Secure Data Environment Street Survey

January 2024

A report for [Client name]

27th February 2024

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Executive summary

Introduction

The NHS are planning a new, secure online system called a Secure Data Environment (SDE) that will give some carefully selected universities and health research organisations access to local people's health data. The local NHS sought to understand public sentiments regarding the sharing of health data into the Secure Data Environment (SDE) – and we were asked to complete an on-street exercise throughout the North East & North Cumbria reaching a representative sample of the population.

This report shares the independent analysis of the feedback from this exercise.

Who we reached

We engaged a total of 405 participants in this exercise across the regions of County Durham, Cumbria, Gateshead, Newcastle, Northumberland, Sunderland, and Teesside.

To ensure the robustness of our sample, we aimed for a representative sample of 385 participants. The percentages required are based on the target of 385. To meet all criteria, we conducted surveys with a participant pool exceeding the specified 385. Consequently, in certain cases, the reported percentages may appear slightly lower than the intended target. We still achieved the necessary quantity of participants to ensure a statistically robust sample for each quota.

The tables below show the total population and the corresponding participation that took part in the street survey for age groups, sex, and ethnicity (Table 1, Table 2, Table 3 respectively). The final table provides a breakdown of surveys completed in each respective area (Table 4). The full demographic breakdown can be found in Appendix 2.

Table 1: Breakdown by age group

Age groups	Total population		Street Survey Participants (N=404)	
	No.	%	No.	%
16-24 years	*290796*	*13%*	*51*	*12.6%*
25-34	*343236*	*15%*	*66*	*16.3%*
35-44	*326116*	*15%*	*65*	*16.1%*
45-54	*317255*	*14%*	*55*	*13.6%*
55-64	*373023*	*17%*	*68*	*16.8%*
65-74	*298862*	*13%*	*51*	*12.6%*

Age groups	Total population		Street Survey Participants (N=404)	
75+	*269154*	*12%*	*48*	*11.9%*

Table 2: Breakdown by sex

Sex	Total population		Street Survey Participants (N=404)	
	No.	**%**	**No.**	**%**
Male	*1323251*	*49%*	*193*	*47.8%*
Female	*1369812*	*51%*	*211*	*52.2%*

Table 3: Breakdown by ethnicity

Ethnicity	Total population		Street Survey Participants (N=405)	
	No.	**%**	**No.**	**%**
Asian / Asian British	*98048*	*3.7%*	*20*	*4.9%*
Black / British Black	*26643*	*1.0%*	*10*	*2.5%*
Mixed or multiple ethnic groups	*33271*	*1.3%*	*6*	*1.5%*
White: British, European or other	*2462717*	*92.9%*	*364*	*89.9%*
Other ethnic group	*2858*	*0.1%*	*5*	*1.3%*

Table 4: Breakdown by area.

Area	Street Survey Participants (N=405)	
	No.	**%**
Carlisle	*55*	*13.6%*
County Durham	*59*	*14.6%*
Gateshead	*64*	*15.8%*
Newcastle	*58*	*14.3%*
Northumberland	*59*	*14.6%*
Sunderland	*55*	*13.6%*
Teesside	*55*	*13.6 %*

Key findings

The local NHS sought to understand public sentiments regarding the sharing of health data into the Secure Data Environment (SDE). After completing an on-street exercise throughout the North East & North Cumbria we can establish that overall the SDE has been perceived positively. Participants, on the whole, express a willingness to share their health records, coupled with a prevailing sense of trust and satisfaction in the data-sharing process. Beyond these overarching sentiments, a subset of individuals shows a keen interest in learning more about the SDE. Also, certain demographic groups exhibit stronger opinions. In terms of funding the SDE, strong opinions also exist. We will now look into each of these factors in a little more detail below.

Positive Perceptions

The overall sentiment towards the sharing of health data within the Secure Data Environment (SDE) is predominantly positive. A significant majority of participants express happiness and perceive benefits in sharing their anonymous health records in the SDE. While participants express definite recognition of the benefits of sharing health records for research purposes, it's worth noting that this satisfaction is dependent upon maintaining anonymity.

Willingness to Share

Participants exhibit a overall willingness to share health records, particularly when it comes to the sharing of their health records directly with the SDE by their GP and other health services. A substantial majority express this willingness, together with a high level of trust in the usage of their data.

Organisational Trust and Satisfaction

When it comes to sharing health data with specific organisations, participants express higher satisfaction levels with Universities, NHS Teaching Hospitals, personal doctors or hospitals, and NHS organisations. Conversely, satisfaction levels were notably lower for pharmaceutical companies, charities, and local councils.

Expressions of Interest

Participants demonstrate varying degrees of interest in learning more about the SDE. One in five expresses interest in understanding the types of projects the SDE supports and their impact on health. Of those interested, nearly three-quarters are willing to share their health records. Additionally, one in four received a leaflet expressing interest in learning more about the SDE, with three-quarters of this group of participants willing to share their health records. However, fewer than one in six show interest in participating in opportunities to provide views on SDE development. Within this group, three in four are willing to share their health records.

Apprehensions and Concerns

Concerns and apprehensions around the SDE focus on perceived risks associated with sharing anonymous health data. One in four participants acknowledges some level of concern, with predominant concerns arising over the security of the SDE. An interesting finding is the higher level of distrust expressed by individuals in the 35-44 age bracket, compared to other age groups.

Demographic Influences

Demographic factors such as age and gender play a significant role in participants' perceptions. Dissatisfaction with sharing health records in the SDE is notably higher among participants aged 35-44. Additionally, distinct age groups demonstrate varying tendencies towards dissatisfaction with sharing health records with charities.

The majority of individuals 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.

Government Funding Preference

Regarding funding, nearly three in four participants believe that the SDE should be funded by the UK Government.

Next steps

This report will be shared with…

1 Summary of findings

In summary, feedback emphasised the following factors as important:

The sharing of health data with the SDE is perceived positively

Most participants are happy and can see the benefits with sharing their anonymous health records in the SDE, with a breakdown of satisfaction levels indicating 19.9% as "Happy" and an overwhelming 63.5% as "Very Happy," as reflected in 72 comments. Regarding participants who expressed happiness with sharing their health data, a notable caveat emerged – this satisfaction is contingent upon the condition that the data remains anonymous, as indicated in 25 comments.

Participants definitely recognise the benefits of sharing their health records to support research into new treatment, medicine and to prevent disease, with a considerable proportion suggesting that an increased pool of data is more likely to produce results and benefit the community (81.4%, 117 comments). Notably, participants aged 35-44 agree, providing 13 comments supporting the idea that an increased data pool will yield results and benefit the community.

Furthermore, a significant majority of participants express willingness for their GP and other health services to directly share their health records with the SDE (80.6%). Importantly, they communicate trust in the usage of their data for the specified reasons, with 67.2% indicating "Completely Trust" and 17.3% expressing "Trust."

When it comes to sharing health data with specific organisations, participants exhibit significantly higher satisfaction, particularly being "very happy," when sharing with Universities NHS Teaching Hospitals, their doctor or hospital, and NHS organisations (64.9%, 78.3%, 88.6%, 75.3% respectively). In contrast, satisfaction levels were notably lower for pharmaceutical companies, charities, and local councils (56.9%, 47.7%, 54.1% respectively).

Expressions of interest

One in five expressed interest in learning more about the types of projects the SDE will support and how this will make an impact on people’s health (19.8%). Among those keen on learning more, a significant majority, nearly three-quarters, also indicated their willingness to share their health records (78.8%).

A quarter of participants received a leaflet and expressed a desire for more information about the SDE (25.0%). Notably, over three-quarters of this subgroup were happy to share their health records (81.0%).

Fewer than one in six showed an interest in taking part in opportunities to provide their views on the development of SDE in the North East and Cumbria (14.0%) Again, within this group over three in four participants were happy to share their health records (78.9%).

Apprehensions regarding the sharing of health data within the SDE

When participants were asked about perceived risks associated with sharing anonymous health data in the SDE, one in four acknowledged some level of concern (26.9%). The identified concerns predominantly centred around the security of the SDE, with some of the comments highlighting the need for robust security measures and a few expressing a lack of trust in the existing security measures (25 comments).

Among those who specifically indicated that security can’t be guaranteed, one in three belonged to the 35-44 age group (2 comments). Additionally, almost one in five individuals in the 35-44 age bracket expressed distrust in the use of their anonymised health records for the specified purposes (19.4%), a level of distrust that is significantly higher than in all other age groups.

Participants who maintained a neutral stance regarding the use of their anonymised health records, (neither trusting nor distrusting), saw a significant majority of two in three, identifying as female (62.9%). This gender distribution holds significance in the overall findings.

Within the cohort of participants aged 35-44, the dissatisfaction with sharing anonymous health records in the SDE was notable (19.4%). More than one in three participants expressed apprehensions about data sharing with inappropriate organisations and the potential for data leaks (58 comments).

In terms of sharing health records with various organisations, a considerable portion, nearly half, expressed dissatisfaction with sharing their health records with charities, with 19.8% indicating they were "not at all happy" and an additional 25.7% stating they were "not happy."

Distinct age groups demonstrated a higher tendency towards dissatisfaction with sharing health records with charities, particularly among individuals aged 35-44, 65-74, and 75+ (30.7%, 31.4%, 38.0% respectively).

Furthermore, participants in the 35-44 age group expressed reluctance to share their health data with pharmaceutical companies, care agencies such as care homes and home care providers, and universities (22.6%, 24.2%, 19.4% respectively).

When participants were asked to provide reasons for their concerns, two smaller themes emerged around 'privacy' and 'personal reasons.' Notably, one-third of those citing 'privacy' and one-fourth attributing concerns to 'personal reasons' belonged to the 35-44 age group (2 comments, 2 comments respectively).

Moreover, individuals uncertain about whether they already share their health data were notably more likely to be female, with two out of three participants in this category identifying as female (68.3%). This gender distribution is noteworthy in the overall context.

Funding

Nearly three in four think the SDE should be funded by the UK Government (72.6%).

2 Introduction

2.1 Context and background.

The NHS are planning a new, secure online system – called a Secure Data Environment (SDE) – that will give some carefully selected universities and health research organisations access to local people's health data. The local NHS sought to gauge public sentiments regarding the sharing of health data into the SDE. To accomplish this, we were assigned the task of conducting an on-street exercise throughout the North East & North Cumbria, reaching a representative sample of the population.

2.2 Duty to involve

NHS bodies have a statutory duty[1] to involve patients and the public ("*by means of providing information, consultation, or in other ways*") in the development and consideration of proposals for changes to services. Stakeholder involvement is important as the Trust has a duty to involve:

The National Health Service Act 2006 (as amended)

S.13Q requires the NHS to make arrangements to involve patients and the public in planning services, developing, and considering proposals for changes in the way services are provided and decisions to be made that affect how those services operate.

S.13G and S.14T also includes a statutory duty for NHSE and CCGs to have regard to the need to reduce health inequalities between patients in access to health services and the outcomes achieved.

Equality Act 2010 (Public Sector Equality Duty)

Requires the NHS to demonstrate how it takes account of the nine protected characteristics of:

- *Age*
- *Disability*
- *Gender reassignment*
- *Marriage and civil partnership*
- *Pregnancy and maternity*
- *Race*

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[1] Section 242/13G/14Z2 of the Health Service Act 2006 (as amended by the Health and Social Care Act 2012)

- *Religion or belief*
- *Sex*
- *Sexual orientation*

The Public Sector Equality Duty requires public sector employees to 'have due regard' to:

- *Eliminate discrimination, harassment, victimisation and any other conduct prohibited under Act*
- *Advance equality of opportunity between persons who share a relevant protected characteristic and those who do not*
- *Foster good relations between persons who share a relevant protected characteristic and persons who do not."*

2.3 Objectives

The objectives of the survey were to:

- Explore public sentiments regarding the sharing of health data.
- Identify specific demographic groups with pronounced views on health data sharing.
- Uncover the underlying reasons behind individuals' perspectives on the sharing of health data.

3 Methodology

3.1 Engagement activity

Members of the public actively engaged in a door-to-door exercise across the regions of County Durham, Cumbria, Gateshead, Newcastle, Northumberland, Sunderland, and Teesside.

3.1.1 Survey

The team conducted fieldwork from January 17th to February 9th, 2024, engaging with 405 members of the public.

To ensure the robustness of our sample, we adhered to a representative sample of the population based on age, sex and ethnicity.

Survey process / development

A series of questions were developed including:

- Closed quantitative
- Ranked
- Likert scaled, and
- Open qualitative / free text responses

The survey questions are available at Appendix 1.

3.1.2 Number and range of responses

To ensure the robustness of our sample, we aimed for a representative sample of 385 participants. The percentages required are based on the target of 385. To meet all criteria, we conducted surveys with a participant pool exceeding the specified 385. Consequently, in certain cases, the reported percentages may appear slightly lower than the intended target. We still achieved the necessary quantity of participants to establish a statistically robust sample.

A total of 405 participants took part in the survey. The subsequent tables define the quotas we adhered to during the exercise and what we achieved based on age group, sex, ethnicity and locality (Table 5, Table 6, Table 7, Table 8 respectively). Tables of the demographic profile of all those who provided feedback is available at Appendix 2.

Table 5: Breakdown by age groups

Age groups	**Total population**		**Street Survey Participants (N=404)**	
	No.	**%**	**No.**	**%**

Age groups	Total population		Street Survey Participants (N=404)	
16-24 years	*290796*	*13%*	*51*	*12.6%*
25-34	*343236*	*15%*	*66*	*16.3%*
35-44	*326116*	*15%*	*65*	*16.1%*
45-54	*317255*	*14%*	*55*	*13.6%*
55-64	*373023*	*17%*	*68*	*16.8%*
65-74	*298862*	*13%*	*51*	*12.6%*
75+	*269154*	*12%*	*48*	*11.9%*

Table 6: Breakdown by sex

Sex	Total population		Street Survey Participants (N=404)	
	No.	**%**	**No.**	**%**
Male	*1323251*	*49%*	*193*	*47.8%*
Female	*1369812*	*51%*	*211*	*52.2%*

Table 7: Breakdown by ethnicity

Ethnicity	Total population		Street Survey Participants (N=405)	
	No.	**%**	**No.**	**%**
Asian / Asian British	*98048*	*3.7%*	*20*	*4.9%*
Black / British Black	*26643*	*1.0%*	*10*	*2.5%*
Mixed or multiple ethnic groups	*33271*	*1.3%*	*6*	*1.5%*
White: British, European or other	*2462717*	*92.9%*	*364*	*89.9%*
Other ethnic group	*2858*	*0.1%*	*5*	*1.3%*

Table 8: Breakdown by area

Area	Street Survey Participants (N=405)	
	No.	**%**
Carlisle	*55*	*13.6%*
County Durham	*59*	*14.6%*
Gateshead	*64*	*15.8%*
Newcastle	*58*	*14.3%*
Northumberland	*59*	*14.6%*

Area	Street Survey Participants (N=405)	
Sunderland	*55*	*13.6%*
Teesside	*55*	*13.6%*

3.2 Quality assurance

Team reviewed and provided initial feedback on the questions.

The revised questionnaire was piloted with a range of internal and external stakeholders, including:

- …

Final amendments were made following very useful feedback from these key stakeholders.

3.3 Data protection

Participants' data has only been collected during this exercise and will be held in line with the latest data protection regulations. Every effort has been taken to ensure that individuals cannot be identified in this report.

3.4 Equalities and health inequalities

There is a requirement for NHS bodies to fulfil their duties in line with equalities legislation, giving due regard to people from protected characteristics and working to reduce health inequalities. The Cancer Alliance reports to the Integrated Care Board (ICB) and the Health and Social Care Act 2022 states that ICBs must:

Reduce inequalities between patients in relation to access to services and outcomes; promote the integration of health services where this would improve quality and; reduce inequalities of access and outcomes for individuals (14Z35).

Whilst the promotion of the survey and the contacts with the public could include people from all groups, the focus groups aimed specifically to involve those identified by the Equality and Health Inequalities Impact Assessment.

The full demographic profile of participants is at Appendix 2.

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4 Analysis of the street survey

4.1 Summary of responses

This section contains the themed analysis of all responses received from the street survey by question.

4.1.1 Question 1: On a scale of 1 – 10, how happy would you feel about your anonymous health records being shared in the Secure Data Environment? (N=403)

Patients were asked on a scale of 1-10, how happy they would feel with their anonymous health records being shared in the SDE.[2]

Over four in five participants were either happy or very happy regarding the sharing of their anonymous health records in the SDE (Table 9 & Figure 1: 19.9%, 63.5% respectively).

Notably, a discernible proportion of individuals aged 35-44, nearly one in five, were not happy with the sharing of their anonymous health records in the SDE (Table 10: 19.4%).

Table 9 Sharing of health records happiness scale

Response	No. of responses	% of responses
Very happy	*256*	*63.5%*
Happy	*80*	*19.9%*
Neither happy nor not happy	*29*	*7.2%*
Not happy	*29*	*2.2%*
Not happy at all	*9*	*7.2%*

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[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

Figure 1: Sharing of health records happiness scale

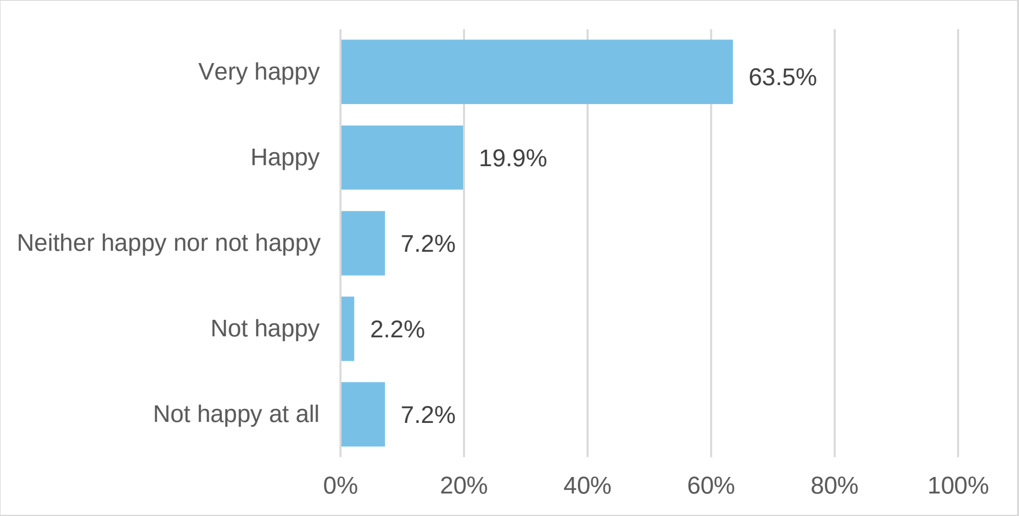

Table 10: Sharing of health records happiness scale / age range

Happiness scale	**16-24**	**25-34**	**35-44**	**45-5**	**55-64**	**65-74**	**75+**
	% *	**% ***	**% ***	**% ***	**% ***	**% ***	**% ***
Happy	*90.2%*	*81.8%*	*72.6%*	*86.4%*	*85.3%*	*80.4%*	*85.4%*
Neither happy nor not happy	*3.9%*	*9.1%*	*8.1%*	*6.8%*	*4.4%*	*9.8%*	*8.3%*
Not happy	*5.9%*	*9.1%*	*19.4%*	*6.8%*	*10.3%*	*9.8%*	*6.3%*

** % of responses*

4.1.2 Question 1.2: Please tell us why you feel this way (N=158)

Participants were asked to tell us why they were either happy or not happy to share their health records. In total, 158 participants completed this question, providing 199 comments.

Positively, many participants can see how the sharing of health data can be helpful or beneficial (Table 11: 72 comments).

> *"It's a good thing in hospital they need all your info. As long as it's secure and can't be abused."*

27 participants engaged in discussions about anonymity, with 25 expressing happiness with the idea of sharing health information as long as it remains anonymous. Two participants raised concerns about the aspect of anonymity (Table 11).

> *"As long as no names."*

The security of the SDE emerged as a recurring theme among 25 participants. While the majority emphasised the necessity for a secure SDE, a minority expressed reservations, conveying a lack of trust in its security measures (Table 11: 21 comments, 4 comments respectively).

> *“I would want it to be as secure as can as I know how internet works.”*

Upon closer examination of the themes, particularly within the 35-44 age group, it becomes evident that one-third of participants who cited “privacy” in their responses belonged to this demographic (Table 12: 2 comments).

> *“I just wouldn’t want my details being shared.”*

Additionally, more than one-fourth of participants attributing their responses to “it’s personal information” fell within the 35-44 age bracket (Table 12: 2 comments).

> *“Good that anonymous but still personal info being shared.”*

Nine comments could not be themed and were categorised as other. These comments can be found in Appendix 3.

Table 11: Reasons for participants response to the happiness scale question

Coding	**No. of comments**
Can be helpful or beneficial	*72*
Happy if it is anonymous	*25*
The SDE needs to be secure	*21*
Depends on organisations who will have access	*10*
The more info/data available the better	*8*
I either have a health condition or care for someone who does	*8*
It’s personal information	*7*
Would want to know where my data would be shared	*6*
Not bothered	*6*
Privacy	*6*
Don't know	*6*
Health data is already shared	*5*

Concerned over data misuse	*4*
Don't trust the SDE will be secure	*4*
Don't trust the SDE will be anonymous	*2*
Other	*9*

Table 12: Reasons for participants response to the happiness scale question / 35-44 years

Coding	**No. of comments**
Can be helpful or beneficial	*10*
Happy if it is anonymous	*4*
It's personal information	*2*
Privacy	*2*
The more info/data available the better	*2*
Depends on organisations who will have access	*1*
Don't trust the SDE will be anonymous	*1*
I either have a health condition or care for someone who does	*1*
Other	*2*

4.1.3 Question 2: Would you be happy to share your health records with any of the following organisations, to use for research? (N=405)

Participants were asked to tell us if they would be happy to share their health records with[3]:

- Universities;
- NHS teaching hospitals;
- Pharmaceutical companies;
- Charities;
- Local councils who are responsible for public health;
- Their doctor, hospital or other health professional that looks after them;
- NHS hospitals for evaluating, planning and improving their services;

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[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

- Care agencies such as care homes and home care providers.

Nearly one in five participants, and significantly more, were not happy at all with sharing their health record with charities (Table 13 & Figure 2: 19.8%). One in four were generally not happy with the prospect of sharing with charities (25.7%).

Specific age groups exhibited a higher tendency of dissatisfaction with sharing their health records with charities, particularly among individuals aged 35-44, 65-74, and 75+. Approximately one in three within these age groups stated they were not happy with the idea of sharing (Table 14: 30.7%, 31.4%, 38.0% respectively).

Participants were significantly happier (very happy) to share their health records with Universities, NHS Teaching Hospitals, their doctor or hospital and NHS organisations (Table 13: 64.9%, 78.3%, 88.6%, 75.3% respectively). Levels were notable lower for pharmaceutical companies, charities, and local councils (56.9%, 47.7%, 54.1% respectively).

Just short of one in four participants in the 35-44 age bracket were not happy with sharing their health data with pharmaceutical companies, or care agencies, such as care homes and home care providers (Table 16: 22.6%, Table 17 5: 24.2% respectively).

Nearly one in five, 35-44 years old were not happy with sharing their health records with universities (Table 15: 19.4%).

Table 13: Sharing of health records with organisations:

Happiness scale	**Universities**	**NHS teaching hospitals**	**Pharmaceutical companies**	**Charities**	**Local councils who are responsible for public health**	**My doctor, the hospital or other medical professional who looks after me**	**NHS organisations for evaluating, planning and improving their services**	**Care agencies, such as care homes and home care providers**
	% *	**% ***	**% ***	**% ***	**% ***	**% ***	**% ***	**% ***
Very happy	*64.9%*	*78.3%*	*56.9%*	*47.7%*	*54.1%*	*88.6%*	*75.3%*	*60.2%*

Happy	*14.3%*	*11.4%*	*16.8%*	*13.3%*	*17.3%*	*5.4%*	*13.6%*	*14.6%*
Neither happy nor unhappy	*7.2%*	*0.03%*	*11%*	*13.3%*	*3%*	*2.5%*	*5.4%*	*9.9%*
Unhappy	*1.5%*	*0.01%*	*4.2%*	*5.9%*	*13.6%*	*0%*	*0.7%*	*2%*
Not at all happy	*12.1%*	*0.062%*	*0.106%*	*19.8%*	*12.1%*	*3.5%*	*4.9%*	*13.3%*

** % of responses*

Figure 2: Sharing of health records with organisations

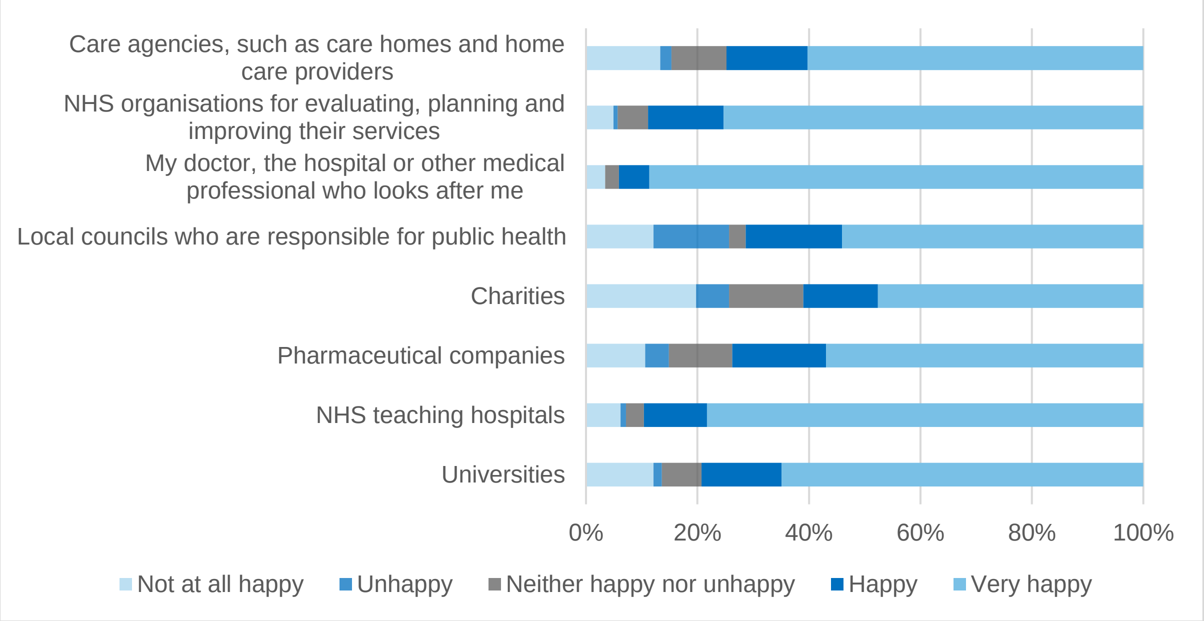


Table 14: Happiness scale of sharing health records with charities / age range

Happiness scale	**16-24**	**25-34**	**35-44**	**45-54**	**55-64**	**65-74**	**75+**
	% *	**% ***	**% ***	**%**	**% ***	**% ***	**% ***
Happy	*70.6%*	*65.2%*	*58.1%*	*71.2%*	*55.9%*	*52.9%*	*52%*
Neither happy nor not happy	*15.7%*	*10.6%*	*11.3%*	*8.5%*	*20.6%*	*25.5%*	*25%*
Not happy	*13.7%*	*24.2%*	*30.7%*	*20.3%*	*23.5%*	*31.4%*	*38%*

** % of responses*

Table 15: Happiness scale of sharing with universities / age range

Happiness scale	16-24	25-34	35-44	45-5	55-64	65-74	75+
	% *	% *	% *	% *	% *	% *	% *
Happy	*88.2%*	*77.3%*	*75.8%*	*78%*	*77.9%*	*82.4%*	*77%*
Neither happy nor not happy	*7.8%*	*7.6%*	*4.8%*	*0.085%*	*10.3%*	*2%*	*8%*
Not happy	*3.9%*	*15.2%*	*19.4%*	*13.6%*	*11.8%*	*15.7%*	*15%*

** % of responses*

Table 16: Happiness scale of sharing health data with pharmaceutical companies / age range

Happiness scale	16-24	25-34	35-44	45-54	55-64	65-74	75+
	% *	% *	% *	% *	% *	% *	% *
Happy	*66.7%*	*69.7%*	*71%*	*76.3%*	*75%*	*78.4%*	*79%*
Neither happy nor not happy	*19.6%*	*13.6%*	*6.5%*	*11.9%*	*11.8%*	*9.8%*	*6%*
Not happy	*13.7%*	*15.2%*	*22.6%*	*11.9%*	*13.2%*	*11.8%*	*15%*

** % of responses*

Table 17: Happiness scale of sharing health data with care agencies such as care home providers / age range

Happiness scale	16-24	25-34	35-44	45-54	55-6	65-74	75+
	% *	% *	% *	% *	% *	% *	% *
Happy	*82.4%*	*77.3%*	*67.7%*	*71.2%*	*76.5%*	*78.4%*	*71%*
Neither happy nor not happy	*9.8%*	*12.1%*	*8.1%*	*15.3%*	*8.8%*	*5.9%*	*8%*
Not happy	*7.8%*	*10.6%*	*24.2%*	*13.6%*	*14.7%*	*15.7%*	*21%*

** % of responses*

Question 3: Would you be happy for your GP practice, and other health services, to share your health records directly with the Secure Data Environment or would you prefer to manage this process yourself? (N=402)

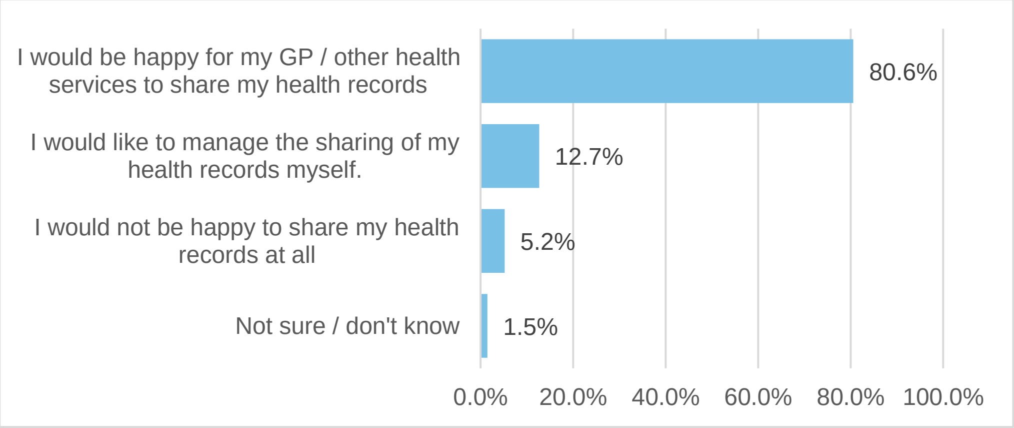
Participants were asked if they would be happy for their GP practice, and other health services to share their health records directly with the SDE, or if they would prefer to manage the process themselves.

Four in five suggested they would be happy for their GP / other health services to share their health records directly in to the SDE (Table 18 & Figure 3: 80.6%).

Table 18: Control over sharing of health records

Response	No. of responses	% of responses
I would be happy for my GP / other health services to share my health records	*324*	*80.6%*
I would like to manage the sharing of my health records myself.	*51*	*12.7%*
I would not be happy to share my health records at all	*21*	*5.2%*
Not sure / don't know	*6*	*1.5%*

Figure 3: Control over sharing of health records



4.1.4 Question 4: Do you trust that your anonymised health records would be used for the reasons described here only (i.e. to help develop new treatments, improve and evaluate services, improve public health, boost the economy, and prevent diseases) (N=405)

Participants were asked if they trusted that their anonymised health records would be used for the reasons described here only.[4]

Over four in five completely trust or trust that their anonymised health records would be used for the reasons described here only (Table 19 & Figure 4: 67.2%, 17.3% respectively).

A notable statistic reveals that almost one in five individuals aged 35-44 don't trust that their anonymised health records will be used for the reasons described here (Table 20: 19.4%). This distrust is notably higher compared to all other age groups.

Among participants who expressed neutrality, neither trusting nor distrusting that their anonymised health records would be used for the reasons described here, a substantial majority—specifically, two out of three—were female (Table 21: 62.9%, 37.1% respectively). This gender distribution holds significance in the overall findings.

Table 19: Do they trust what the health records will be used for?

Response	**No. of responses**	**% of responses**
Completely trust	*272*	*67.2%*
Trust	*70*	*17.3%*
Not strong feelings either way	*35*	*8.6%*
Little trust	*7*	*1.7%*
No trust at all	*21*	*5.2%*

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[4] Using a ten-point scale ranging from 1-10: Not 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 4: Do they trust what the health records will be used for?

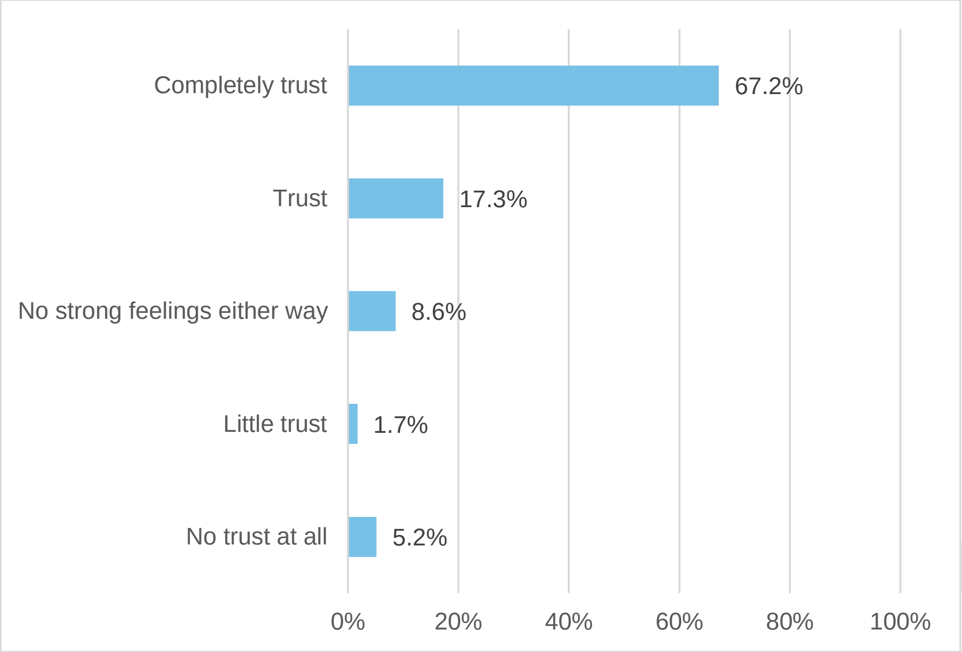


Table 20: Trust in usage / age range

Trust scale	**16-24**	**25-34**	**35-44**	**45-54**	**55-64**	**65-74**	**75+**
	% *	**% ***	**% ***	**% ***	**% ***	**% ***	**% ***
Trust	*96.1%*	*83.3%*	*69.4%*	*86.4%*	*83.8%*	*90.2%*	*85.4%*
Neither trust nor don't trust	*2%*	*10.6%*	*11.3%*	*11.9%*	*8.8%*	*2%*	*12.5%*
Don't trust	*2%*	*6.1%*	*19.4%*	*1.7%*	*7.4%*	*7.8%*	*2.1%*

** % of responses*

Table 21: Trust in usage: sex

Trust scale	**Females**		**Males**	
	No.*	**%****	**No.***	**%****
Completely trust	*145*	*68.7%*	*127*	*65.8%*
Trust	*32*	*15.2%*	*38*	*19.7%*
Neither trust nor don't trust	*22*	*10.4%*	*13*	*6.7%*
Little Trust	*5*	*2.4%*	*2*	*1.0%*

No trust at all	*7*	*3.3%*	*13*	*6.7%*

** No. of response*
*** % of responses*

4.1.5 Question 5: Do you think there are benefits to people sharing their health records to support research into new treatments, medicine and to prevent disease? (N=403)

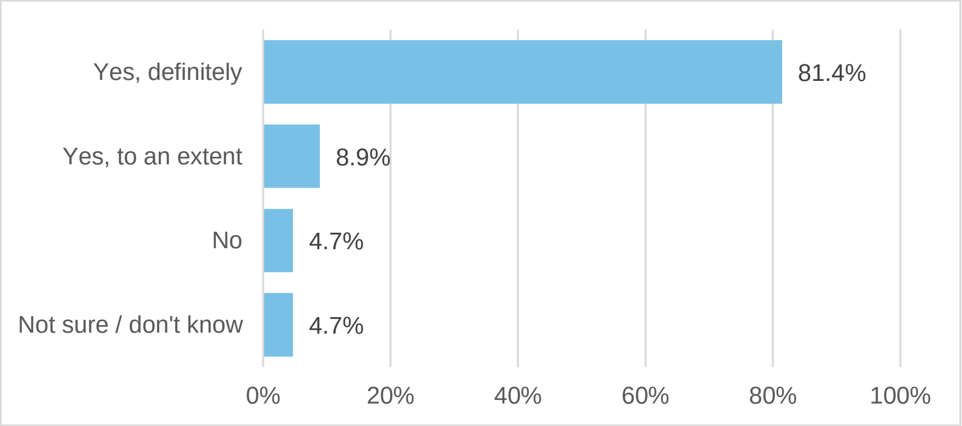
Participants were asked if they think there are any benefits to people sharing their health records to support research into new treatments, medicine and to prevent disease.

Four out of five participants definitely think there are benefits to people sharing their health records to support research into new treatment, medicine and to prevent disease (Table 22 & Figure 5: 81.4%).

Table 22: Are there benefits to people sharing health records?

Response	**No. of responses**	**% of responses**
Yes, definitely	*329*	*81.4%*
Yes, to an extent	*36*	*8.9%*
No	*19*	*4.7%*
Not sure / don't know	*19*	*4.7%*

Figure 5: Are there benefits to people sharing health records?



4.1.6 Question 5.2: Please tell us why you feel this way [in response to the above question] (N=152)

Participants were asked if they thought there were any benefits with sharing their health records with the SDE and why they felt this way. In total, 152 participants completed this question providing 166 comments.

A considerable proportion, of the participants (3 out of 4) can see that an increased pool of data will produce results and benefit the community (Table 23: 117 comments).

> *"The more we know about how many people have things, even likelihood of getting things. Be able to prioritise which conditions to focus treatment on."*

> *"The more info they have, the more that can help people and understand more. My husband had dementia, if they had more knowledge then - they would've been able to help. The more info available the more it will help."*

Regarding responses from the 35-44 age group, an overwhelming majority endorse the aforementioned theme, that a larger data pool will produce results and benefit the community (Table 24: 13 comments).

> *“The more research the better. You need large amounts of data in order for it to be seen as reliable.”*

In total nine comments could not be themed and were categorised as other. These comments can be found in Appendix 3.

Table 23: Are there benefits to the sharing of health records?

Coding	**No. of comments**
Increased pool of data equals more likely to produce results and benefit the community	*117*
Concerns over proper use of data - needs to be ethical/used for research only and not biased	*14*
Needs to be secure / done properly- concerns over hacking and anonymity	*6*
Don't trust any company / lost trust / may not be in our interests	*5*
More transparency needed – who would be accessing the data? Would want to know more	*4*
Don't know	*4*

I either have a health condition or care for someone who does.	*3*
Personal reasons	*2*
I don't see the benefits	*2*
Other	*9*

Table 24: Are there benefits to the sharing of health records? / 35-44 years

Coding	**No. of comments**
Increased pool of data equals more likely to get results and benefit the community	*13*
Concerns over proper use of data - needs to be ethical/used for research only and not biased	*2*
Don't trust any company / lost trust / may not be in our interests	*1*
More transparency needed – who would be accessing the data? Would want to know more	*1*
I don't see the benefits	*1*
Other~~Other~~	*~~2~~1*

4.1.7 Question 6: Do you think there are risks to people sharing their health records to support research into new treatments, medicine and to prevent disease? (N=402)

Participants were asked if they think there are risks to people sharing their health records to support research into new treatments, medicine and to prevent disease.

One in two feel that there are no risks to people sharing their health records to support research into new treatment, medicine and to prevent disease (Table 25 & Figure 7: 53.7%).

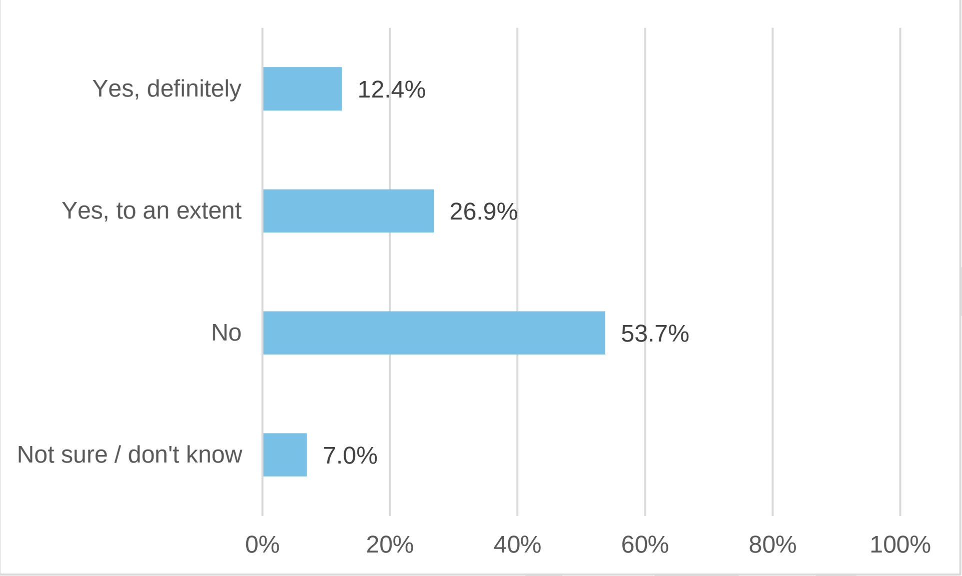
One in four think that that to an extent there are risks (Table 25 & Figure 7: 26.9%).

Table 25: Are there risks to people sharing health records?

Response	**No. of responses**	**% of responses**
Yes, definitely	*50*	*12.4%*

Yes, to an extent	*108*	*26.9%*
No	*216*	*53.7%*
Not sure / don't know	*28*	*7.0%*

Figure 6: Are there risks to people sharing health records?



4.1.8 Question 6.1: If you have concerns, please tell us what they are [in relation to the above question] (N=136)

Participants were invited to express any concerns they may have about the sharing of health records. In total, 136 participants completed this question providing 147 comments.

Over one in three expressed apprehensions about the sharing of data with inappropriate organisations and the potential for data leaks (Table 26: 58 comments).

> *"Data is not always neutral and can be manipulated. One statistic can be used to build one argument. If slightly shifted could be used for another argument. In wrong hands or used in certain ways it could be dangerous. If for instance you just use it to get 100 people with a terrible disease but if you don't add in context that it's out of 1 million people - it can be said differently."*

Close to a quarter of participants who exhibited no concerns about sharing data, particularly if it was anonymous, fell within the age group of 35-44 years (Table 27: 2 comments).

> *"It's anonymous so I don't think so."*

One in five individuals who expressed concerns, about the perceived lack of overall security, noting that total security can’t be guaranteed, fell within the age group of 35-44 (Table 27: 2 comments).

> *“Computers and systems are never completely safe.”*

In total, three comments could not be themed and were therefore categorised as other. These comments can be found in Appendix 34.

Table 26: If you have concerns, please tell us what they are?

Coding	**No. of comments**
Data falling into the 'wrong hands' or potential data leaks	*59*
There is no guarantee of complete security – always risks	*24*
Concerns over data misuse / sharing the data or selling it to a third party	*17*
Concerns over anonymity	*10*
No issue if the records are anonymous	*9*
No risks if the system is secure	*8*
There is a potential for scams to arise.	*4*
Data can be manipulated/bias	*3*
The data should be kept private, as some individuals prefer not to have this information shared.	*2*
No control over data use / more people having access / more chance of a data breach	*2*
No risks	*2*
Don’t know	*2*
Other	*5*

Table 27: If you have concerns please tell us what they are? / 35-44 years

Coding	**No. of comments**
Data falling into the 'wrong hands' or potential data leaks	*9*

There is no guarantee of complete security – always risks	*5*
No issues if the records are anonymous	*2*
Concerns over data misuse / sharing the data or selling it to a third party	*2*
No risks if the system is secure	*1*
No control over data use / more people having access / more chance of a data breach	*1*
Don't know	*1*

4.1.9 Question 7: Do you already share your health information with research organisations? (N= 405)

Participants were asked if they already share their health information with research organisations. Over four in five do not share their health information with research organisations (Table 28 & Figure 7: 87.1%).

Individuals uncertain about whether they share their health data were notably more likely to be female, with two out of three participants in this category identifying as female. (Table 29: 68.3%). This is significant.

19 participants disclosed additional organisations with which they shared their data, and this detailed information can be located in Appendix 3.

Table 28: Current sharing of health records

Response	**No. of responses**	**% of responses**
Yes, as part of the UK Biobank	*2*	*0.5%*
Yes, Our Future Health	*4*	*1.0%*
Yes, as part of Zoe	*2*	*0.5%*
Yes, as part of a local research organisation	*9*	*2.2%*
Don't know	*16*	*4.0%*
No	*353*	*87.2%*
Other	*19*	*4.7%*

Figure 7: Current sharing of health records

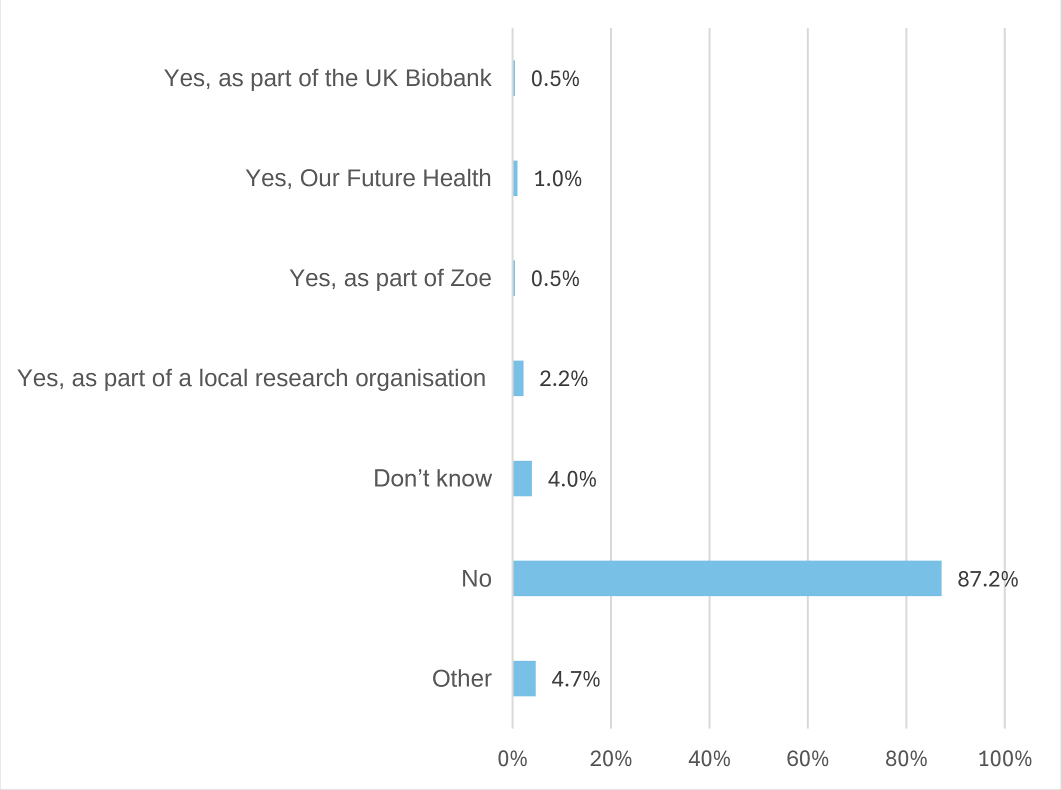


Table 29: Current sharing of health records / sex

Response	Female		Male		Total
	No.	%	No.	%	
Yes, as part of the UK Biobank	*2*	*100.0%*	*0*	*0.0%*	*2*
Yes, Our Future Health	*2*	*50.0%*	*2*	*50.0%*	*4*
Yes, as part of Zoe	*1*	*50.0%*	*1*	*50.0%*	*2*
Yes, as part of a local research organisation	*2*	*22.2%*	*7*	*77.8%*	*9*
Don't know	*11*	*68.8%*	*5*	*31.3%*	*16*
No	*182*	*51.6%*	*170*	*48.2%*	*353*
Other	*11*	*57.9%*	*8*	*42.1%*	*19*

4.1.10 Question 8: How do you think the Secure Data Environment should be funded? (more than one response could be selected) (N=405)

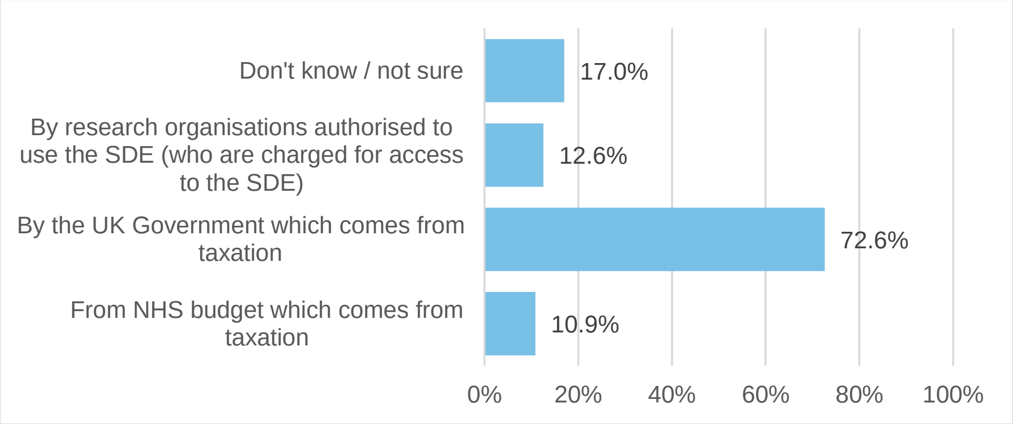
Participants were asked how they think the SDE should be funded.

Nearly three in four think the SDE should be funded by the UK Government (Table 30 & Figure 8: 72.6%).

Table 30: How should the SDE be funded?

Response	No. of responses	% of responses
From NHS budget which comes from taxation	*44*	*10.9%*
By the UK Government which comes from taxation	*294*	*72.6%*
By research organisations authorised to use the SDE (who are charged for access to the SDE)	*51*	*12.6%*
Don't know / not sure	*69*	*17.0%*

Figure 8: How should the SDE be funded?



4.1.11 Question 9: When the Secure Data Environment is operational would you be interested in learning more about the types of projects it supports and how this is making an impact on people's health? (N=400)

Participants were asked when the SDE is operational would they be interested in learning more about the types of projects it supports and how this is making an impact on people's health.

One in five would be interested in learning more (Table 31 & Figure 9: 19.8%).

In terms of participants that said they would be interested in learning more about the types of projects it supports and how this is making an impact on people's health, the majority, nearly three-quarters were happy to share their health records (Table 32: 78.8%).

Table 31: Interest in learning more

Response	**No. of responses**	**% of responses**
Yes	*79*	*19.8%*
No	*311*	*77.8%*
Don't know	*10*	*2.5%*

Figure 9: Interest in learning more

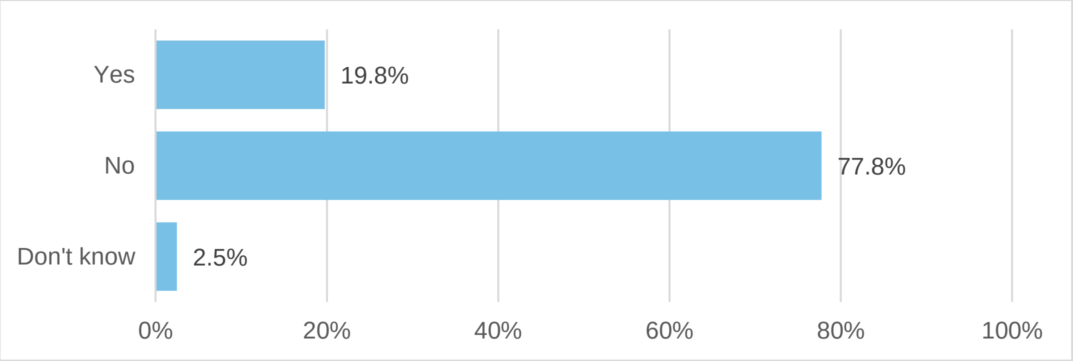


Table 32: Interest in learning more / happiness scale

Happiness scale	**Yes**		**No**	
	No.*	%**	No.*	%**
Happy	*63*	*78.8%*	*263*	*84.6%*
Neither nor not happy	*8*	*10.0%*	*19*	*6.1%*
Not happy	*9*	*11.3%*	*29*	*9.3%*

4.1.12 Question 10: Would you like to know more about the Secure Data Environment? (N=402)

Participants were asked if they would like to know more about the SDE, if they said yes, they were provided with a leaflet outlining frequently asked questions. A copy of this leaflet can be seen in Appendix 4.

One in four participants received a leaflet and wanted to know more about the SDE (Table 33 & Figure 10: 25.0%).

Regarding participants that expressed interest in learning more about the SDE, a significant majority - over three in four - were happy to share their health records (Table 34: 81.0%).

Table 33: Would participants like to know more about the SDE?

Response	No. of responses	% of responses
Yes	*100*	*25.0%*
No	*302*	*75.1%*

Figure 10: Would participants like to know more about the SDE?

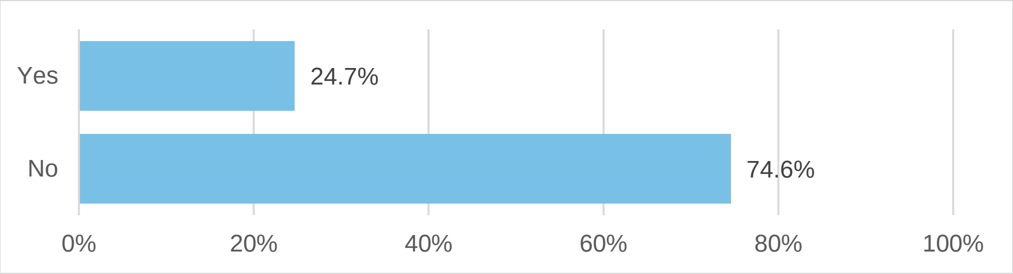


Table 34: Would participants like to know more about the SDE? / Happiness scale

Happiness scale	Yes		No	
	No.*	%**	No.*	%**
Happy	*81*	*81.0%*	*252*	*84.0%*
Neither happy nor not happy	*8*	*8.0%*	*21*	*7.0%*
Not happy	*11*	*11.0%*	*27*	*9.0%*

** No. of responses*
*** % of responses*

4.1.13 Question 11: Would you like to take part in opportunities to provide your views on the development of the Secure Data Environment in the North East and Cumbria? (N=400)

Participants were asked if they would like to take part in opportunities to provide their views on the development of SDE in the North East and Cumbria.

Fewer than one in six said they would like to take part in opportunities (Table 35 & Figure 11: 14.0%).

In terms of participants expressing interest in participating in opportunities to share their views on the development of the SDE, a substantial majority - over three in four - were happy to share their health records (Table 36: 78.9%).

Table 35: Would participants like to take part in opportunities to provide their views?

Response	No. of responses	% of responses
Yes	*56*	*14.0%*
No	*344*	*86.0%*

Figure 11: Would participants like to take part opportunities to provide their views?

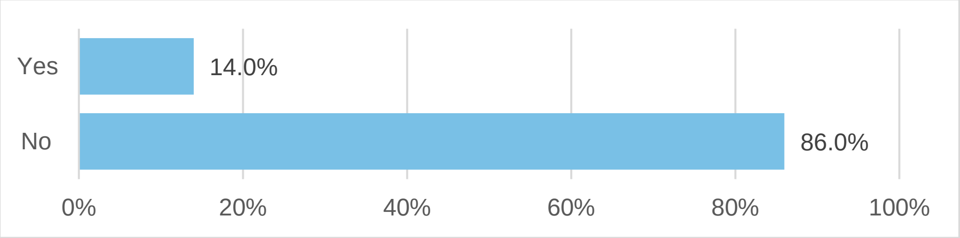


Table 36: Would participants like to take part opportunities to provide their views? / happiness scale

Happiness scale	Yes		No	
	No.*	%**	No.*	%**
Happy	*45*	*78.9%*	*289*	*84.3%*
Neither happy nor not happy	*5*	*8.8%*	*23*	*6.7%*
Not happy	*7*	*12.2%*	*31*	*9.0%*

** No. of responses*
*** % of responses*

4.1.14 Question 13: Is there anything else you would like to add? (N=62)

Participants were asked if there was anything else they would like to add. In total 62 participants provided 62 comments.

Only 62 out of the 405 participants who took part in this survey provided responses to this question. Consequently, 343 participants did not offer any additional comments. Furthermore, among the received comments, the majority similarly expressed that they had nothing further to add (Table 37: 41 comments).

Only nine comments were received from those aged 35-44 years, with, again, the majority indicating they had nothing further to add (Table 38: 6 comments).

Half of those that expressed support or satisfaction with the use of data for R&D were in the 35-44 years age bracket (Table 38: 2 comments).

> *"It's for research and developmental improvement really, I support that."*

In total three comments could not be themed and were therefore categorised as other. These comments can be found in the Appendix 3.

Table 37: Do participants have anything else to add?

Coding	**No. of comments**
No further comments	*41*
Good to hear about security of records as it needs to be secure	*4*
Support / happy with the use and the plan to use health records for R&D	*4*
Hope it's useful/improves things	*2*
Other	*11*

Table 38: Participants have anything else to add / 35-44 years

Coding	**No. of comments**
No further comments	*6*
Support / happy with the use and the plan to use health records for R&D	*2*
Other	*1*

5 Next steps

Emerging findings from this report were presented…

There will be a further meeting on...

The report forms part of the review to decide XXX and will be considered alongside clinical, quality and other reports.

Decisions about next steps will follow…

6 Appendices

Appendix 1 – Survey Questions

SDE baseline survey Nov-Dec 2023

Introduction

This survey is about sharing your NHS health records, also known as 'health data'.

A lot of anonymous health records is already shared with researchers, such as universities, teaching hospitals and local authority public health teams. This could include your NHS health records. Your personal details, like your name and address, are removed for privacy and you can opt out anytime.

This information is used as part of important research to support new health and care discoveries that will help people live healthier lives for longer.

Sharing data from health records helps develop new treatments, improve and evaluate services, improve public health, boost the economy, and prevent diseases.

However, the NHS want to improve the way this information is stored and used by researchers. They plan to do this with a new, secure, online system called the 'Secure Data Environment' (SDE). The new system will ensure:

- Data safety and security.
- Strict monitoring of data usage.
- Restricted access to authorised people only.
- Data accuracy and timeliness.
- Better transparency of NHS data use
- Improve public member involvement

Strict controls and penalties will in place to prevent data misuse. Only approved and authorised organisations and trained and approved individuals will be able to access the SDE. The sort of authorised organisations include:

- Universities and NHS teaching hospitals for health research.
- Pharmaceutical companies for medication development.
- National charities for health issues.
- NHS organisations for service improvement.

We will publish a summary of the survey results and more details about the SDE on the NHS North East and North Cumbria website. Similar to how council tax usage is shared, we'll inform locals about how their data benefits the NHS.

---

1. On a scale of 1 – 10, how happy would you feel about your anonymous health records being shared in the Secure Data Environment?

1 – Not happy at all

10 – Very happy

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Please tell us why you feel this way

2. Would you be happy to share your health records with any of the following organisations, to use for research?

1 = Not at all happy

10 = Very happy

	1	2	3	4	5	6	7	8	9	10
Universities										
NHS teaching hospitals										
Pharmaceutical companies										
Charities										
Local councils who are responsible for public health										
My doctor, the hospital or other medical professional who looks after me										
NHS organisations for evaluating, planning and improving their services										
Care agencies, such as care homes and home care providers										

3. Would you be happy for your GP practice, and other health services, to share your health records directly with the Secure Data Environment or would you prefer to manage this process yourself?

- ○ I would be happy for my GP / other health services to share my health records
- ○ I would like to manage the sharing of my health records myself.

- ○ I would not be happy to share my health records at all
- ○ Not sure / don’t know

4. Do you trust that your anonymised health records would be used for the reasons described here only (i.e. to help develop new treatments, improve and evaluate services, improve public health, boost the economy, and prevent diseases)?

1 - No trust at all
10 - Completely trust

1	2	3	4	5	6	7	8	9	10
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

5. Do you think there are benefits to people sharing their health records to support research into new treatments, medicine and to prevent disease?

- ○ Yes, definitely
- ○ Yes, to an extent
- ○ No
- ○ Not sure / don't know

Please tell us why you feel this way:

6. Do you think there are risks to people sharing their health records to support research into new treatments, medicine and to prevent disease?

- ○ Yes, definitely
- ○ Yes, to an extent
- ○ No
- ○ Not sure / don't know

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

7. Do you already share your health information with research organisations?

- ☐ Yes, Our Future Health

- ☐ Yes, as part of the UK Biobank
- ☐ Yes, as part of Zoe
- ☐ Yes, as part of a local research organisation (such as your hospital of a university trial)
- ☐ No
- ☐ Don’t know
- ☐ Yes, other (please specify):

8. How do you think the Secure Data Environment should be funded?

- ☐ From NHS budget which comes from taxation
- ☐ By the UK Government which comes from taxation
- ☐ By research organisations authorised to use the SDE (who are charged for access to the SDE)
- ☐ Don't know / not sure
- ☐ Other (please specify):

9. When the Secure Data Environment is operational would you be interested in learning more about the types of projects it supports and how this is making an impact on people's health?

- ○ Yes
- ○ No
- ○ Don't know

10. Would you like to know more about the Secure Data Environment?

- ○ Yes [Hand out leaflet] There are some frequently asked questions you may find useful here.
- ○ No

11. Would you like to take part in opportunities to provide your views on the development of the Secure Data Environment in the North East and Cumbria?

- ○ Yes [Go to Q12]
- ○ No [Go to Q13]

12. If yes:

Name:

Email:

13. Is there anything else you would like to add?

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7. Demographics

About you

We would like to ask some questions about you. These questions are completely optional, but we hope you will complete them. This will help us understand who we have reached with our survey, and whether different groups have different views or needs. Any information you provide will be kept entirely confidential and will never be traced back to you as an individual.

Postcode: Postcode is recommended where a geographic spread of respondents is needed.

14. Please provide the first four characters of your postcode:

15. What age are you?

16. Which of the following best describes you?

○ Female
○ Male
○ Non-binary
○ Prefer not to say
○ Prefer to self-describe:

17. Is the gender you identify with the same as your sex registered at birth?

○ Yes
○ No
○ Prefer not to say

18. What is your ethnic group?

Asian or Asian British

○ Bangladeshi
○ Chinese
○ Indian
○ Pakistani
○ Any other Asian background (please describe below)

Black, black British, Caribbean or African

○ African
○ Caribbean
○ Any other black, black British, African or Caribbean background (please describe)

Mixed or multiple ethnic groups

○ White and black African
○ White and Asian
○ White and black Caribbean
○ Any other mixed or multiple ethnic background (please describe below)

White

○ English, Welsh, Scottish, Northern Irish or British
○ Irish
○ Gypsy or Irish Traveller
○ Roma
○ Any other white background (please describe below)

Any other Ethnic Group

○ Arab

○ Other (please describe below)
○ I do not wish to disclose my ethnic origin
○ Other (please specify):

19. What is your religion? (Please select only one)

○ No religion or belief
○ Christian (including Church of England, Catholic, Protestant, and other Christian denominations)
○ Buddhist
○ Hindu
○ Jewish
○ Muslim
○ Sikh
○ Prefer not to say
○ Other (please specify):

20. Which of the following best describes your sexual orientation?

○ Straight or Heterosexual
○ Gay or lesbian
○ Bi or bisexual
○ Prefer not to say
○ Prefer to self-describe:

21. Do you have any physical or mental health conditions, impairments, or learning differences that impact on your ability to carry out day-to-day activities? Please select all that apply.

○ Long term health condition

○ Physical impairment or mobility issues
○ Sensory impairment, such as blind or visual loss and Deaf or hearing loss
○ Mental health condition
○ Learning disability
○ Neurodivergence
○ No condition or impairment
○ Other (please specify):

22. Are you pregnant or have you been pregnant in the last six months?

○ Yes
○ No
○ Prefer not to say
○ Not applicable

23. What is your legal marital or registered civil partnership status?

○ Never married or in a civil partnership
○ Married
○ In a legally registered civil partnership
○ Separated but still legally married
○ Separated but still legally in a civil partnership
○ Divorced
○ Formerly in a civil partnership which is now legally dissolved
○ Widowed
○ Surviving partner from a civil partnership
○ Prefer not to say

Appendix 2 – Full demographic profile of participants

Postcodes	**% of responses**	**Number of responses**		**% of responses**	**Number of responses**
CA1 3	*30%*	*12*	*NE5 4*	*5.7%*	*23*
CA1 7	*0.7%*	*3*	*NE63 0*	*14.6%*	*59*
CA2 7	*9.9%*	*40*	*NE8 2*	*1.7%*	*7*
DH1 1	*5.4%*	*22*	*NE8 3*	*4.9%*	*20*
DH1 4	*6.4%*	*26*	*NE8 4*	*1%*	*4*
DH1 5	*2.7%*	*11*	*SR4 6*	*4.9%*	*20*
NE10 9	*0.7%*	*3*	*SR4 7*	*1.2%*	*5*
NE11 9	*7.4%*	*30*	*SR5 4*	*7.4%*	*30*
NE3 1	*4.2%*	*17*	*TS18 3*	*3.0%*	*12*
NE4 4	*0.2%*	*1*	*TS26 8*	*3.5%*	*14*
NE4 5	*1.7%*	*7*	*TS26 9*	*2.7%*	*11*
NE5	*0.2%*	*1*	*TS5 6*	*4.4%*	*18*
NE5 3	*2.2%*	*9*			

Which of the following best describes you?	**% of responses**	**Number of responses**
Female	*52.1%*	*211*
Male	*47.7%*	*193*
Prefer not to say	*0.2%*	*1*

Is the gender you identify with the same as your sex registered at birth?	**% of responses**	**Number of responses**
Yes	*98.3%*	*398*
No	*1.0%*	*4*

Prefer not to say	*0.7%*	*3*

What is your ethnic group?	**% of responses**	**Number of responses**
African	*2.5%*	*10*
Any other Asian background (please describe below)	*4.9%*	*20*
Any other mixed or multiple ethnic background (please describe below)	*1.5%*	*6*
Any other white background (please describe below)	*2.2%*	*9*
Arab	*0.5%*	*2*
English, Welsh, Scottish, Northern Irish or British	*87.7%*	*355*
Sudan	*0.2%*	*1*
Syria	*0.5%*	*2*

What is your religion?	**% of responses**	**Number of responses**
Christian	*35.8%*	*145*
Hindu	*1.0%*	*4*
Muslim	*2.5%*	*10*
Sikh	*0.2%*	*1*
No religion or belief	*58.8%*	*238*
Other Religion	*0.7%*	*3*
Prefer not to say	*1.05%*	*4*

Which of the following best describes your sexual orientation?	**% of responses**	**Number of responses**

Straight or Heterosexual	*86.7%*	*351*
Gay or lesbian	*1.5%*	*6*
Bi or bisexual	*3.7%*	*15*
Prefer not to say	*8.1%*	*33*

Are you pregnant or have you been pregnant in the last six months?	**% of responses**	**Number of responses**
Yes	*2.5%*	*10*
No	*88.1%*	*357*
Not applicable	*9.1%*	*37*
Prefer not to say	*0.2%*	*1*

What is your legal marital or registered civil partnership status?	**% of responses**	**No. of responses**
Married	*36.3%*	*147*
In a legally registered civil partnership	*6.4%*	*26*
Never married or in a civil partnership	*33.3%*	*135*
Separated but still legally in a civil partnership	*0.2%*	*1*
Separated but still legally married	*1.0%*	*4*
Divorced	*8.9%*	*36*
Widowed	*12.3%*	*50*
Prefer not to say	*1.5%*	*6*

Do you have any physical or mental health conditions, impairments, or learning differences that impact on your ability to carry out day-to-day activities?	**% of responses**	**Number of responses**
Long term health condition	*9.9%*	*40*
Physical impairment or mobility issues	*11.6%*	*47*

Sensory impairment, such as blind or visual loss and Deaf or hearing loss	*0.0%*	*0*
Mental health condition	*9.4%*	*38*
Learning disability	*1.0%*	*4*
Neurodivergence	*2.0%*	*8*
No condition or impairment	*66.9%*	*271*

Appendix 3 – Other comments

During the analysis some comments could not be themed and were categorised as other. Below are the comments received per question.

Question 1.2 - Please tell us why you feel this way
"I spent the first 6 years in Netherlands, everything there very quick, in the UK everything is slow."
"Been waiting for an appointment for my eyes 2 years in April. Telephone appointment system all wrong~~.~~."
"Don't understand charity element."
"I have some experience of finding out about where my health records have been shared, quite recently. I needed to get some serious spine treatment (as a result of surgery going wrong almost 30 years ago) - and we looked into options available. In the process, my sons had to find more out about my health history and discovered that my health records were with an organisation in Cambridge. They knew everything about my health history all the way back approx. 26 years. Then, when we needed more info about a month later, the records had transferred to America. This really surprised me."
"No problem for NHS is I'm living for years in England."
"I don't think my info has been misused."
"I've had terrible experience of bad medical practices and negligence and don't trust anyone "
"Very difficult to get appt with GP so not happy with NHS."
"Nothing has helped me health wise. I've been waiting for a hip replacement since the late 90s. Other health issues have followed. In the end, I gave up and I can't be bothered with it anymore. "

Question 5.2 - Please tell us why you feel this way
"Obvious there's Alzheimer's, a cure for cancers been going for years. It's a Postcode lottery, it could help with that and medication to help them."
"I work at hospital it just gives you a wider knowledge of a person if they can't tell you something. People forget things all of the time."
"…When in hospital with cancer two students talking to me."
"Need new things and to try new things since things haven't improved that much."

"Not my own experience but friends not sharing letters not received so can't be operated on. Not knowing what painkillers someone was given."
"My experience says they're all useless."
"You see the pitfalls."
"I just don't think that people or organisations listen anyway."
"Not convinced it will boost the economy."

Question 5.2 – What are your concerns?
"Addictions. Can go online and buy different medications no face-to-face actual contacts."
"Pretty much for the same reasons. Everyone is different and there could be mix ups - both in the research and their data. It could result in complications."
"Localised issues possibly."
"As long as with consent."
"Limited access limited info should be shared."

Q7. Do you already share your health information with research organisations?
"I share my health history with a Cancer research / NHS organisation."
"Private dentist and acupuncturist."
"University of Cambridge 'Safer Trial."
"Insurance."
"Private dental and pension."
"Insurance co."
"Private health care."
"It was a university, can't recall which. Relating to research / medications I was on at the time."
"Private organisations."
"Life insurance."

"University tests."
"My GP probably does."
"DVLA."
"Healthcare at home."
"Covid research and breast cancer."
"Counsellors."
"Parents organised it."

Question 13 – Is there anything else you would like to add?
"Councils messed me around trying to get adaptations in house."
"Just push it all through quickly so that I can get my new hip."
"G."
"It's all confusing."
"It would be good to get an update."
"Data once out there it is out there."
"Only info that is needed should be shared."
"Not really - just that I was so happy with the treatment that I received for my cancer 2/3 years ago. It was quick, and the surgery was successful. It was a worrying time because Covid was around, but I'm grateful for the advancements in medicine and treatments that have helped me."
"NHS is a nightmare and don't trust it."
"I don't mind looking through and trying to help people but don't want everybody looking at my record unless I'm anonymous."
"Feel like sometime within NHS one dept not sharing info with another dept very well and this can lead to discrepancies, GP at hospital has no full record if your health history. It should be shared amongst NHS."

Appendix 4 – SDE frequently asked questions (FAQs)

North East and North Cumbria
SECURE DATA ENVIRONMENT

Part of the
NHS Research Secure Data Environment Network

NHS
North East and North Cumbria

A summary of what Secure Data Environments are

We know from the COVID-19 pandemic that data saves lives.

Data helps our doctors and nurses make better decisions in delivering care and helps our researchers to discover life-changing new treatments.

It is critical that patient data is handled safely and ethically. To achieve this, the department of Health and Social Care and the NHS in England are investing to move from processes that rely on data being shared to a system where data is accessed. This will be done on platforms known as Secure Data Environments (SDEs), which is designed to give your NHS data more protection.

For the purposes of research:

- An SDE will securely hold anonymous local health data
- your anonymous data will be shared unless you 'opt out'
- you can opt out of giving any confidential data at anytime
- the data will only be available to authorised organisations
- the data will help to develop new treatments, improve services, boost the economy and prevent disease
- no identifiable, personal information will be shared.

For more information see: https://northeastnorthcumbria.nhs.uk/our-work/workstreams/digital-care/secure-data-environment/

Thank you for taking part in our survey today.

We will publish a summary of the survey results and more details about the SDE on the NHS North East and North Cumbria ICB website.