to the data and for what purpose.
- Don’t want my records shared – these respondents do not want their data to be shared in the SDE, even if all their identifiable information was removed.
- Lack of control / NHS will do what they want – there was a feeling among a few that individuals have no control in this situation, and the NHS will ‘do what they want anyway’.

- Data access and use – these individuals queried what organisations will have access to the SDE and for what purpose (i.e. local councils). There were concerns about data being used for profit.

Additional comments	No. of comments
Sounds good/beneficial	58
Concern about data security / stringent data management needed	24
Not sure / never thought about it / not interested	19
Lack of / no trust	18
Don't know enough / want to know more	14
Other comment	13
Don't want my records shared	12
Lack of control / NHS will do what they want	8
Concerns about data access and use	6

Table 11: Additional comments – free text responses (N=165)

Summary of findings

The survey sought the opinion of individuals residing across the Yorkshire and Humber SDE region with regard to perceptions of the SDE and sharing health records for research and non-research purposes.

In terms of general willingness to share data -

- 66% would be happy for an approved NHS organisation to access their identifiable health record and then remove all identifiable details.
- 72% would be happy to share their health record via the SDE for research purposes and 56% for non-research purposes. Perceived benefits include helping others and future generations, saving lives, supporting medicine/treatment developments, and improving the NHS more generally.
- The discrepancy in satisfaction with sharing for research and non-research is likely explained by the proportion of people who feel that non-research purposes are too broad and not well defined, with concerns about the necessity of this.
- For both purposes, respondents were happier about data sharing with their doctor, hospital, or other medical professional looking after them and with NHS Teaching Hospitals. They had greater concerns about sharing with charities and local councils, and for non-research purposes pharmaceutical companies.

In terms of trust and control -

- 49% would prefer to approve sharing of their health record themselves, whilst 37% would be happy for their GP/health service to share their record directly.
- 60% trust that their anonymised health record would only be used for the described reasons of the SDE, 20% have little or no trust.

In terms of risks and concerns -

- 29% feel there are risks to sharing health records via the SDE, whilst 31% feel there are to some extent. Main concerns related to:
    - Data security (leaks, hacks, breaches) and information getting into the wrong hands – there was acknowledgement that there are always risks to data sharing and that mistakes can happen and concern about the implications that this can have on individuals.
    - Data access and use – there were concerns about who would be accessing the data and for what purpose, with concerns about potential misuse and exploitation for profit.
    - Lack of trust and confidence – some respondents lacked trust and confidence in online systems and with government and NHS organisations.
    - Privacy – some feel strongly that sharing health records via the SDE is a personal choice and would prefer not to share their health records (9% said they did not want their health records shared at all).

Respondents repeatedly sought assurances that their records would be anonymised, that the SDE would be fully secure and that it would be used properly and for the right reasons. This was the case even among some of those who were happy to share their health records for research and non-research purposes. More information and greater transparency would also help people to understand the SDE better and to make more informed choices about the sharing of their health records.

Some sub-group differences were evident and are summarised here -

Older respondents (50-74 years)	● More likely to have concerns about data sharing for both research and non-research purposes (16–21% not happy for research; 28–32% not happy for non-research). ● With increasing age, more likely to be happy for their GP/health service to share their record on their behalf (24% of 16–24s vs. 46% of 75+).
Ethnic minority groups	● More likely to be happy with NHS access to their records after anonymisation (74% vs. 64% for White/other White). ● More likely to be happy to share for non-research purposes (67% vs. 55% for White/other White). ● More likely to be happy for their GP/health service to share their record on their behalf (48% vs. 36%).
Financial status	● Financially stable respondents showed higher satisfaction with data sharing for research purposes, although had the greatest concerns about the risks associated with sharing data (70% vs. 55–60% for other groups). ● Those struggling financially were more likely to be unhappy about sharing for research (17% “not happy at all”) and more likely not to want their records to be shared at all (15% vs. 5–6% for other groups).
Region	City of York ● Lowest satisfaction with NHS access to records after anonymisation and with sharing for research and non-research purposes. ● Highest preference for individuals to manage sharing themselves (61% vs. 38–55% elsewhere). West Yorkshire ● Lowest trust in how anonymised records would be used (54% vs. 62–70% elsewhere). ● Lowest satisfaction with sharing for non-research purposes (50%).

	North and North East Lincolnshire • Highest satisfaction with sharing for non-research purposes (67% and 66%).

Appendix

Additional equality monitoring information collected

		No.	%
Legal marital or registered civil partnership status	Married	360	40%
	Never married or in a civil partnership	342	38%
	Divorced	71	8%
	Widowed	43	5%
	In a legally registered civil partnership	18	2%
	Separated but still legally married	5	1%
	Separated but still legally in a civil partnership	4	0%
	Formerly in a civil partnership, which is now legally dissolved	1	0%
	Surviving partner from a civil partnership	7	1%
	Unknown	50	6%
Religion	No religion or belief	510	57%
	Christian (including Church of England, Catholic, Protestant, and other Christian denominations)	292	32%
	Buddhist	1	0%
	Muslim	48	5%
	Hindu	7	1%
	Other	6	1%
	Sikh	0	0%
	Jewish	2	0%
	Unknown	35	4%
Sexual orientation	Straight or Heterosexual	840	93%
	Bi or bisexual	11	1%
	Gay or lesbian	8	1%
	Prefer to self-describe	0	0%
	Unknown	42	5%
Health status (shown as a proportion of total sample)	Long-term health condition	122	14%
	Physical impairment or mobility issues	46	5%
	Sensory impairment	6	1%
	Mental health condition	31	3%
	Learning disability	11	1%
	Neurodivergence	13	1%
	No condition or impairment	659	73%
	Yes	21	2%

Pregnant or have been in the last six months	No	846	94%
	Unknown	34	4%
Gender identity match sex registered at birth	Yes	874	97%
	No	5	1%
	Unknown	22	2%
Ethnic group	Bangladeshi	5	1%
	Chinese	5	1%
	Indian	10	1%
	Pakistani	31	3%
	Any other Asian background	12	1%
	African	33	4%
	Caribbean	3	0%
	Any other black, black British, African or Caribbean background	0	0%
	White and black African	10	1%
	White and Asian	3	0%
	White and black Caribbean	4	0%
	Any other mixed or multiple ethnic background	4	0%
	English, Welsh, Scottish, Northern Irish or British	728	81%
	Irish	7	1%
	Gypsy or Irish Traveller	0	0%
	Roma	5	1%
	Any other white background	12	1%
	Arab	2	0%
	Other	4	0%
	Unknown	23	3%