

# **NENC SDE**

# **Local population street survey**

# **Findings report**

**October 2024**

Study title: North East North Cumbria Secure Data Environment  
CAG reference: 24/CAG/0080  
IRAS project ID: 341429

<b>Document filename: Report template</b>			
Programme:	Sub National Secure Data Environment – NENC ICB		
Document Ref:	NENC SDE Patient Evaluation Group application review process/cycle		
Programme Director:	Mark Walsh	Status:	Draft
Document Owner:	Caroline Latta	Version:	0.1
Author:	Jenny Harvey	Version issue date:	10/10/2024

## Document Management

### Revision history

Version	Date	Summary of changes

### Reviewers

This document has been reviewed by the following people:

Reviewer name	Title/responsibility	Date	Version
Caroline Latta	Director, Stand	11/10/24	0.1
Helen Gray	Associate, Stand	11/10/24	0.1
SDE Programme board	All group members invited to review and comment	9/11/24	0.1

### Approved by

This document must be approved by the following people:

Name	Signature	Title	Date	Version
Caroline Latta		Director, Stand	11/11/24	0.1
SDE Programme board		Members	9/11/24	0.1

### Related documents

Title	Owner	Location

### Document control

The controlled copy of this document is maintained by the SNSDE NENC programme. Any copies of this document held outside of that area, in whatever format (e.g. paper, email attachment), are considered to have passed out of control and should be checked for currency and validity.

Contents

**Executive summary ..... 3**

    Introduction..... 3

    Key findings..... 3

    Next steps ..... 5

**Introduction ..... 5**

**Methodology..... 6**

**Analysis of the street survey ..... 9**

    Notes on analysis ..... 9

**Question responses..... 9**

**Sharing health records for research purposes ..... 13**

**Sharing health records for non-research purposes ..... 19**

**Risks of sharing health records ..... 24**

**Discussion of findings..... 31**

Appendix..... 35

**Respondent demographics..... 35**

Executive summary

**Introduction**

A street survey was undertaken to explore perception of the Secure Data Environment (SDE) programme – a secure data and analysis platform which allows approved researchers with approved projects secure access to NHS data. 1,149 individuals from across North East and North Cumbria participated in the survey during the months of August to September 2024. The sample was population representative based on age, sex and ethnic group. An equal number of individuals responded from each NENC area.

**Key findings**

The majority (79%) would be very happy or happy about an approved and authorised NHS organisation having access to their identifiable health record and removing all their identifiable details, whilst 8% would not be happy.

Respondents have greater satisfaction about sharing their health record via the SDE for research purposes than non-research purposes, however two thirds still support data sharing for non-research purposes (78% & 67% very happy or happy, respectively). Members of the public are happiest about sharing their health record for research and non-research purposes with their doctor, hospital or other medical professionals looking after them, NHS teaching hospitals and universities. Greatest concern surrounds sharing their health record with charities, for both research and non-research purposes with just over half (55%) very happy / happy to do this for research purposes and 42% for non-research purposes.

16% feel there are definitely risks to people sharing their health record via the SDE for both research and non-research purposes, whilst 37% feel there are to some extent. Respondents are most concerned about the security of their personal data and information getting into the wrong hands through data leaks / hacks / breaches, which may lead to personal information becoming identifiable. It is felt that there is always an element of risk with data sharing and recognise that mistakes can happen. Other concerns relate to data being misused and/or exploited for profit, uncertainty about who and how many people would be accessing their data and lack of, or not trust in online systems / data sharing more generally.

Respondents identified how sharing their health record for research purposes would lead to greater understanding and improvements in medication / drugs, treatment and care, healthcare services and facilities, and health (29%). Others highlighted how it would 'help' in general as well as specifically for current and future generations (21%), and how having more data / access to health record would enable a greater knowledge base and therefore better research (8%).

In terms of data sharing for non-research purposes, respondents recognised that this would enable a greater understanding of current and future needs to support service planning and management, and help improve the delivery and quality of healthcare services (24%). A slightly smaller proportion (19%) talked about how it would 'help' in general as well as specifically for current and future generations, whilst 8% talked about how sharing their data record would lead to developments and improvements in medicine, treatment and care, and health. Compared to the same question asked about research purposes, slightly more respondents reported being unsure or were not able to give a reason (14%) or felt that there would be no benefits (5%). Others added caveats highlighting the importance of consent and anonymity, security of the system, context of usage and that it is actually of benefit. Specially, 3% felt that sharing their health record for non-research purposes is less important than doing so for research purposes.

Just over half (57%) would be happy for their GP / other health service to share their health record directly in to the SDE, whilst 32% would prefer to approve the sharing of their health record themselves and 6% do not want their health record to be shared at all.

Approximately two thirds (69%) completely trust or trust that their anonymised health record would be used for the described reasons of the SDE only, whilst 11% have little or no trust.

The findings suggest that some demographic groups do have more negative views and reservations about data sharing than others, particularly younger age groups (under 44 years), those from ethnic minority groups and those who are less financially stable / struggling to make ends meet.

Some differences by area were also observed with respondents from Cumbria and Northumberland happier about sharing the health record via the SDE for both research and non-research purposes. In contrast, those living in Teesside, Durham and Newcastle were less happy about doing so, with those from Durham and Newcastle having greater concerns about the risks involved and less trust that their health record would be shared for the described purposes of the SDE only.

## Next steps

The results from the survey will be used by the SDE programme steering group to respond to queries raised by the Confidentiality Advisory Group (CAG) with regard to whether patients, service users or members of the public have been asked about the acceptability of processing identifiable patient data without consent to create anonymised and pseudonymised data sets. They will also be used to inform future communication and engagement activities with members of the public.

## Introduction

The report provides an overview of the findings from the street survey conducted in August to September 2024 exploring perception of the Secure Data Environment (SDE). Specifically, the survey focused on understanding opinion about sharing of data records for research and non-research purposes via the SDE.

The survey builds upon the findings of an initial street survey conducted in February 2024 with 405 individuals from across North East and North Cumbria.

Key findings from the Feb 2024 street survey:

- The SDE was received positively with 84% very happy or happy to share their anonymous health records in the SDE, with most perceiving that it would be helpful and/or beneficial. For some however, their happiness was dependent upon their data being anonymous and the SDE being secure. Conversely, 9% were not happy about their records being shared.
- Respondents expressed higher satisfaction towards sharing their anonymous health records data with personal doctors or hospitals (94% very happy / happy), NHS teaching hospitals (90% very happy / happy) and NHS organisations (89% very happy / happy). Although satisfaction levels were lower for universities, care agencies, pharmaceutical companies and local councils (79%, 75%, 74% & 71% very happy / happy, respectively), there was more support for this than objection. The lowest satisfaction was found for data sharing with charities with 61% very happy / happy.
- 81% would be happy for their GP / other health services to share their anonymous health records directly with the SDE. In contrast however, 13% would like to manage this process themselves, whilst 5% would not be happy to share their records at all.
- 85% completely trust / trust that their anonymised health records would be used for the described reasons of the SDE only, whilst 6.9% have little / no trust.
- Four out of five (81%) think there are definitely benefits to people sharing their health record to support research into new treatment, medicine and to prevent disease, with a further 9% perceiving there are to some extent. Participants

feel that an increased pool will more likely produce results and benefit the community.

- 12% feel there are definitely risks to people sharing their health record, whilst 27% think there are to some extent. Key concerns predominantly centred on the security of the SDE, with some highlighting the need for robust security measures and a few expressing a lack of trust in existing security measures.
- Dissatisfaction and distrust with sharing health records in the SDE was notably higher amongst those aged 35-44 years (19% were not happy to share their data and the same proportion do not trust that their data will be used for the described reasons of the SDE only). Their primary concerns relate to data security i.e., data falling into the wrong hands or potential data leaks. Furthermore, the majority who expressed uncertainty about trusting their health data to be used as described, as well as those uncertain about whether they already share their health data, were female, constituting two-thirds of each respective group.

Based on findings from the Feb 2024 street survey, along with other reports produced for the SDE programme team, a number of groups have been identified that may hold stronger views towards data sharing via the SDE. These groups are presented here and were a particular focus in the current engagement activity:

- 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 areas (particularly Morpeth, Cramlington, Hexham, Bellingham, Otterburn & Redesdale in Northumberland, and Rowlands Gill & Lockhaugh and Chopwell & High Spenn in Gateshead)
- Those who are well educated and affluent, and those who struggle to make ends meet.

## Methodology

Fieldwork was conducted from August to September 2024, engaging with 1,149 members of the public.

The survey was largely based upon the survey used in the Feb 2024 street survey, however some changes were made to respond to queries raised by the Confidentiality Advisory Group (CAG) specifically whether patients, service users or members of the public have been asked about the acceptability of processing identifiable patient data without consent to create anonymised and pseudonymised data sets.

To ensure robustness of the sample, a target of 1,050 individuals was set with quotas for age, gender and ethnicity with an equal distribution of respondents from all NENC areas. This allows an 8% margin of error at the 95% confidence level.

This means that if the research shows us that 52% of people would not be happy sharing their health record with a +/-8 percentage point margin of error at a desired confidence

level of 95%, the actual percentage of people in the overall population who would not be happy is between 44% and 60% 95 times out of 100.

To meet all quotas, surveys were conducted with a participant pool exceeding the target of 1,050. The subsequent tables define the quotas adhered to during the engagement and what was achieved based on age group, sex, ethnicity and locality.

*Note: Percentages are rounded to the nearest whole number so total percentages may not equate to 100%.*

**Table: Breakdown by age group**

	Total population		Street survey participants (N=1,149)	
	No.	%	No.	%
16 – 24	290,796	13%	164	14%
25 – 34	343,236	15%	191	17%
35 – 44	326,116	15%	168	15%
45 – 54	317,255	14%	150	13%
55 – 64	373,023	17%	150	13%
65 – 74	298,862	13%	151	13%
75+	269,154	12%	150	13%
Unknown	-	-	25	2%

**Table: Breakdown by gender**

	Total population		Street survey participants (N=1,149)	
	No.	%	No.	%
Male	1,323,251	49%	534	46%
Female	1,369,812	51%	592	52%
Non-binary	-	-	1	<1%
Prefer to self-describe	-	-	1	<1%
Unknown	-	-	21	2%

**Table: Breakdown by ethnicity**

	Total population		Street survey participants (N=1,149)	
	No.	%	No.	%
Asian / Asian British	98,048	3.7%	157	14%
Black / British Black	26,643	1.0%	204	18%

Mixed, multiple or other ethnic groups	36,129	1.4%	54	3%
White: British, European or other	2,462,717	92.9%	718*	62%
Unknown	-	-	16	1%

\*Identified as English, Welsh, Scottish, Northern Irish or British in the current survey.

**Table: Breakdown by area\*\***

	Street survey participants (N=1,149)	
	No.	%
Cumbria	153	13%
County Durham	152	13%
Gateshead ( <i>particular focus on rural areas of Rowlands Gill &amp; Lockhaugh and Chopwell &amp; High Spen</i> )	160	14%
Newcastle	155	13%
Northumberland ( <i>particular focus on rural areas such as Morpeth, Cramlington, Hexham, Bellingham, Otterburn &amp; Redesdale</i> )	151	13%
Sunderland	169	15%
Teesside	171	15%
Unknown	38	3%

\*\*Population sizes were not considered in the sampling, but instead an equal number of respondents from all areas was prioritised.

Financial status was not included within the quotas, however was included as a question in the equality and monitoring section of the survey. Similar proportions indicated that they have 'more than enough money for basic necessities and a little spare' (34%) and that they 'have just enough money for basic necessities and little else' (39%).

**Table: Breakdown by financial status**

	Street survey participants (N=1,149)	
	No.	%
I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure	100	9%
I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure	385	34%



I have just enough money for basic necessities and little else	445	39%
I don't have enough money for basic necessities and sometimes or often run out of money	77	7%
Prefer not to say / unknown	142	12%

Other equality and monitoring information collected is available within the Appendix.

## Analysis of the street survey

### Notes on analysis

Figures have been rounded to the nearest whole number, for this reason, total 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. Percentages are calculated as a proportion of those who provided a free text response. For these reasons, percentages will not equate to 100%.

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

Section 2.2 provides an overview of the responses to each of the questions, with a discussion of these in Section 3.

### 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?**

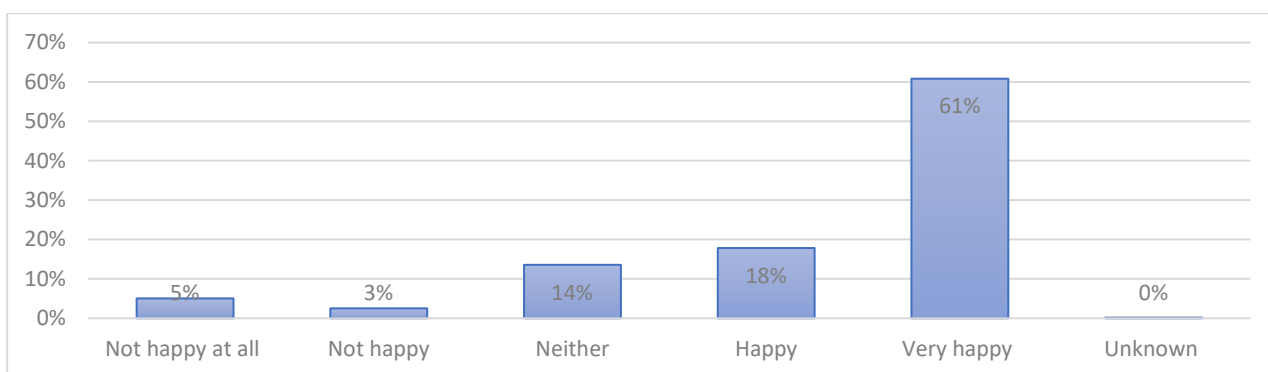
Respondents were asked on a scale of 1 – 10<sup>1</sup>, how they would feel about an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details.

Four in five (79%) would be happy (61% very happy and 18% happy), whilst 8% would not be happy (3% not happy and 5% not happy at all).

Figure: 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=1,149)

---

<sup>1</sup> 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



Sub-group analysis revealed the following differences:

- Satisfaction is greatest amongst those from Northumberland (85%), Cumbria (83%) and Gateshead (82%) and lowest amongst those from Teesside (74%) and Newcastle (73%).
- Satisfaction is greatest amongst those aged 45 to 54 years (85%) and lowest amongst those aged 35 to 44 years (72%).
- Satisfaction is greatest amongst those who identified as English, Welsh, Scottish, Northern Irish or British and Black / Black British (81% for each group), and lowest for those who identified as Asian / Asian British and mixed, multiple or another ethnic group (72% & 76%, respectively).
- Satisfaction is greatest amongst those who are more financially stable and lowest for those who struggle to make ends meet.

**Table:** 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 – by area

	Cumbria (N=153)	Durham (N=151)	Gateshead (N=160)	Newcastle (N=154)	Northumberland (N=151)	Sunderland (N=169)	Teesside (N=171)
Not happy / not happy at all	7%	9%	6%	8%	4%	9%	9%
Neither	10%	11%	12%	18%	11%	13%	17%
Happy / very happy	83%	79%	82%	73%	85%	78%	74%

**Table:** 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 – by age group

	16 to 24 (N=163)	25 to 34 (N=191)	35 to 44 (N=168)	45 to 54 (N=150)	55 to 64 (N=149)	65 to 74 (N=151)	75+ (N=150)
Not happy / not	7%	6%	9%	2%	9%	8%	11%

happy at all							
Neither	14%	13%	19%	13%	11%	15%	6%
Happy / very happy	79%	81%	72%	85%	81%	77%	83%

**Table:** 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 – by ethnic group

	Asian / Asian British (N=157)	Black / Black British (N=203)	English, Welsh, Scottish, Northern Irish or British (N=717)	Mixed, multiple or other ethnic groups (N=54)
Not happy / not happy at all	5%	7%	8%	9%
Neither	23%	12%	12%	15%
Happy / very happy	72%	81%	81%	76%

**Table:** 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 – by financial status

	I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure (N=99)	I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure (N=385)	I have just enough money for basic necessities and little else (N=445)	I don't have enough money for basic necessities and sometimes or often run out of money (N=76)
Not happy / not happy at all	2%	6%	7%	11%
Neither	10%	11%	12%	18%
Happy / very happy	88%	83%	80%	71%

## **Question: Please tell us why you feel this way**

Respondents were asked to tell us why they are happy or not happy about an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details; 793 individuals provided a response.

Positively, 20% recognised the benefits of this and its importance, whilst 17% felt it was 'good' or 'fine' and that they had no problem with it. Much smaller proportions trusted that the data will be secure (3%) and that there will be no harm in it, with their health record being anonymised (3%).

*“Cause I had cancer and giving them my data would help to improve treating this disease”*

*“Things will improve more info people have”*

*“Have no problem”*

Some added caveats to their response stating that they would be happy as long as their health record was anonymous (2%) and others that it was shared securely (1%). A few also added that it depended upon who their health record was shared with (<1%).

*“As long as identity removed don't mind as long as it helps”*

*“It depends who these individuals are. Are they part of the NHS, or are they drafted in as third party?”*

Notably, 4% felt that they don't know enough about how it will be shared and what it will be used for, and/or requested more information, whilst 11% were not sure or had not thought about it.

*“Seems good in theory, just don't know enough”*

*“Not sure for how long they will ask permission and ask for consent.”*

For those not happy, concerns related to privacy and not wanting to share their personal information with people other than their GP / healthcare services or private organisations (5%), concerns about the system and security (i.e. data breaches) (3%) and lack of, or no trust (2%).

*“I'd only be happy for my local dr to have access to my details and the local hospital too”*

*“Data is shared no matter what you do. Not safe anymore”*

*“Don't trust the online systems”*

*“A lot of stuff have been happening within the NHS, I don't trust them that much”*

**Table:** Please tell us why you feel this way - free text responses (N=793)

	No.	%
<b>Positive comments</b>		
Important / it helps / recognise benefits	155	20%
Good / no problem	131	17%
Trust that data will be secure / appears well monitored	26	3%
All anonymised / no harm in it	22	3%
As long as anonymised (caveat)	19	2%
Positive comment about NHS	7	1%
Nothing to hide / NHS has data already	7	1%
Understand how it works	4	1%
As long as shared securely (caveat)	10	1%
Depends who data shared with (caveat)	3	<1%
<b>Neutral comments</b>		
Comment uncoded*	202	25%
Not sure / not thought about it	86	11%
Don't know enough / more information required	28	4%
<b>Negative comments</b>		
Privacy concerns and not wanting to share personal details	37	5%
Concern about security / systems (i.e. data breach)	24	3%
Lack / no trust	13	2%
Other negative comment	20	3%

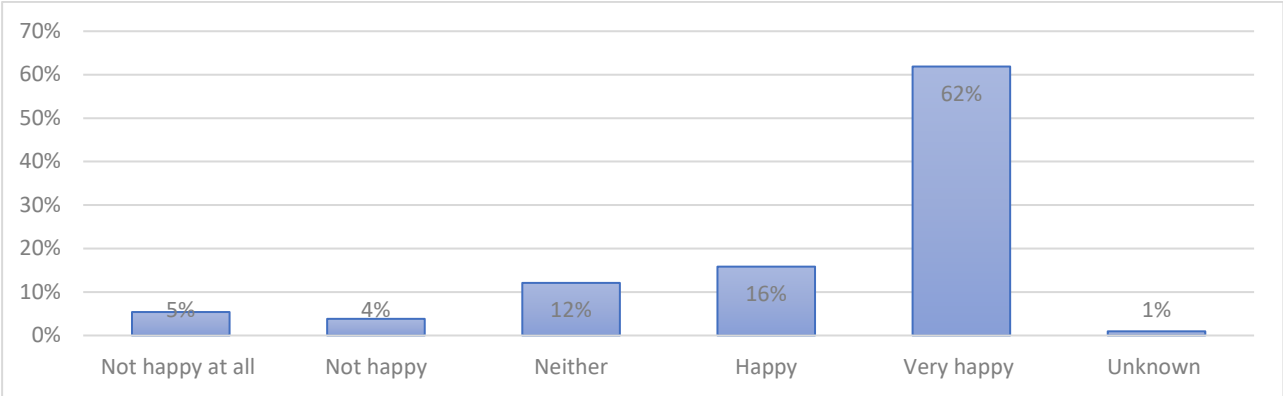
*\*169 respondents answered 'yes' to the question which could not be categorised as positive or negative.*

## 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?**

78% would be happy to share their health record via the SDE for research purposes (62% very happy and 16% happy), whilst 9% would not be happy (4% not happy and 5% not happy at all).

**Figure:** How respondents feel about sharing their health record via the SDE for research purposes (N=1,149)



Sub-group analysis revealed the following differences:

- Satisfaction is greatest amongst those from Cumbria (89%) and Northumberland (87%) and lowest for those from Durham (63%).
- Satisfaction is greater amongst those aged over 45 years, with the 45-to-54-year age group having the greatest satisfaction (85%). Satisfaction is lowest amongst those aged 25 to 34 (75%) and 35 to 44 years (72%).
- Satisfaction is greatest amongst those who identify as English, Welsh, Scottish, Northern Irish or British (81%) and Black / Black British (78%), and lowest for those who identify as Asian / Asian British (75%) and mixed, multiple or other ethnic groups (69%).
- Satisfaction is greatest amongst those who are more financially stable and lowest for those who struggle to make ends meet.

**Table:** How respondents feel about sharing their health record via the SDE for research purposes – by area

	Cumbria (N=152)	Durham (N=151)	Gateshead (N=159)	Newcastle (N=154)	Northumberland (N=147)	Sunderland (N=168)	Teesside (N=169)
Not happy / not happy at all	4%	19%	8%	10%	3%	13%	8%
Neither	7%	19%	13%	16%	10%	10%	12%
Happy / very happy	89%	63%	79%	75%	87%	77%	80%

**Table:** How respondents feel about sharing their health record via the SDE for research purposes – by age group

	16 to 24 (N=162)	25 to 34 (N=191)	35 to 44 (N=166)	45 to 54 (N=149)	55 to 64 (N=148)	65 to 74 (N=149)	75+ (N=148)
Not happy / not happy at all	9%	8%	13%	7%	10%	8%	8%
Neither	14%	16%	15%	8%	8%	11%	9%
Happy / very happy	77%	75%	72%	85%	82%	81%	82%

**Table:** How respondents feel about sharing their health record via the SDE for research purposes – by ethnic group

	Asian / Asian British (N=155)	Black / Black British (N=203)	English, Welsh, Scottish, Northern Irish or British (N=710)	Mixed, multiple or other ethnic groups (N=54)
Not happy / not happy at all	8%	9%	9%	13%
Neither	17%	13%	10%	19%
Happy / very happy	75%	78%	81%	69%

**Table:** How respondents feel about sharing their health record via the SDE for research purposes – by financial status

	I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure (N=97)	I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure (N=380)	I have just enough money for basic necessities and little else (N=442)	I don't have enough money for basic necessities and sometimes or often run out of money (N=77)
Not happy / not happy at all	4%	5%	9%	21%
Neither	5%	9%	14%	17%
Happy / Very happy	91%	86%	77%	62%

**Question: What do you think are the benefits to people sharing their health record via the Secure Data Environment for research?**

Respondents were asked what they felt the benefits would be of sharing their health record via the SDE for research purposes; 815 responded to the question.

Most talked about how this would lead to greater understanding and improvements in medication / drugs, cures and treatment, care, and healthcare services and facilities – ultimately resulting in better health (29%).

*“They could use the data wisely to discover better ways of treating people”*

*“I think it helps gaining some information on some diseases”*

*“It’s going to help society with their health with new treatments like MND, Parkinson’s and cancer”*

A slightly smaller proportion (21%) indicated that it ‘helps’. Where respondents elaborated, they said it helped everyone / communities and future generations.

*“Not sure but I think it helps somehow”*

*“Helps improve care in future for young ones of today. Positive care in future is a bonus”*

To a lesser extent, respondents recognised that having access to more data / health records would enable a greater knowledge base and therefore better research (8%).

*“Bigger the sample to test on”*

*“It is useful. Research and development can only happen when we a pool of data”*

Other benefits included supporting research (4%), helping to identify trends and needs (2%) and saving lives (2%).

Notably, 9% were unsure or were unable to provide a reason, 3% felt there were no benefits and 2% provided a negative comment.

*“A lot of information is leaked, so I don’t trust anything”*

*“Naturally I don’t trust anything that has to do with information sharing”*

**Table:** Benefits of sharing health records for research purposes – free text responses (N=815)

	No.	%
<b>Positive comments</b>		
Better medicine / treatment / services / health	238	29%
Helps others / future generations	170	21%
Better sample and knowledge base	68	8%
Good / fine / no issues with sharing health records	56	7%
Supports research	35	4%
Other positive comment	19	2%
Helps identify patterns, trends and needs	15	2%
Saves lives	13	2%



Benefits everyone / everything	8	1%
Important	6	1%
Supports service planning and management	3	<1%
<b>Neutral or negative comments</b>		
Not sure / no reason	74	9%
Comment uncoded	55	7%
No benefits	25	3%
Negative comment	15	2%
As long as confidential / consent sought	6	1%
Don't know enough / more information needed	6	1%
No choice / information already shared	1	<1%

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

Respondents were asked to tell us if they would be happy to share their health record with the following organisations for research purposes<sup>2</sup>:

- Universities
- NHS Teaching Hospitals
- Pharmaceutical companies
- Charities
- Local councils
- My doctor, the hospital or other medical professional who looks after me
- Care agencies, such as care homes and home care providers.

Respondents were happiest about sharing their health record for research purposes with their doctor, hospital or other medical professional looking after them (87% very happy / happy). High satisfaction was also found for NHS teaching hospitals (86%) and universities (80%).

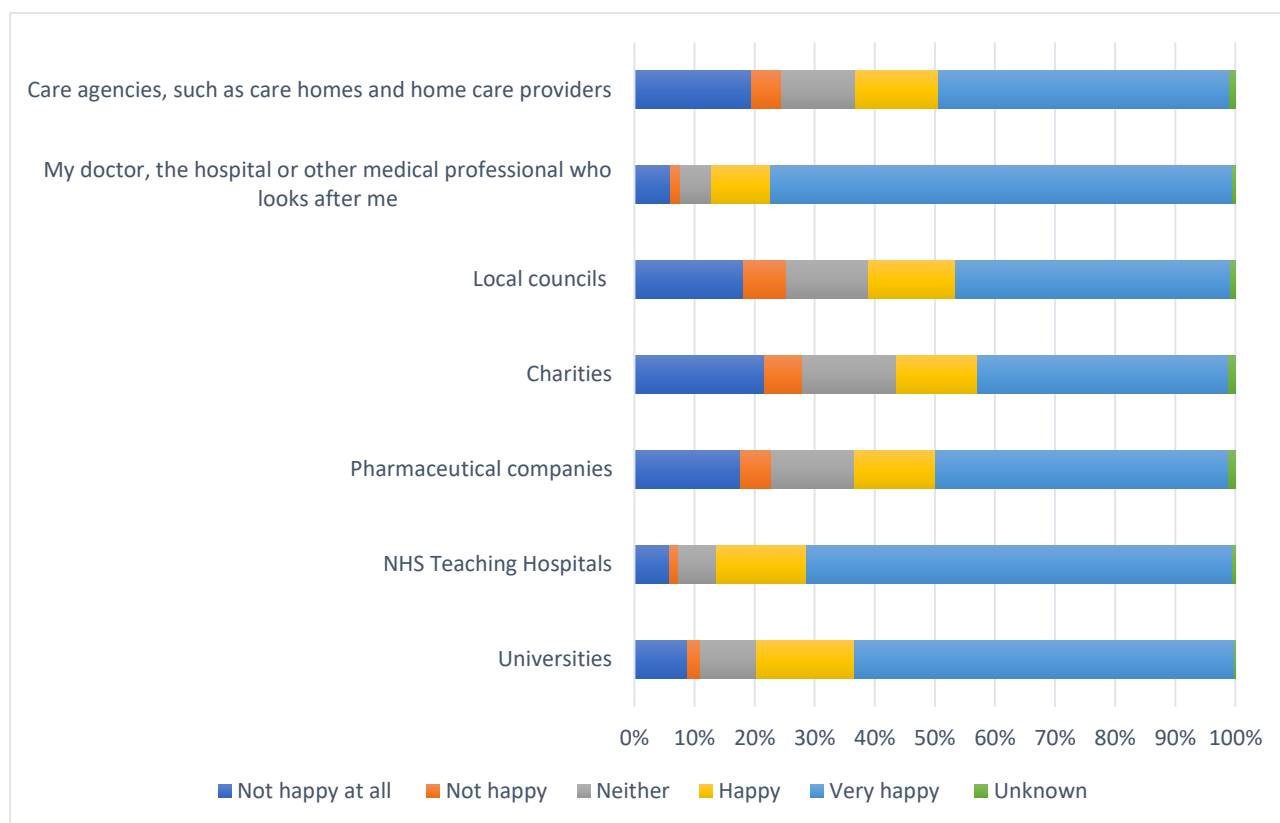
Similar satisfaction was found for pharmacies, care agencies and local councils with approximately two thirds happy to share their records for research purposes (62%, 62% & 60%, respectively).

Respondents were most concerned about sharing their health record for research purposes with charities with just over half (55%) very happy or happy to do this.

---

<sup>2</sup> 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:** Sharing of health records with organisations for research purposes (N=1,149)



**Table:** Sharing of health records with organisations for research purposes (N=1,149)

	Not happy at all	Not happy	Neither	Happy	Very happy	Unknown
Universities	9%	2%	9%	16%	63%	0%
NHS Teaching Hospitals	6%	2%	6%	15%	71%	0%
Pharmaceutical companies	18%	5%	14%	14%	49%	1%
Charities	22%	6%	16%	14%	42%	1%
Local councils	18%	7%	14%	15%	46%	1%
My doctor, the hospital or other medical professional who looks after me	6%	2%	5%	10%	77%	0%
Care agencies, such as care homes and home care providers	19%	5%	12%	14%	48%	1%

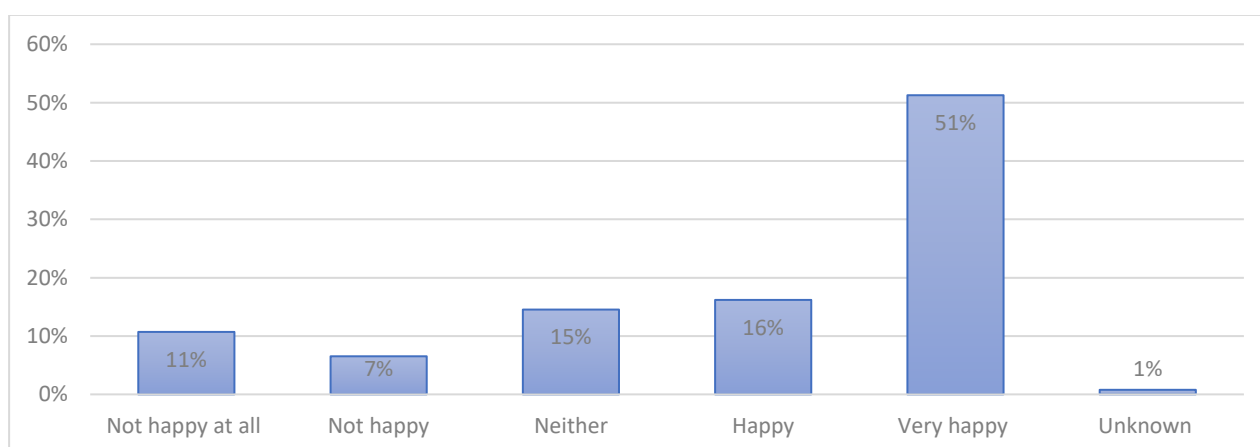
## Sharing health records for non-research purposes

**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?**

67% would be happy (51% very happy & 16% happy) to share their health record via the SDE for non-research purposes. This is a lower proportion than those that would be happy to share their health record for research purposes (78%).

In contrast, 18% would not be happy (7% not happy and 11% not happy at all). Again, this is higher than those who would not be happy to share their health record for research purposes (9%).

**Figure:** How respondents feel about sharing their health record via the SDE for non-research purposes (N=1,149)



Sub-group analysis revealed the following differences:

- Satisfaction is greater amongst those from Cumbria and Northumberland (78% & 77%, respectively) and notably lower amongst those from Durham (51%), Newcastle (63%) and Teesside (66%).
- Satisfaction is greater amongst those aged over 45 years, with the 45-to-54 and 75+ age groups having the greatest satisfaction (77%). Similar satisfaction is observed amongst those aged 16 to 44 years.
- Satisfaction is greater among those who identify as English, Welsh, Scottish, Northern Irish or British (72%) and lowest for those who identify as mixed, multiple or ethnic group (55%) and Asian / Asian British (61%).
- Satisfaction is greater amongst those who are more financially stable and lowest for those who struggle to make ends meet.

**Table:** How respondents feel about sharing their health record via the SDE for non-research purposes – by area

	<b>Cumbria (N=153)</b>	<b>Durham (N=149)</b>	<b>Gateshead (N=158)</b>	<b>Newcastle (N=154)</b>	<b>Northumberland (N=150)</b>	<b>Sunderland (N=168)</b>	<b>Teesside (N=170)</b>
Not happy / not happy at all	10%	30%	16%	17%	15%	18%	15%
Neither	12%	19%	13%	20%	8%	11%	19%
Happy / Very happy	78%	51%	70%	63%	77%	71%	66%

**Table:** How respondents feel about sharing their health record via the SDE for non-research purposes – by age group

	<b>16 to 24 (N=162)</b>	<b>25 to 34 (N=190)</b>	<b>35 to 44 (N=168)</b>	<b>45 to 54 (N=146)</b>	<b>55 to 64 (N=149)</b>	<b>65 to 74 (N=151)</b>	<b>75+ (N=149)</b>
Not happy / not happy at all	17%	19%	22%	12%	17%	17%	14%
Neither	21%	17%	15%	12%	10%	17%	9%
Happy / very happy	62%	63%	63%	77%	72%	66%	77%

**Table:** How respondents feel about sharing their health record via the SDE for non-research purposes – by ethnic group

	<b>Asian / Asian British (N=157)</b>	<b>Black / Black British (N=203)</b>	<b>English, Welsh, Scottish, Northern Irish or British (N=711)</b>	<b>Mixed, multiple or other ethnic groups (N=53)</b>
Not happy / not happy at all	18%	18%	16%	21%
Neither	21%	18%	12%	25%
Happy / very happy	61%	65%	72%	55%

**Table:** How respondents feel about sharing their health record via the SDE for non-research purposes – by financial status

	I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure (N=99)	I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure (N=381)	I have just enough money for basic necessities and little else (N=441)	I don't have enough money for basic necessities and sometimes or often run out of money (N=77)
Not happy / not happy at all	10%	11%	20%	31%
Neither	7%	15%	14%	25%
Happy / Very happy	83%	73%	67%	44%

**Question: What do you think are the benefits to people sharing their health record via the Secure Data Environment for non-research purposes?**

Respondents were asked what they felt the benefits would be of sharing their health record via the SDE for non-research purposes; 740 responded to the question.

Most respondents recognised how sharing their health record for non-research purposes would help provide a greater understanding of current and future needs to support service planning and management, and help improve the delivery and quality of healthcare services (24%).

*“It is very important to find out what our community needs when it comes to health issues”*

*“Helps manage resources better”*

A slightly smaller proportion (19%) talked about how it would help others and future generations, whilst 8% talked about how sharing their data record would lead to developments and improvements in medicine, care and treatment and health.

*“Improve medication and care”*

To a lesser extent, respondents commented about it being ‘good’ or ‘fine’ and how they didn’t have any issues (7%), how it would enable a better sample and knowledge base (4%) and help support research (3%).

Compared to the same question asked about research purposes, slightly more respondents reported being unsure or were not able to give a reason (14%) or felt that there would be no benefits (5%). Others added caveats highlighting the importance of consent and anonymity, security of the system, context of usage and that it is actually of benefit.

*“If it shared with people who need to know about it and use if appropriately, I don’t see any problem”*

*“As long as improves efficacy in hospitals”*

Specially, 3% felt that sharing their health record for non-research purposes is less important than doing so for research purposes.

*“Not as important as others stuff”*

*“In my point of view, there is no use. They don’t need it”*

*“Don’t think they need to be shared for the planning and organisation”*

**Table:** Benefits of sharing health records for non-research purposes – free text responses (N=740)

	No.	%
<b>Positive comments</b>		
Supports service planning, management and delivery	180	24%
Helps others / future generations	139	19%
Better medicine / treatment / health	60	8%
Good / no issues	50	7%
Better sample / knowledge	32	4%
Other positive comment	31	4%
Supports research	21	3%
Improve efficiency / cost saving	11	1%
Everything / benefits all	10	1%
<b>Neutral or negative comments</b>		
Not sure / no reason	107	14%
No benefits	35	5%
Comment uncoded	31	4%
Caveat added	22	3%
Prefer for research purposes / less important	19	3%
Don’t trust / not comfortable / concern about security	13	2%
Need to know more information	8	1%
Other negative comment	3	<1%

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

Respondents were asked to tell us if they would be happy to share their health record with the following organisations for non-research purposes<sup>3</sup>:

- Universities
- NHS Teaching Hospitals

<sup>3</sup> 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

- Pharmaceutical companies
- Charities
- Local councils
- My doctor, the hospital or other medical professional who looks after me
- Care agencies, such as care homes and home care providers.

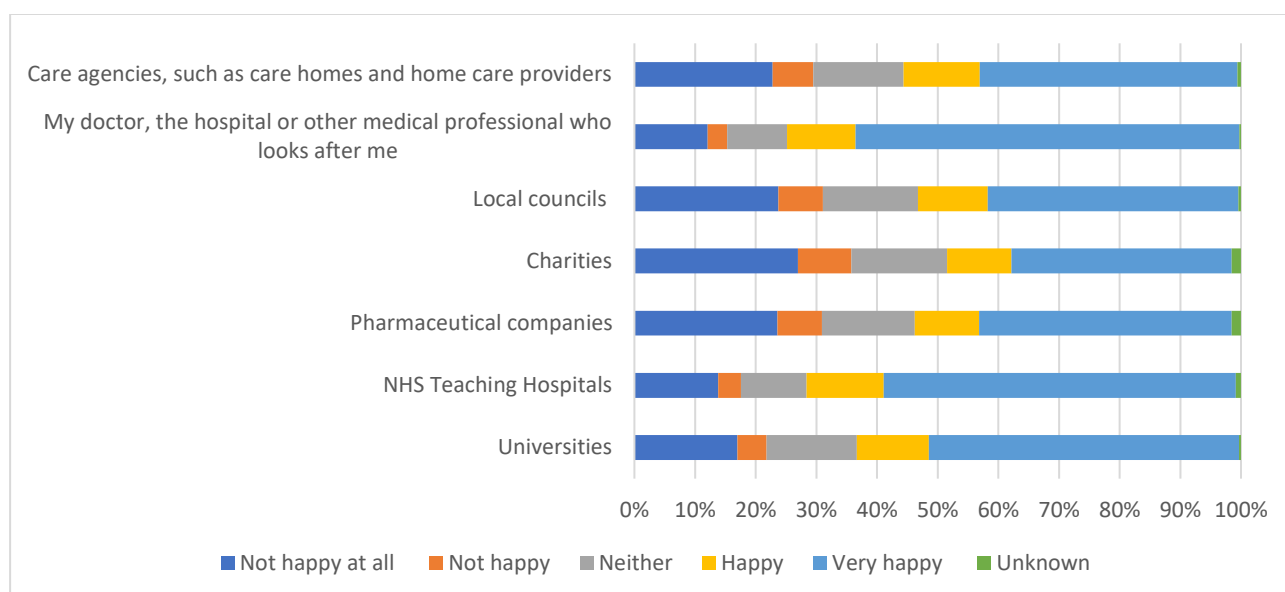
Generally, respondents are happier to share their health record with all organisations for non-research purposes, than not. However, satisfaction in doing so, is less than that found for research purposes.

Respondents are happiest about sharing their records with their doctor, hospital or other medical professional (75% very happy or happy), NHS teaching hospitals (71%) and universities (63%).

Satisfaction was similar for sharing with pharmaceutical companies (52%), local councils (53%) and care agencies (55%).

Satisfaction is lowest for charities with 42% very happy or happy to do this, 16% neither happy nor not happy and 36% not happy / not happy at all.

**Figure:** Sharing of health records with organisations for non-research purposes (N=1,149)



**Table:** Sharing of health records with organisations for non-research purposes (N=1,149)

	Not happy at all	Not happy	Neither	Happy	Very happy	Unknown
Universities	17%	5%	15%	12%	51%	0%
NHS Teaching Hospitals	14%	4%	11%	13%	58%	1%
Pharmaceutical companies	24%	7%	15%	11%	42%	2%
Charities	27%	9%	16%	11%	36%	2%

Local councils	24%	7%	16%	11%	41%	0%
My doctor, the hospital or other medical professional who looks after me	12%	3%	10%	11%	63%	0%
Care agencies, such as care homes and home care providers	23%	7%	15%	13%	42%	1%

## Risks of sharing health records

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

16% feel there are definitely risks to people sharing their health record via the SDE for both research and non-research purposes, whilst 37% feel there are to some extent. In contrast, 36% feel there are no risks.

Table: Whether respondents feel there are any risks to sharing their health record via the SDE for both research and non-research purposes (N=1,149)

	No.	%
Yes, definitely	185	16%
Yes, to an extent	422	37%
No	415	36%
Not sure/don't know	125	11%
Unknown	2	<1%

Sub-group analysis revealed the following differences:

- Greater concerns amongst those from Newcastle and Durham.
- Greater concerns amongst those aged 44 and under, the greatest proportion of those aged 16-24 feel there are definitely / to some extent risks to data sharing (60%).
- Those who identified as Asian / Asian British and Black / Black British have greater concerns than those who identify as English, Welsh, Scottish, Northern Irish or British and other ethnic groups.
- Greater concerns amongst those who are less financially stable.

**Table:** Whether respondents feel there are risks to sharing their health record via the SDE for research and non-research purposes – by area

	Cumbria (N=153)	Durham (N=152)	Gateshead (N=160)	Newcastle (N=154)	Northumberland (N=150)	Sunderland (N=169)	Teesside (N=171)
Yes, definitely	18%	22%	15%	17%	15%	15%	12%
Yes, to an extent	33%	35%	37%	47%	41%	32%	32%
No	41%	28%	42%	25%	41%	46%	34%



Not sure / don't know	9%	16%	6%	11%	3%	7%	23%
-----------------------	----	-----	----	-----	----	----	-----

**Table:** Whether respondents feel there are risks to sharing their health record via the SDE for research and non-research purposes – by age group

	16 to 24 (N=164)	25 to 34 (N=190)	35 to 44 (N=168)	45 to 54 (N=150)	55 to 64 (N=150)	65 to 74 (N=150)	75+ (N=150)
Yes, definitely	16%	15%	21%	11%	19%	15%	15%
Yes, to an extent	44%	39%	36%	35%	34%	36%	31%
No	28%	33%	29%	43%	40%	39%	46%
Not sure / don't know	12%	13%	14%	11%	7%	11%	8%

**Table:** Whether respondents feel there are risks to sharing their health record via the SDE for research and non-research purposes – by ethnic group

	Asian / Asian British (N=157)	Black / Black British (N=203)	English, Welsh, Scottish, Northern Irish or British (N=717)	Mixed, multiple or other ethnic groups (N=54)
Yes, definitely	13%	19%	15%	19%
Yes, to an extent	45%	41%	34%	35%
No	29%	29%	40%	39%
Not sure/don't know	13%	11%	11%	7%

**Table:** Whether respondents feel there are risks to sharing their health record via the SDE for research and non-research purposes – by financial status

	I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure (N=100)	I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure (N=384)	I have just enough money for basic necessities and little else (N=445)	I don't have enough money for basic necessities and sometimes or often run out of money (N=77)
Yes, definitely	18%	13%	15%	31%
Yes, to an extent	30%	39%	36%	29%
No	47%	40%	38%	29%

Not sure/don't know	5%	9%	11%	12%
---------------------	----	----	-----	-----

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

Respondents were asked to tell us about their concerns; 389 individuals responded to the question.

Most revealed a concern relating to security of their personal data and information getting into the wrong hands through data leaks / hacks / breaches (19%). Some felt that this may lead to their personal information being identified. Notably, just 2% commented specifically on the recent incident involving NHS data as well as other data breaches.

*“It might say to me it’s secure and anonymous to me, but to people who designed the system it might not be”*

*“It may affect people’s personal information if by chance it wasn’t protected”*

Others acknowledged how there are always risks to data sharing and how mistakes can happen (12%).

*“There could be a risk, isn’t there with everything”*

*“There are some risks, especially with the AI”*

To a lesser extent, respondents talked about their concerns about their data being misused and/or exploited for profit (6%), uncertainty about who and how many people would be accessing their data (4%) and lack of, or no trust in online systems / data sharing more generally (3%).

*“Sold on to third parties. Accessed by mortgage companies insurance companies.”*

*“Depending upon who accesses it. Biometrics all targeted at individual could manipulate advertisements”*

Notably, 5% felt they don’t know enough or need more information, particularly around where their data is going, the technology and for how long it will be used, whilst a small proportion (2%) added a caveat that it would depend upon the process being monitored properly and the benefits of doing so.

*“I’m 90 and don’t know how this works”*

Table: Please tell us about your concerns – free text responses (N=389)

	No.	%
Security and information getting into wrong hands through data hacks / leaks / breaches	130	33%
Always a risk / mistakes can happen	72	19%
None (as long as anonymous, secure & well managed)	47	12%
Not sure / personal preference	35	9%
Exploited for profit / data misuse	22	6%
Need more info / don’t know enough	21	5%
Other concern	18	5%
Uncertainty about who / how many people are accessing	15	4%
Lack / no trust	12	3%

IT system / process dependent	9	2%
Comment uncoded	9	2%
Depends if monitored properly / it helps (caveat)	8	2%
Comment re: recent NHS / other data breach	6	2%

**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.

Just over half (57%) would be happy for their GP / other health service to share their health record directly in to the SDE, whilst 32% would prefer to approve the sharing of their health record themselves and 6% do not want their health record to be shared at all.

In terms of those who do not want their health record to be shared at all, these were least likely to be from Cumbria and more likely to identify as mixed, multiple or other ethnic group.

**Table:** 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=1,149)

	No.	%
I would be happy for my GP / other health services to share my health record	653	57%
I would prefer to approve the sharing of my personal health record myself	366	32%
I would not be happy to share my health record at all	70	6%
Not sure / don't know	54	5%
Unknown	6	1%

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

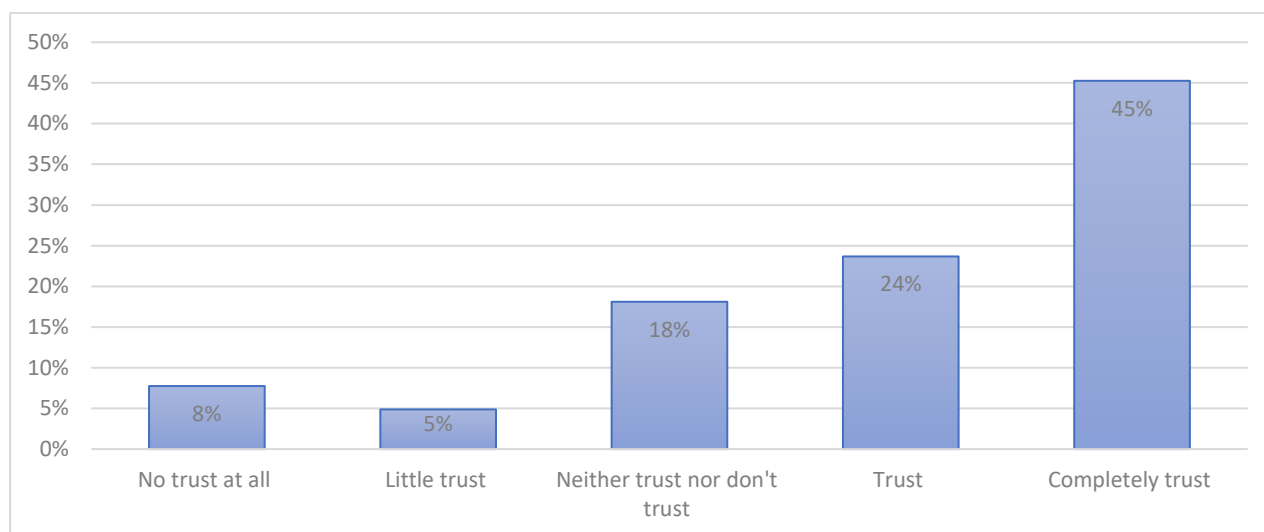
Respondents were asked if they trusted that their anonymised health record would be used for the described reasons in the SDE only<sup>4</sup>.

Approximately two thirds (69%) 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 11% have little or no trust at all.

---

<sup>4</sup> 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:** Whether respondents trust how their anonymised health record will be used in the SDE (N=1,149)



Sub-group analysis revealed the following differences:

- Trust is greater among those from Sunderland (76%), Cumbria (74%), Gateshead (73%) and Northumberland (72%) and lower for those from Newcastle (59%) and Durham (62%).
- Trust is greater amongst those aged 45 years and over, peaking at 76% for those aged 75 years or more. The lowest proportion of those aged 25-34 years trusted that their health record would be used for the described reasons of the SDE only (62%).
- Trust is greater among those who identified as English, Welsh, Scottish, Northern Irish or British (72%) and noticeably lower for Asian / Asian British respondents (59%).
- Trust is greater amongst those who are more financially stable.

**Table:** Whether respondents trust how their anonymised health record will be used in the SDE – by area

	Cumbria (N=153)	Durham (N=152)	Gateshead (N=160)	Newcastle (N=154)	Northumberland (N=150)	Sunderland (N=169)	Teesside (N=171)
No trust at all / little trust	10%	13%	14%	14%	13%	14%	9%
Neither	16%	25%	13%	26%	15%	10%	25%
Trust / completely trust	74%	62%	73%	59%	72%	76%	66%

**Table:** Whether respondents trust how their anonymised health record will be used in the SDE – by age group

	16 to 24 (N=164)	25 to 34 (N=190)	35 to 44 (N=167)	45 to 54 (N=149)	55 to 64 (N=150)	65 to 74 (N=151)	75+ (N=150)
No trust at all / little trust	9%	14%	16%	9%	13%	10%	14%
Neither	25%	24%	17%	16%	15%	18%	10%
Trust / completely trust	66%	62%	66%	75%	71%	72%	76%

**Table:** Whether respondents trust how their anonymised health record will be used in the SDE – by ethnic group

	Asian/Asian British (N=157)	Black/Black British (N=204)	English, Welsh, Scottish, Northern Irish or British (N=715)	Mixed or multiple ethnic groups (N=54)
No trust at all / little trust	10%	13%	13%	13%
Neither	31%	19%	15%	17%
Trust / completely trust	59%	68%	72%	70%

**Table:** Whether respondents trust how their anonymised health record will be used in the SDE – by financial status

	I have more than enough money for basic necessities, and a lot spare, that I can save or spend on extras or leisure (N=100)	I have more than enough money for basic necessities, and a little spare, that I can save or spend on extras or leisure (N=385)	I have just enough money for basic necessities and little else (N=442)	I don't have enough money for basic necessities and sometimes or often run out of money (N=77)
No trust at all / little trust	10%	8%	10%	29%
Neither	13%	17%	19%	26%
Trust / completely trust	77%	75%	71%	45%

**Question:** Would you be interest in learning more about the Secure Data Environment and/or like to take part in opportunities to provide your views on the development of the Secure Data Environment in the North East and Cumbria?

27% (308 respondents) were keen to learn more about the SDE programme and took a leaflet from one of the fieldworkers.

8% (87 respondents) indicated that they would be interested in taking part in opportunities to provide their views on the development of the SDE programme.

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

Respondents were given the opportunity to provide any additional comments they had; 124 individuals provided a response.

In terms of responses relating to the SDE programme, 5% commented positively – perceiving that it was much needed and identifying benefits that it will bring.

*“Just that this is vital to improve people’s health”*

*“I’m really happy that things like this is happening. Without research how will we know what needs to be done and how to improve healthcare”*

Other very small proportions expressed their concerns about the programme in terms of the security of the information (5%), preference to not have their health record / personal information shared (3%) and lack of, or no trust for the NHS / more generally (3%).

*“The NHS isn’t trust worthy and have done my son wrong. I wish I could put zero not one for the answers”*

*“I think it’s not good to share people’s information, even if it is anonymised”*

*“I’d only like my GP or hospital seeing my personal information”*

**Table:** Additional comments (N=124)

	No.	%
Positive comment about the NHS	47	38%
Other comment not related to the SDE	32	26%
Sounds good / beneficial	6	5%
Concern about security of information	6	5%
Not sure / never thought about it	5	4%
Don’t want my details shared	4	3%
Lack of / no trust	4	3%
Need to have stringent security management of data / terms and conditions	3	2%
Other negative / neutral comment about the SDE; <ul style="list-style-type: none"> <li>- GDPR</li> <li>- Data shared must be accurate</li> <li>- Guarantee of anonymity needed</li> <li>- Sharing for non-research purposes is not necessary</li> <li>- Need to understand more</li> </ul>	5	4%

## Discussion of findings

The street survey builds upon the findings from the survey conducted earlier in the year with 405 individuals from across NENC. 1,149 individuals completed the latest street survey which ensured a population representative based on age, sex and ethnic group and an equal split of respondents from all NENC areas.

The majority (79%) would be happy about an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details, whilst 8% would not be happy. Providing reason for their response, 20% recognised the importance of this and the benefits that this will lead to (20%), whilst others felt it would be 'good' or 'fine' and had no issues with it (17%). Smaller proportions trusted that the data will be secure (3%) and that there will be 'no harm in it' due to their health record being anonymised (3%). Some added caveats stating that they would be happy as long as their health record was anonymous (2%) and/or that it is shared securely (1%). A few felt it would depend upon who their health record was shared with (<1%).

For those who would not be happy, their concerns relate to privacy and not wanting to share their personal information with people other than their GP / immediate healthcare services (5%), the system and its security (3%) and lack of, or no trust (2%). Notably, 4% felt that they didn't know enough about how their health record would be shared and what it would be used for, and/or requested more information.

The majority (78%) would be very happy or happy to share their health record via the SDE for research purposes, whilst 9% would not be happy. Respondents expressed higher satisfaction about sharing their health record for research purposes with their doctor, hospital or other medical professionals looking after them (87%), NHS teaching hospitals (86%) and universities (80%). Although satisfaction levels were lower for pharmacies, care agencies and local councils (62%, 62% & 60%, respectively), there was still more support than objection. Respondents were most concerned about sharing their health record for research purposes with charities with just over half (55%) very happy or happy to do this. This follows a similar trend to findings reported in the Feb 24 street survey, although respondents reported a lower satisfaction for all organisations in the latest survey.

The key benefit of sharing their health record for research purposes was identified as enabling greater understanding and improvements in medication / drugs, care and treatment, and healthcare services (29%). Others described how it would 'help' in general as well as specifically for current and future generations (21%) as well as ensure a greater sample / knowledge base (8%).

Two thirds (67%) would be very happy or happy to share their health record via the SDE for non-research purposes, whilst 18% would not be happy. This shows that people have more reservations about sharing their health record for non-research purposes.

In terms of the organisations' respondents would be happy to share their health record with for non-research purposes, a similar pattern of findings was observed to that reported for research purposes, although satisfaction was lower for all. Respondents were happiest about sharing their health record with their doctor, hospital or other medical professional (75%), NHS teaching hospitals (71%) and

universities (63%), whilst satisfaction was lowest for charities with 42% very happy or happy to do this and 36% not happy.

Respondents recognised that sharing their health record for non-research purposes would help provide a greater understanding of current and future needs to support service planning and management, and improve the delivery and quality of healthcare services (24%). A slightly smaller proportion (19%) noted how it would 'help' in general as well as specifically 'others' and 'future generations', whilst 8% talked about how sharing their data record would lead to developments and improvements in medicine, care and treatment. Compared to the same question asked about research purposes, slightly more respondents reported being unsure or were not able to give a reason (14%) or felt that there would be no benefits (5%). Others added caveats highlighting the importance of consent and anonymity, security of the system, context of usage and that it is actually of benefit. Specially, 3% felt that sharing their health record for non-research purposes is less important than doing so for research purposes.

16% felt there are definitely risks to people sharing their health record via the SDE for both research and non-research purposes, whilst 37% feel there are to some extent. In contrast, 36% feel there are no risks. The proportion who felt there are risks is greater than that reported in the Feb 24 street survey where 12% said there are definitely risks and 27% that there are to some extent, however the phrasing of the question was slightly different to explore perceptions about data sharing for research and non-research purposes, which we know people are less satisfied with.

Key concerns relate to the security of their personal data and information getting into the wrong hands through data leaks / hacks or breaches – which may lead to personal information being identified (19%). Others simply feel there are always risks with sharing data and recognised that mistakes can happen (12%). Smaller proportions expressed concern about their data being misused and/or exploited for profit (6%), uncertainty about who and how many people would be accessing their data (4%) and their lack of, or not trust in online systems / data sharing more generally (3%).

Just over half (57%) would be happy for their GP / other health service to share their health record directly into the SDE, whilst 32% would prefer to approve the sharing of their health record themselves and 6% do not want their health record to be shared at all. The proportion who would be happy for their GP / health service to share their health record is notably lower than the 81% reported in the Feb 24 report, although the proportions of those not willing to share their record at all is comparable (6% & 5% in the Feb 24 survey).

Approximately two thirds (69%) completely trust or trust that their anonymised health record would be used for the described reasons of the SDE only, whilst 11% have little or no trust. Again, the proportion who indicated their trust is lower than that reported in the Feb 24 survey (85%).

Sub-group analysis was undertaken to understand any differences in the findings by area, age group, gender, ethnicity and financial status. Below is an overview of these, drawing findings from previous reports developed for the SDE programme team.

### **Area**

Exploration of 2024 National Opt-Out data demonstrated that Northumberland is significantly different to other parts of the NENC, with the areas of Morpeth,



Cramlington and Hexham having out-out proportions higher than other areas of NENC. Rural areas of Gateshead around Cropwell Woodland also have some of the highest opt-out proportions. These areas were therefore identified as focus areas in this engagement activity.

The current survey revealed some differences by area with those living in Cumbria and Northumberland happier about sharing the health record via the SDE for both research and non-research purposes. In contrast, those living in Teesside, Durham and Newcastle were less happy about doing so, with those from Durham and Newcastle having greater concerns about the risks involved and less trust that their health record would be shared for the described purposes of the SDE only.

### **Gender**

Recent research suggests that females may be more likely to have concerns about sharing their health record. Specifically, the Feb 24 street survey found that females were more likely to have concerns about their health data being used for other reasons, above and beyond those described in the SDE programme. The current survey however found no noticeable differences in terms of gender.

### **Age**

The Feb 24 street survey found greater dissatisfaction and distrust amongst those aged 35-44 years (19% were not happy to share their data and the same proportion do not trust that their data will be used for the described reasons of the SDE only). Their primary concerns relating to data security i.e., data falling into the wrong hands or potential data leaks.

Evidence collated for the SDE steering group also suggests that younger students, couples or singles (i.e. those aged 16-24 years) and those aged 30-59 years may hold more negative views towards data sharing, than older cohorts.

Findings from the current survey provide support for this, with those aged 45 and over found to have more positive views about data sharing via the SDE for both research and non-research purposes and less concern about the risks involved and their health record being used for other reasons, above and beyond those detailed in the SDE programme. Specifically, those aged 16-24 years were the most likely to indicate that there are definitely / to some extent risks to data sharing (60%) and those aged 25-34 the least likely to trust that their health record would be used for the described reasons of the SDE only (62%).

### **Ethnicity**

Limited research has been undertaken to explore perceptions about data sharing by ethnic group. Findings from the current survey suggest greater satisfaction among those who identify as English, Welsh, Scottish, Northern Irish, compared to those from other ethnic minority groups, particularly Asian / British Asian groups. These ethnic groups are more likely to have concerns about the risks involved and less trust that their health record will be used for the described purposes of the SDE only.

## **Financial status**

Recent data from the National Opt-Out suggests that opt-out is higher for least deprived deciles and lowest for the most deprived. This contradicts previous research by the Patient Experience Library (2021) which revealed that those better off are more likely to view the use of health data as being benefit to society.

The findings from the current survey support these latter findings, with those who are more financially stable consistently showing greater satisfaction about the sharing of their health data for both research and non-research purposes. Additionally, these individuals have less concerns about the risks involved and greater trust, than those who are less financially stable / struggling to make ends meet.

It must be noted, that this is a general trend observed amongst those sampled and may not be reflective of the NENC population due to the constraints in collecting accurate information about financial status.

## **Summary**

Respondents are mostly happy about an approved and authorised NHS organisation having access to their identifiable health record and removing all their identifiable details. They have greater satisfaction about sharing their health record via the SDE for research purposes than non-research purposes, however two thirds still support data sharing for non-research purposes. There is greatest concern about sharing their health record with charities, for both research and non-research purposes.

A significant proportion do have concerns about the SDE in particular the security of their personal data and data being leaked / hacked. There is also appreciation that there is always an element of risk with data sharing and how mistakes can happen. To a lesser extent, there is some concern about data being misused / exploited for profit by some organisations.

The research would suggest that some demographic groups do have more negative views and reservations about data sharing, particularly younger age groups (under 44 years), those from ethnic minority groups and those who are less financially stable / struggling to make ends meet. It would also appear that those living in Cumbria and Northumberland have more favourable views than those living in Teesside, Durham and Newcastle.

Whilst there are some variations in results compared to the Feb 24 street survey, it must be considered that there was some changes in the phrasing of questions and that the current sample is larger and more robust.

## Appendix

### Respondent demographics

<b>Gender match sex registered at birth</b>	Yes	1113	97%
	No	14	1%
	Unknown	22	2%
<b>Ethnic group</b>	Bangladeshi	23	2%
	Chinese	22	2%
	Indian	69	6%
	Pakistani	19	2%
	Any other Asian background	24	2%
	African	196	17%
	Caribbean	4	0%
	Any other black, black British, African or Caribbean background	4	0%
	White and black African	6	1%
	White and Asian	4	0%
	Any other mixed or multiple ethnic background	4	0%
	English, Welsh, Scottish, Northern Irish or British	718	62%
	Irish	1	0%
	Roma	1	0%
	Any other white background	13	1%
	Arab	12	1%
	Other	13	1%
Unknown	16	1%	
<b>Religion</b>	No religion or belief	476	41%
	Christian (including Church of England, Catholic, Protestant, and other Christian denominations)	456	40%
	Muslim	91	8%
	Hindu	29	3%
	Other	10	1%
	Buddhist	5	0%
	Sikh	3	0%
	Jewish	2	0%
	Unknown	77	7%
<b>Sexual orientation</b>	Straight or Heterosexual	1082	94%
	Unknown	32	3%
	Bi or bisexual	19	2%
	Gay or lesbian	14	1%
	Prefer to self-describe	2	0%

<b>Health status</b>	Long-term health condition	209	18%
	Physical impairment or mobility issues	66	6%
	Sensory impairment	65	6%
	Mental health condition	42	4%
	Learning disability	14	1%
	Neurodivergence	455	40%
	No condition or impairment	211	18%
	Other condition / illness / impairment	64	6%
<b>Pregnant or have been in the last six months</b>	Yes	17	1%
	No / not applicable	1109	97%
	Unknown	21	2%
<b>Legal marital or registered civil partnership status</b>	Married	482	42%
	Never married or in a civil partnership	389	34%
	Divorced	93	8%
	Widowed	84	7%
	In a legally registered civil partnership	26	2%
	Separated but still legally married	17	1%
	Separated but still legally in a civil partnership	5	0%
	Formerly in a civil partnership which is now legally dissolved	1	0%
	Surviving partner from a civil partnership	1	0%
	Unknown	51	4%