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North East and North Cumbria Secure Data Environment

Engagement with young people

February 2025

Contents

Executive summary

Stand were commissioned to drive the engagement of key stakeholders on the North East and North Cumbria Integrated Care Board’s (NENC ICB) Secure Data Environment (SDE) programme. This work is being delivered in partnership with the regional Health Innovation Network who are leading on the communications around the programme. Previous segmentation work identified six key personas across the region’s population who have concerns about data sharing, the 16–24-year-old age group being one of them.

This report outlines the approach taken to engage with this age group and further their views on sharing health records via the Secure Data Environment (SDE) for research and non-research purposes. The feedback will be used to respond to a clarification request from the Confidentiality Advisory Group (CAG).

Young people living across the region were given the opportunity to share their views in an online survey and social media poll during the months of September 2024 - January 2025.

Key findings

Between 44-63% are comfortable with an authorised NHS organisations accessing their health record and then removing all their identifiable details *(the range is explained by the results in the two different engagement methods*).

For research purposes, 68-73% are willing to share their health records, with 90% comfortable sharing with their doctor and 64% with NHS Teaching Hospitals. However, less than half feel comfortable sharing with care agencies, universities, charities, local councils, and pharmaceutical companies, although support still outweighed opposition.

Young people are less inclined to share their health records for non-research purposes, with only 23-51% willing to do so. Just over half (54%) would share their health record with their doctor or health professional, but fewer were willing to share with other organisations.

Concerns about sharing health data included risks to privacy and security, and the potential for identifying individuals. Most (71%) would prefer to approve data sharing themselves rather than having their GP or other health services do it on their behalf. Trust that their health records would be used for the described reasons of the SDE only ranged from 21-39%, whilst 24-39% had little or no trust.

Overall, compared to the general population, 16-24-year-olds showed less satisfaction with an authorised NHS organisations accessing their health records and removing all their identifiable details, higher concerns about risks, lower trust in data use, and a preference for self-approval of data sharing. A significant number of young respondents provided neutral responses, indicating uncertainty or lack of interest, which may explain the low response to the online survey.

Further qualitative research is planned to better understand their concerns and identify mitigation steps.

Introduction

Stand were commissioned to drive the engagement of key stakeholders on the NENC Integrated Care Board's (ICB) Secure Data Environment (SDE) programme. This work is being delivered in partnership with the regional Health Innovation Network who is leading on the communications around the programme.

As part of an important 'S251 application', that will allow the ICB to transfer data from organisations across the region into the SDE, the Confidentiality Advisory Group (CAG) requested clarification of local people's understanding and opinions about the use of personal health and care data for research and non-research purposes.

In gathering a response to CAG, PPIE leads at Stand developed a survey to engage and involve patients and the public with the work of the SDE and gain a better understanding of their views about sharing health and care records for research and non-research purposes.

Previous segmentation work identified six key personas across the region's population who have concerns about data sharing, the 16–24-year-old age group being one of them. This report outlines the approach taken and the findings from the engagement with this age group. Engagement was undertaken September 2024 – January 2025.

Starting outers – Students, younger couples and singles in flats (i.e. those aged **16-24 years**)	Examination of national opt-out rate by NENC Acorn type reveals that *Younger couples & singles in flats* have one of the highest opt-out rates in NENC (Acorn group 3.I.26; 4.8% Opt-Out, 0.4% of NENC population). Furthermore, *Students & sharers in multi-occupancy flats* have been found to be the most concerned about the lack of security of their online data (Acorn group 6.U.59). Exploring opt-out by age band revealed that 2.9% of those aged 10 – 19 years chose to opt-out with this figure rising to 6.4% of those 20 – 29 years. [The highest opt-out was 8.0% for women aged 30-39 years and 6.0% of men aged 40-49 years]. The Office for National Statistics (2023) suggests however that younger age groups (particularly those aged 18-24 years) tend not to question or spend time worrying about data sharing, because they have been sharing data their whole lives. They cannot see what difference it would make to share just that little bit more, as so much is already out there. It is therefore important to understand the perspective of this cohort of individuals and how this differs with other age bands.

Methodology

Online survey

An online survey was launched on 9 September and closed on 22 November 24.

This was a repeat of the on-street survey carried out in August this year which targeted a North East and North Cumbria (NENC) population representative sample. To make it more concise, two open questions were removed.

The aim was to engage with a demographically and geographically representative sample of young people aged 16-24 years living in NENC. It was hoped that a minimum response rate of 250 would provide confidence in the results.

The survey was delivered:

- 'organically' – by contacting partner organisations to share a link to the survey with the target group.
- via social media channels in a paid campaign, sharing the same link.

Attempts were made to include as many young people within the protected characteristics as possible.

The total response rate on close of the survey was 41 (22 organic completions and 19 responding to the paid campaign). With the desired response rate not being achieved, an alternative approach was taken.

Social media polling questions

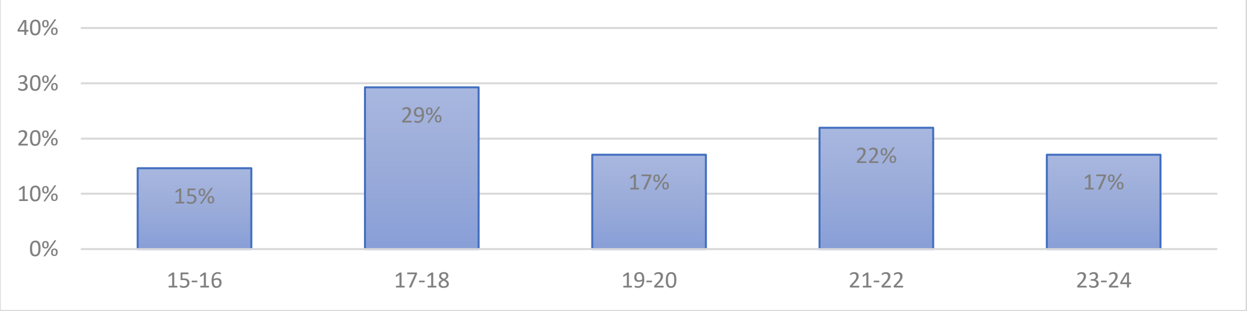
During the month of January 25, key questions from the survey were targeted at this age group using social media polls. During this time, 139 young people from NENC responded to the poll questions. The method did not allow demographic information to be captured.

Analysis of the online survey

Respondent sample

The online survey was completed by 41 young people aged 16 to 24 years. The figure below shows the age breakdown of these respondents.

Figure: Age breakdown (N=41)



The highest proportions were from Newcastle and Teesside (24% from each area) with smaller and similar proportions from Northumberland (15%), Cumbria (10%), Durham (10%) and Sunderland (10%). Just 5% were from Gateshead.

Table: Location (N=41)

	No.	%
Newcastle	10	24%
Teesside	10	24%
Northumberland	6	15%
Cumbria	4	10%
Durham	4	10%
Sunderland	4	10%
Gateshead	2	5%
Unknown	1	2%

A full breakdown of the equality and monitoring information collected is available in the Appendix, with a summary provided here:

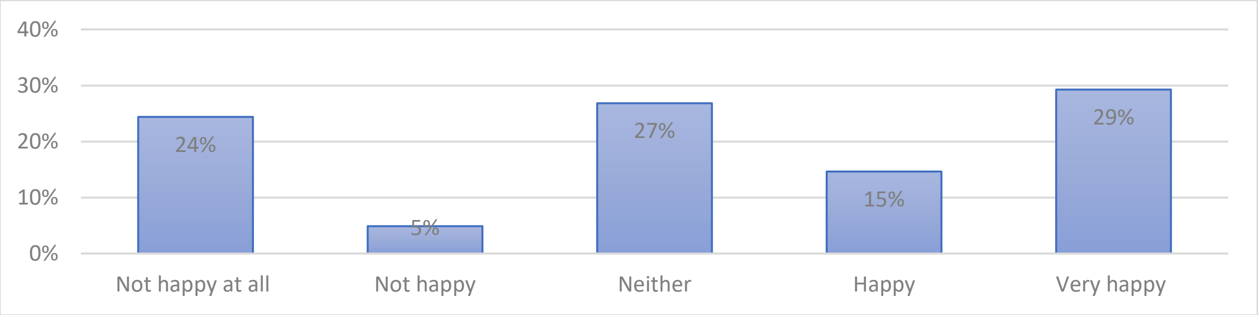
- 66% were female and 17% male. Additionally, 2% identified as non-binary, whilst 2% preferred to self-describe (12% chose not to respond).
- 2% told us their gender did not match their sex registered at birth.
- 76% were English, Welsh, Scottish, Northern Irish or British, and 2% Indian (22% chose not to respond).
- 51% had no religion or belief, 22% said they were Chrisitan, 2% Hindu and 2% another religion / belief (22% chose not to respond).
- 59% told us they were straight or heterosexual, whilst 7% were Bi/bisexual and the same proportion gay / lesbian. An additional 2% prefer to self-describe (24% chose not to respond).
- 32% said they have a mental health condition, 10% a long-term condition, 15% neurodivergent, 7% a learning disability, 5% a sensory impairment and 2% a physical impairment or mobility issues.
- No respondents were currently pregnant or have been in the last six months.
- 73% said they have never been married / in a civil partnership, whilst 2% were divorced (24% chose not to respond).
- Most said they have enough money for basic necessities, and a little spare, that they can save or spend on extras or leisure (34%), with a slightly smaller proportion having just enough money for basic necessities and little else (22%). Smaller proportions have more than enough money for basic necessities and a lot to spare (15%) or have just enough money for basic necessities (10%) (20% chose not to respond).

Question responses

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

Respondents were asked on a scale of 1 – 10[1], how they would feel about an approved and authorised NHS organisation having access to their identifiable health record and then removing all their identifiable details.
44% indicated that they were happy or very happy, whilst 29% were not happy. Notably, 27% said they were neither happy nor unhappy.

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=41)



The young people who indicated that they were happy talked about how the process would ensure that all their identifiable information was removed. Additionally, two individuals identified benefits of using anonymised health records in the SDE in terms of *'making improvements'* to the NHS and for '*testing and other things*'.

"If it's not containing any information that can identify me then I am not bothered."

"Fine if there was no identifiable information or that was personal tag could identify me. Especially in Cumbria it's a small community and it could be that a person reading it could know of the information and be able to identify the person that way"

"I would be happy to do anything that helps research or improvements for the NHS. In addition, all my identifiable information is being removed and therefore my privacy is not violated."

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

“Because then it is easy to identify when things are able to be used for testing and other things”

“I feel fine with authorized personnel having my information if relevant to me and needed, if not needed in that moment I’d like my name etc covered for personal information”

Those who were neither happy nor unhappy to discussed how they weren’t ‘*really fussed’* and how they would like more information as to why this is needed.

“I would like to know why as this can all depend on the reason why this has happened and what was the reason for this.”

“Not really fussed”

Those who were not happy discussed how consent should be sought from individuals for their health record to be used, whilst another does not want anyone looking at their confidential information.

“Nobody should ever have access to my data without my explicit consent.”

“Don’t mind the info being used but patients should be able to consent first”

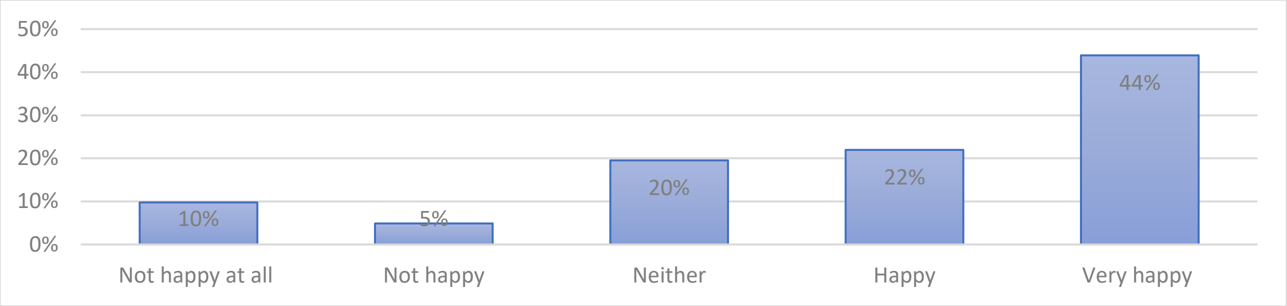
“Would not like anyone to see my confidential information“

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?

68% would be happy to share their health record for research purposes, whilst 15% would be unhappy and 20% neither happy nor unhappy.

Figure: How respondents feel about sharing their health record via the SDE for research purposes (N=41)



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

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

- 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.

Young people were happiest about sharing their health record with their doctor, hospital or other healthcare professional looking after them (90% happy) and to a lesser extent NHS Teaching Hospitals (64% happy) for research purposes.

Although under half were happy about sharing their health record with care agencies (46%) universities (44% happy), charities (44% happy), local councils (44% happy) and pharmaceutical companies (41%), there was still more support than objection.

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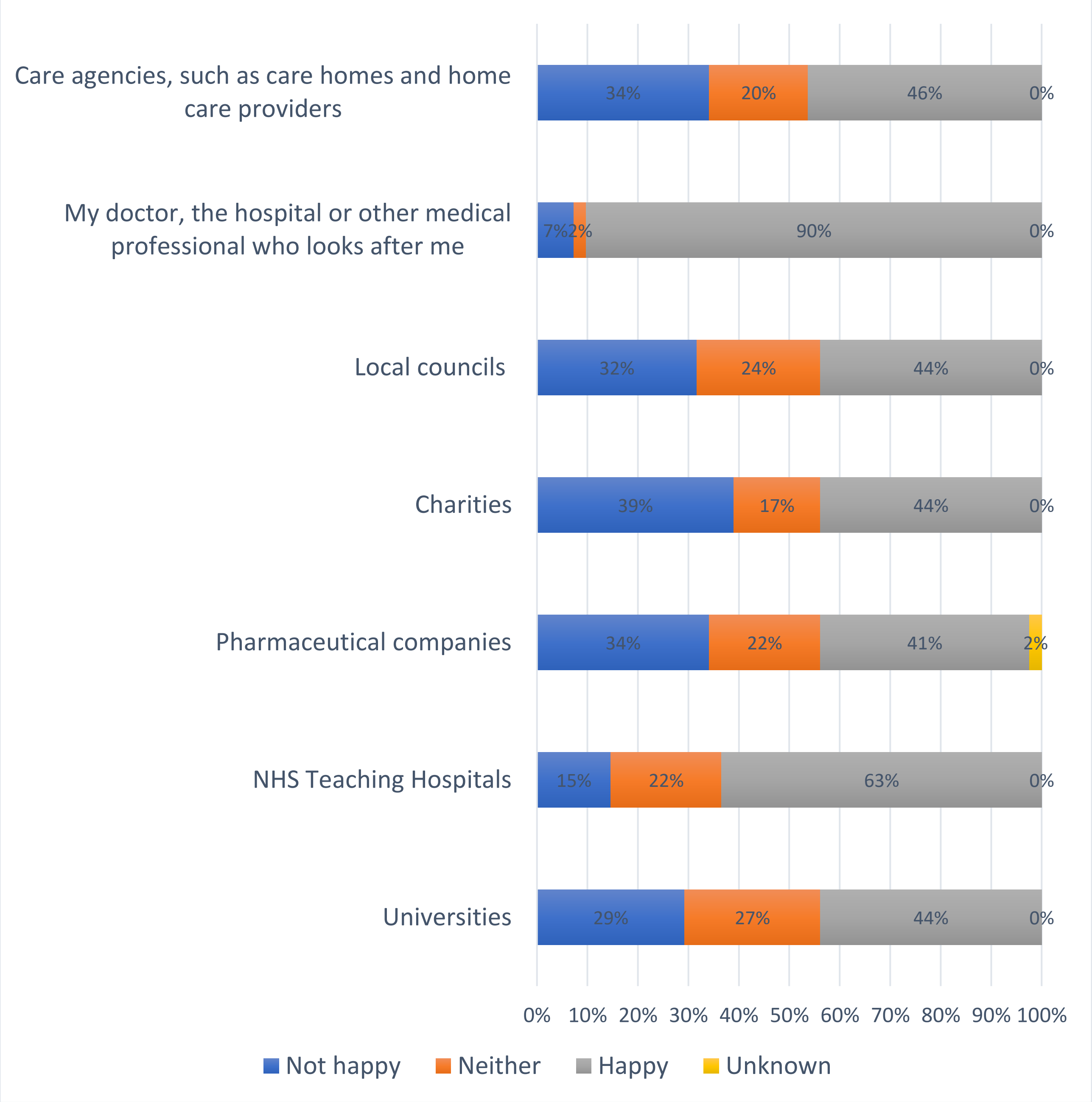
[2] Using a ten-point scale ranging from 1-10: Not at all happy: 1-2, Not happy 3-4, Neither happy nor not happy: 5-6, Happy: 7-8, Very happy: 9-10

Figure: Sharing of health records with organisations for research purposes (N=41)



Sharing health records for non-research purposes

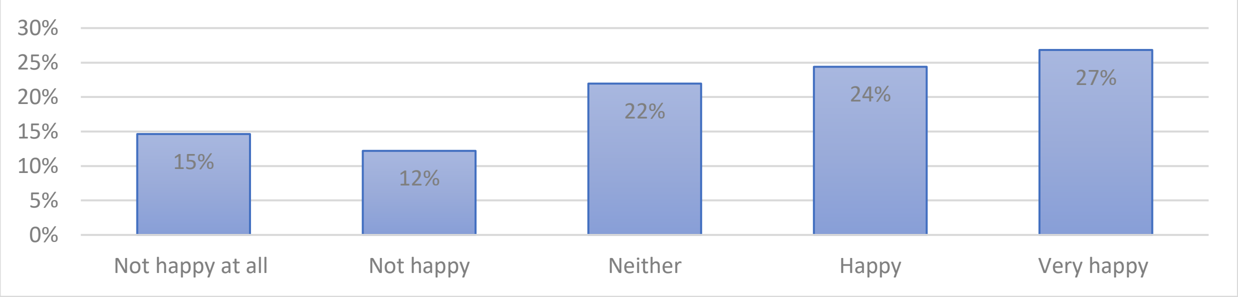
Question: **How happy would you be to share your health record via the Secure Data Environment for non-research purposes such as understanding regional health trends to manage and improve services. This might include how it responds to an increase in flu or to help emergency services respond better when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

In terms of sharing of health record for non-research purposes, 51% indicated that they would be happy. This compares to 68% who would be happy to share their health record for research purposes.

In contrast, 27% would be unhappy, again this is higher than those that would be happy to share their health record for research purposes (15%).

Notably, 22% would not be happy nor unhappy about sharing their record for non-research purposes.

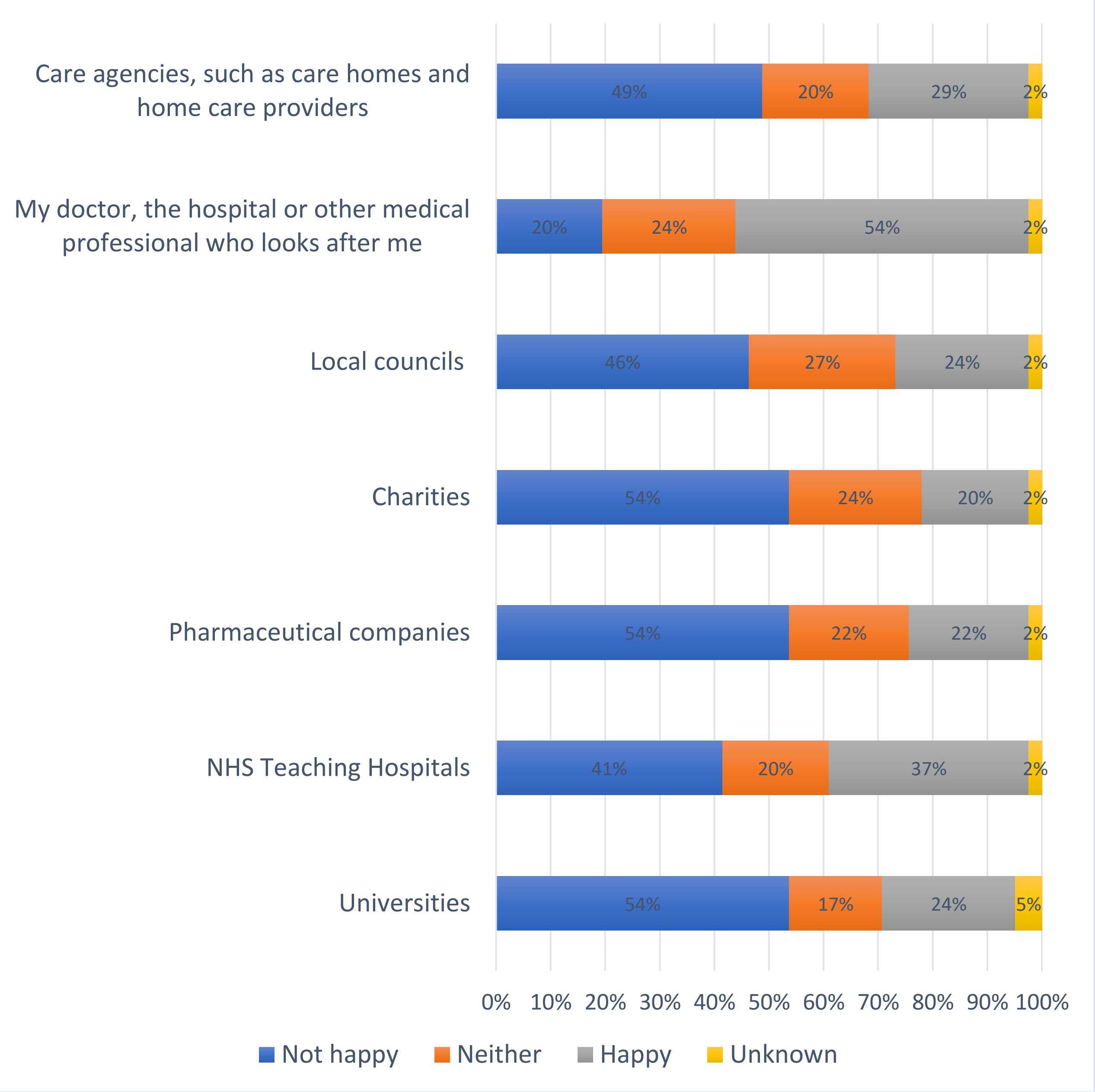
Figure: How respondents feel about sharing their health record via the SDE for non-research purposes (N=41)



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

Just over half (54%) of young people would be happy to share their health record for non-research purposes with their doctor, the hospital or another health professional that looks after them. For all other organisations, more young people would prefer not to share their health record for non-research purposes. For example, 54% would be unhappy to share their health record with pharmaceutical companies and local councils, compared to 22% and 20% that would be happy to share their health record with these organisations respectively.

Figure: Sharing of health records with organisations for non-research purposes (N=41)



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?

Approximately a third (29%) feel that there are definitely risks to people sharing their health record via the SDE, whilst 51% feel there are to an extent. Just 7% feel there are no risks, whilst 12% are unsure.
A small number (N=5) commented on their concerns. These related to:

- Information not being secure
- It being dependent on who or where the health records are shared, and why

- Possibility of people from very specific groups being identified (i.e. those with rare health conditions).

"Just in case the information may be lost in transit or kept somewhere not secure"
"Because they don't know who their records are being seen by"

"Depending on who or where you are going to be sharing your records."

"It would depend on the individual such as how and why they would like to use this confidential information."

"You cannot anonymise all data. Even if could, a researcher looking at rare conditions or even very, very old people could identify them very quickly"

Table: Whether respondents feel there are any risks to sharing their health record via the SDE for both research and non-research purposes (N=41)

	No.	**%**
Yes, definitely	12	29%
Yes, to an extent	21	51%
No	3	7%
Not sure/don't know	5	12%

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

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

Whilst 24% would be happy for their GP / other health services to share their health record, most (71%) would prefer to approve the sharing of their health record themselves.

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=41)

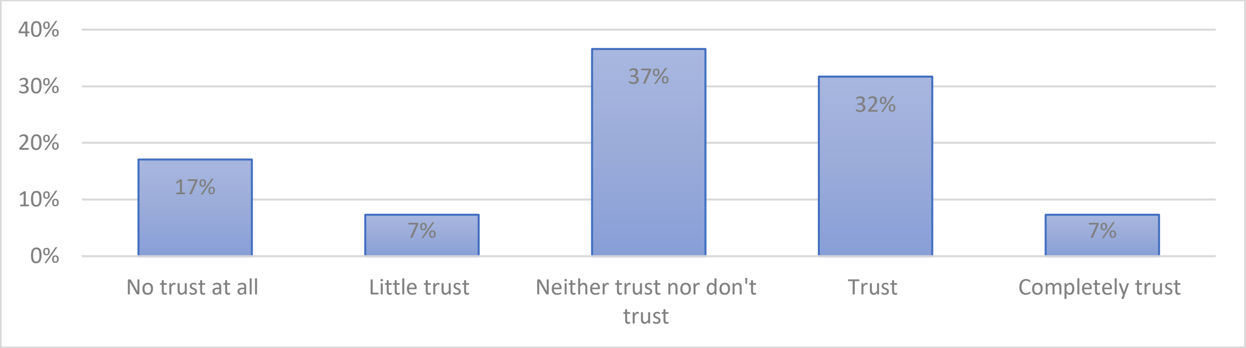
	No.	**%**
I would be happy for my GP / other health services to share my health record	10	24%
I would prefer to approve the sharing of my personal health record myself	29	71%
I would not be happy to share my health record at all	0	0%
Not sure / don't know	2	5%

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[3].

39% trust that their health record would be used for the described reasons in the SDE only, whilst 24% have little / no trust. Additionally, 37% neither trust nor don't trust that it will be used for the described reasons only.

Figure: Whether respondents trust how their anonymised health record will be used in the SDE (N=41)



Poll findings

Findings from the social media polls were as follows:

- 63% are happy about an approved NHS organisation having access to their health data and then removing all their personal details, whilst 32% would not be happy.
- 73% feel happy about their health data being used for research purposes, whilst 22% would not be happy. In comparison, 23% would be happy for their health data to be used for non-research purposes, whilst 50% would be unhappy and 27% are unsure.
- 38% feel there are risks to sharing health data in the SDE, whilst 48% feel there are to some extent.
- 21% trust that their health data would be used for research / non-research only, whilst 32% trust to some extent. In contrast, 39% have no trust.

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[3] 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: How do you feel about an approved NHS organisation having your health data and removing all your details, such as your name and address? (N=139)

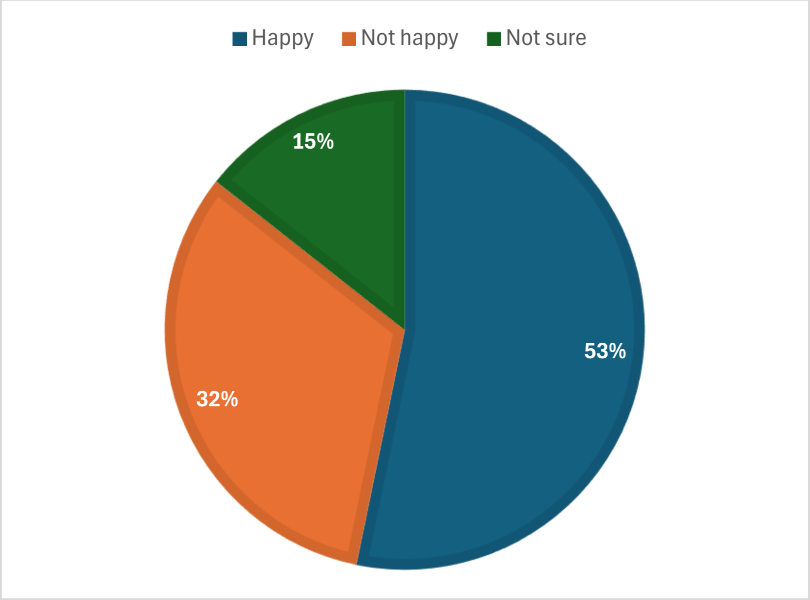


Figure: How do you feel about your health data (with your details removed) being used for research / non-research? (N=139)

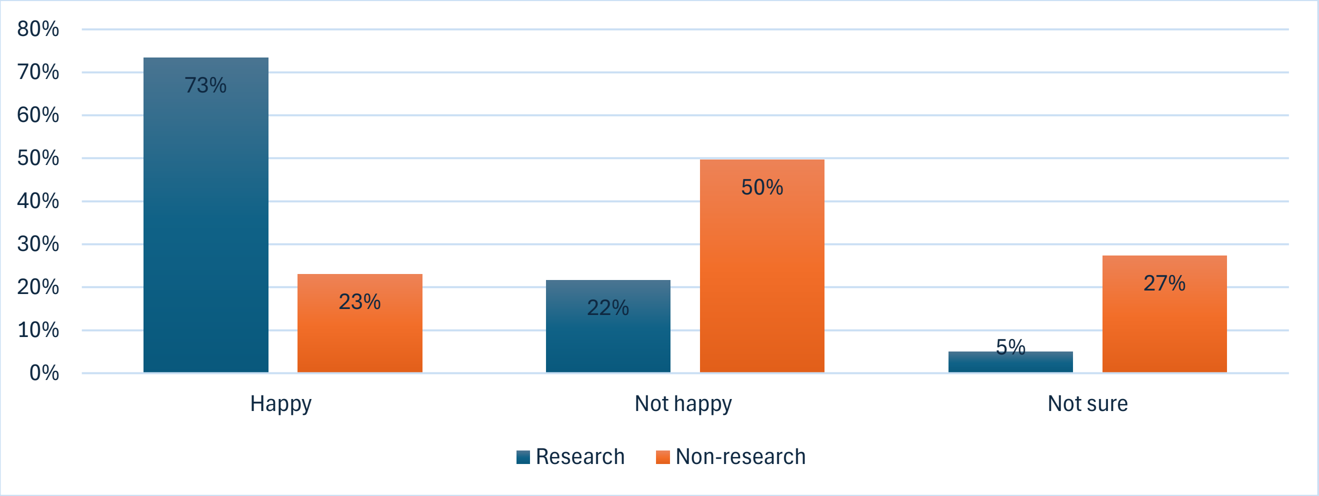


Figure: Do you think there are risks to sharing health data in the SDE? (N=139)

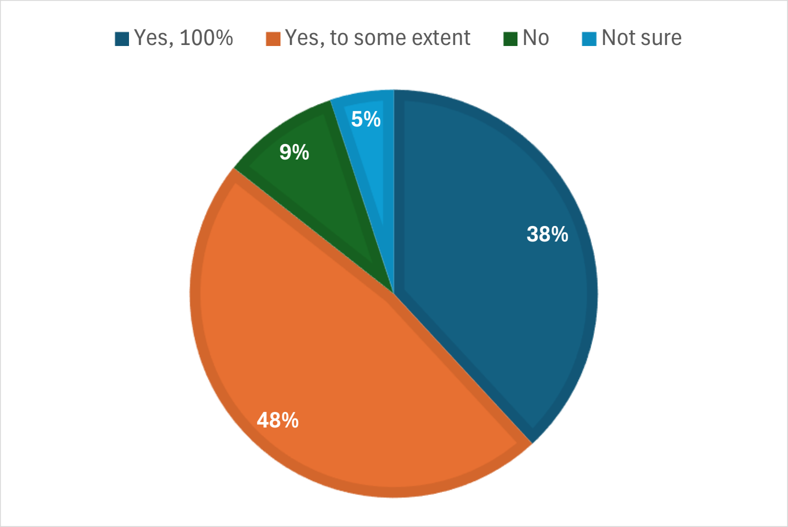
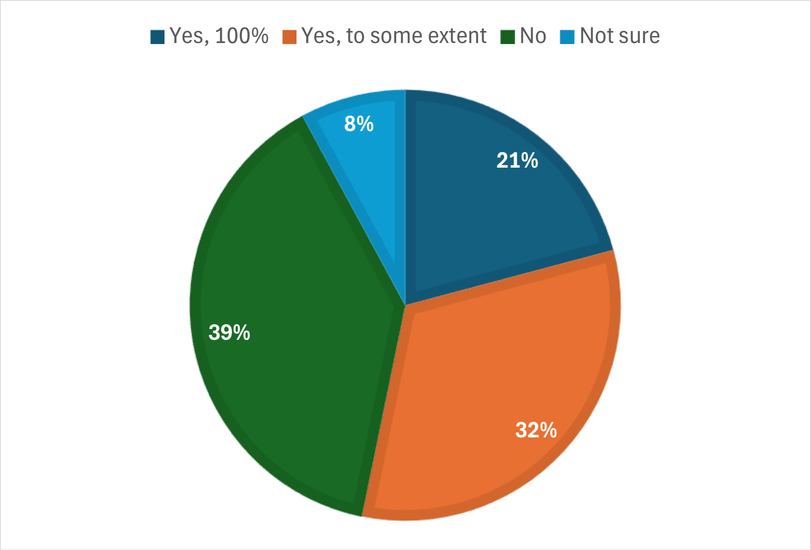


Figure: Do you trust that your health data would only be used for research or non-research only? (N=139)



Discussion of findings

To provide a response to the CAG in terms of local people's understanding and opinions about the use of personal health and care data for research and non-research purposes, a targeted piece of engagement was undertaken with 180 young people aged 16 – 24 years. Considering the results of the online survey and social media polls:

- Between 44 - 63% would be happy with an approved NHS organisation having access to their health data. For those that wouldn't be happy and those who indicated that their views were neutral, comments were made about them not being bothered / interested, more information being needed about why information sharing is necessary, and how consent should be sought from individuals before their health record is used.
- Between 68 - 73% would be happy to share their health record for research purposes. Young people were happiest about sharing their health record with their doctor, hospital or other healthcare professional looking after them (90% happy) and to a lesser extent NHS Teaching Hospitals (64% happy) for research purposes. Although under half were happy about sharing their health record with care agencies (46%) universities (44% happy), charities (44% happy), local council (44% happy) and pharmaceutical companies (41%), there was still more support than objection.
- Young people are less happy about sharing their health record for non-research purposes, with between 23 - 51% happy to do this. In terms of the organisations, young people would be happy to share their health record with, just over half (54%) would be happy to share their health record for non-research purposes with their doctor, the hospital or another health professional that looks after them. However, for all other organisations, more young people would prefer not to share their health record.
- Between 29 - 38% feel that there are risks to people sharing their health record via the SDE, whilst 48-51% feel there are to an extent. Concerns related to information not being secure, it being dependent on who or where their health records are shared, and why, as well as the possibility of people from very specific groups being identified (i.e. those with rare health conditions).
- Most (71%) would prefer to approve the sharing of their health record themselves, as opposed to their GP / other health services sharing their record on their behalf (24%).
- 21 - 39% trust that their health record would be used for the described reasons in the SDE only, whilst 24 - 39% have little / no trust.

The findings presented here add to those from the population representative sample in September 2024. They show that compared to the general population, there is less satisfaction among the 16–24-year-old age group with an approved and authorised NHS organisation having access to their health record and then removing all their identifiable information, as well as sharing their health record via the SDE for both research and non-research purposes. Further, greater proportions of young people have concerns about the risks of sharing their health record, lower trust that their health record would be used for the described reasons in the SDE only and a greater preference for approving the sharing of their health record themselves.

It must be noted however, that for many of these questions, compared to the general population larger proportions of 16–24-year-olds provided a neutral response indicating that they were either unsure, didn't really have an opinion or that they weren't particularly interested in the subject matter, which potentially explains the low survey response rate to the initial online survey.

- To delve deeper into the views of this age cohort, qualitative research will be undertaken to allow exploration into the concerns that these individuals have and understand the steps / actions that can be taken to mitigate these.

This report has been authored by Olovus, independent specialists in involving people and communities in health service transformation.
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The project was carried out in line with best practice industry standards for engagement.