

North East and North Cumbria's Secure Data Environment programme - Overview report

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Purpose of the document

The purpose of this overview report is to inform a forward plan for communications and Patient and Public Involvement and Engagement (PPIE) in the delivery of the North East and North Cumbria Secure Data Environment (NENC SDE) programme. Insights in the report will also provide a benchmark from which the NENC ICB can monitor ongoing public perception and tailor communications and messaging as the SDE is established, and support the development of the evaluation criteria that will be used by public members to review applications.

This document has been prepared for the SDE Steering group, bringing together key findings from three documents:

- Stand (Jan 2024) Academic Health Science Network – Secure Data Environments; Situational Review – Second edition
- North East Commissioning Support (Feb 2024) Health Data Sharing in North East and North Cumbria; Secure Data Environment – Public Engagement
- Stand (Feb 24) Secure Data Environment Street Survey.

Following completion of Stand's situational review in January 2024, Understanding Patient Data released the first outputs of their 'What Words to Use' project with Research Works (Feb 24). Given the purpose of this overview report, key findings from this rapid evidence review have also been incorporated within this document.

A national perspective

Key events relating to the SDE programme

The following provides an overview of key programmes and initiatives that have been introduced relating to the sharing of patient data.

- Care.data (2014) – an initiative to extract data from all English GP care records. The programme received heavy criticism from the public and GPs with regards to the lack of information about the programme, uses of the data, and perceived risk of the data being sold for commercial interests (Sterckx et al., 2016; Ford et al., 2020). The planned extraction was stopped in May 2014 and later in the year reduced to only pathfinder areas in six specific Clinical Commissioning Groups (CCGs).
- General Data Protection Regulation (GDPR) (2018) – GDPR was launched alongside the National Opt-out – a service which allows patients to opt-out of their confidential patients information being used for research and planning. Opt-out affects other NHS organisations who may want to use confidential patient information for planning as well as researchers and commercial organisations who use patient data to provide research and analysis expertise to the NHS. The effectiveness of datasets is reliant on opt-out being low, as even low opt-out can have a potentially detrimental impact on some types of analysis (Evans, 2018).
- GP Data for Planning and Research (GDPDR) – a national initiative launched in 2021 to update how GP data is collected for secondary use, mainly service planning and research. The initiative was paused later in the year with public and NHS staff perceiving that the timelines were rushed, there was insufficient communication and insufficient data privacy protections (NHS Digital, 2023).

It is against this background that SDEs are being established allowing approved users to access and analyse data.

The national response to SDEs has been broadly positive (Understanding Patient Data, 2024; Baxter et al. 2023), particularly as a result of how effective they were during the pandemic. As cited in NECS (2024), the National Data Guardian (2020) conducted a poll to explore public opinion to the use of data. Key findings from the research included:

- 56% agreed that during the pandemic they have learned more about how health and care data can be used to monitor public health and for research.
- 63% agreed what they have learned during the pandemic has made them more accepting of the need for sharing health and care data.
- 64% said they would trust government agencies to use information about them such as COVID-19 test results. However, 17% disagreed with this and 19% were unsure.
- 60% agreed that after the pandemic, organisations such as local authorities, university and hospital researchers, and private companies should be allowed to carry on using health and care data to improve care.

Barriers to sharing personal healthcare data

Stand's situational review (2024) explores some of the barriers for the public participating in sharing of their personal healthcare data. These are found to relate to awareness and understanding, and trust.

Awareness and understanding

- Poor public engagement was identified as the root cause of the failure of care.data and GDPR (Patient Experience Library, 2021; Stand, 2024).
- Lack of awareness about ethics practices used in academia, resulting in concerns about how personal data is being used (Patient Experience Library, 2021).
- Misinformation was felt to play a part in this - for example how the public did not trust the COVID-19 App because it was run by Serco (Patient Experience Library, 2021) and more recently the confusion about the role (or lack thereof) of Palantir in the SDE programme (Stand, 2024). The latter was felt to provide an additional challenge for the SDE programme, in terms of raising awareness and providing reassurance about its distinction from the Federated Data Platform (FDP) and Palantir.
- The variety of names used to describe SDEs such as Trusted Research Environments (TREs), Safe Havens and Data Spaces has been deemed confusing for public understanding of SDEs and has given rise to debates over the best terms to be used (Understanding Patient Data, 2024).
- Difficulties in meeting information needs relating to technical processes and terminology and nuances of using data for different types of activities (i.e. where individuals are not satisfied by the basics) (Understanding Patient Data, 2024).

Trust

- Public faith in the NHS to keep their data safe has been damaged over the past decade from programmes such as care.data, as well as events such as the Wannacry ransomware attack (Stand, 2024).
- There is concern about why third-parties want access to patient data, the security of which affects public perceptions (Patient Experience Library, 2021).

Enablers to sharing personal healthcare data

The review by Stand (2024) also looks at some of the enablers for the public for sharing their personal healthcare data.

Awareness and understanding

The research suggests that public understanding of data sharing is generally low. In a large public survey by The Health Foundation (2023) approximately two thirds (61%) were found to know 'very little' or 'nothing at all' about how the NHS is using the healthcare data it collects.

The concept of sharing access to large-scale datasets for secondary purposes has been shown to be a difficult concept for the public to grasp with many struggling to move beyond the idea of medical notes/individual health records being shared for the purpose of individual care (Baxter et al, 2023).

Furthermore, stark differences are evident in public perceptions data use by NHS organisations and data use by organisations outside of the NHS such as health technology companies, pharmaceutical companies and universities (Dare UK, 2022a; The Health Foundation, 2023). For example, BCG (2023) reported that whilst 90% of the public surveyed are willing to share data with the NHS for any purpose, support was lower for data being shared with pharmaceutical companies (41%), central government (39%), academic institutions (38%), life science companies (33%). Despite these lower proportions, there was still more support than opposition. The exception to this was tech companies (13% support vs 58% opposition).

Recommendations from this research and others in terms of raising awareness and building understanding of secondary data use, include:

- The Five Safes Framework¹ has been broadly accepted as the overarching conceptual basis for educating the public about SDEs (Understanding Patient Data, 2024). This is a set of principles which enable data services to provide safe research access to data.
- Conducting a UK-wide public information campaign with two overarching goals (Understanding Patient Data, 2024):
 - Highlighting the benefits of data use
 - Addressing concerns over data security and confidentiality, but also a range of other specific issues including data linkage and cloud-based storage.
- Certain principles for communicating about SDEs have been highlighted as potentially effective (Understanding Patient Data, 2024):
 - Not assuming any prior technical knowledge
 - Using visual representations to show data processes
 - Demonstrating rather than explaining physical and logical controls by taking the public through the processes of data collection, access, handling and use.

¹ What is the Five Safes framework: <https://ukdataservice.ac.uk/help/secure-lab/what-is-the-five-safes-framework/>

- Better explanation of commercial data use has been identified as a way of providing transparency and support public understanding of controls (Understanding Patient Data, 2024). Providing tangible examples of secondary use data purposes is thought to help those who are reluctant to share their data (Baxter et al. 2023; Patient Experience Library, 2012).
- Highlighting the opportunity cost of not sharing patient data may also improve public support (Patient Experience Library, 2021).

Inclusive and meaningful PPIE

Dare UK (2022) made recommendations about the value of PPIE in data sharing programmes:

- Culture shift needed to recognise the crucial importance of inclusive and meaningful PPIE, embedded throughout the sensitive data research lifecycle (Dare UK 2022a, Dare UK 2022b).
- Establishment of an independent coordinating function for PPIE with sensitive data research, either as a new entity or as an off-shoot of a relevant existing body (Dare UK, 2022b) (this links to the establishment of the SDE governance groups in NENC).

Benefits of data sharing

Findings from the BCG public health data survey (2023) report that 35% are comfortable with health data generating profit if some of the profit is reinvested back into health services, whilst 29% are uncomfortable with any profits generated from health data. Furthermore, a quarter (25%) are comfortable with health data generated profit if it also generates wider public benefits and 6% are comfortable with health data generating profit in any scenario.

Recommendations from this research and others, include:

- All accepted research proposals must demonstrate that they are in the public's interest (NHS England, 2020).
- Potential benefits of data sharing to the public must be clearly communicated (BCG, 2023).
- Benefits of data access must be shared with the NHS including: shared Intellectual Property, royalties, stake (in companies), profits and outputs (i.e. discount on new drugs) and be shared across to the NHS to avoid inequalities and to maintain the principles of the NHS (NHS England, 2020).
- The NHS charging for the use of such systems was identified as way in which the NHS can recover maintenance/usage costs. It was also felt that a tiered charging system, based on relative turnover, would make access to the data more equitable (NHS England, 2020).

Trust and transparency

The Health Foundation (2023) found that around two thirds (69%) of the public surveyed trust GP practices with their data, and similar proportions for local NHS hospitals/clinics (68%) and national NHS organisations (64%). Trust was lower for commercial organisations and charities and national / local government.

Recommendations from this research and others, include:

- Dare UK (2022) explored the conditions that respondents would want to see in place before their data was shared;
 - The removal of personal identifying information
 - Strict rules that data could not be passed on to any other organisation
 - Contracts put in place so data can only be used for agreed purposes
 - Data only being accessible in a secure IT environment.
- Ensuring the right processes are in place to manage trust (BCG, 2023). For example:
 - Publishing and maintaining standardised and accessible data use registers (Dare UK, 2022b).
 - Ensuring no access is granted to insurance companies or for marketing purposes (NHS England, 2020).
 - Ensuring regular reviews are undertaken of the 'Five Safes' model (NHS England, 2020; Understanding Patient Data, 2024).
 - NHS to publish criteria for vetting potential partners – i.e. the process they need to go through to obtain access (e.g. charities, commercial companies, universities) (NHS England, 2020).
- Consistently practicing proactive transparency about what sensitive data is being used for research, how, why and by whom (Dare UK 2022a, Dare UK, 2022b). A recommendation was made by NHS England (2020) that a publicly available annual report is produced, in plain English, detailing who has accessed and used the data (and why), the impact of the research undertaken, and distribution of any financial benefits to the NHS.

Relationships

- Patient / professional relationships will be key to SDEs being a success, particularly with the failings of care.data being attributed to the heavy criticism that GPs had about the initiative in relation to the lack of information about the programme, uses of the data, and perceived risk of the data being sold for commercial interests. GPs are very powerful as data controllers (Ford et al. 2020) with their personal and professional views likely to have a great impact on patients in their practices.

A regional perspective

Stand's SDE street survey (2024) provides the most recent insight as to the sentiments of North East and North Cumbria (NENC) residents regarding the sharing of health data in the SDE programme. It reports on a door-to-door engagement exercise with a population representative sample of 405 individuals from across NENC.

The research encapsulates current public sentiment towards data sharing for research purposes updating past research which has explored this on a national / regional level e.g. Ipsos MORI, 2016.

- 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. Although lower than recently reported national figures (The Health Foundation reported this figure to be 1 in 5 people in 2023), it still raises concern about the quality and representativeness of SDEs if these people were to opt-out of their data being used in this way.
- 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 was 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.

This latter finding highlights the need to provide clarity as to the types of charities that would benefit from secondary data use and for what purpose.

- The majority (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. There is a stark difference between this finding and those reported by Ipsos MORI in 2016 where much higher proportions were found to want control over their privacy settings / data sharing.
- 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 records 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 records, 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.

Interestingly, this supports the findings by Ipsos MORI in 2016 with those who opposed data sharing with commercial organisations concerned about safe data storage and potential harm to individuals and their families.

- 87% do not already share their health information with research organisations.
- Nearly three in four (73%) believe that the SDE should be funded by the UK Government, whilst smaller proportions feel that it should be funded by research organisations authorised to use the SDE (13%) or from NHS budget which comes from taxation (11%).
- Certain demographic groups were found to exhibit stronger opinions. 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). Additionally, this age group expressed greater reservations about data sharing with charities, universities, pharmaceutical companies and care agencies. 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.
- 20% expressed a keen interest in understanding the types of projects the SDE supports and their impact on health. Of those interested, 79% are willing to share their health records.

The latest published figures of National Opt-Out is explored in the report by NECS (2024). Opt-out levels represent real numbers of people actively choosing to remove their data from existing NHS data sources. It is therefore less effected by the bias of these individuals proactively excluding themselves from data collection processes and surveys.

The NECS report reveals some interesting findings in terms of opt-out at a regional / local level:

- NENC Integrated Care Board (ICB) has the 5th lowest proportion (3.94%) of opt-out across England, and considerably lower than the national proportion (5.35% as of Feb 2024).
- All NENC sub-ICBs (previous clinical commissioning groups) have opt-out below the national proportion. The highest being Northumberland (5.16%; 336,500

patients) and the lowest being Tees Valley (3.55%; 26,000 patients), Sunderland (3.56%; 10,500 patients) and North Cumbria (3.57%; 12,000 patients).

- Females generally exhibit higher opt-out proportion than males across age bands, the exception being people aged 80+. In age there is a peak at 30 to 39, decreasing over age bands for females but remaining relatively static for males.
- Opt-out is higher for least deprived deciles and lowest for the most deprived. This contradicts that reported by the Patient Experience Library's literature review (2021) which revealed that those better off are more likely to view the use of health data as being of benefit to society.
- Four GP practices have significantly higher opt-out than the England mean – three in Northumberland (these are not all within the same Primary Care Network) and one in North Tyneside;
 - Cramlington Medical Group, Northumberland – 16.7% opt-out
 - Bellingham Practice, Northumberland – 15.4% opt-out
 - Redburn Park Medical Centre, North Tyneside – 10.6% opt-out
 - Humshaugh & Wark Medical Group, Northumberland – 9.4% opt-out

Recognising the role that GPs can have in educating and influencing their patients, this highlights the need to engage with GPs at these practices to understand their perceptions of opt-out / sharing of personal data and how these influence the views of their patients.

- Further investigation at Middle-layer Super Output Area (MSOA) level shows that Northumberland is significantly different to other areas of NENC. The areas of Morpeth, Cramlington and Hexham have opt-out proportions higher than other areas of NENC. The Northumberland MSOA Bellingham, Otterburn & Redesdale has the highest opt-out across NENC at 10.5% (MSOA location of Bellingham Practice). Rural areas of Gateshead around Cropwell Woodland also have some of the highest opt-out proportions in the ICB; Rowlands Gill & Lockhaugh (9.7%) and Chopwell & High Spenn (7.4%).
- Examination of opt-out rate by NENC Acorn type (CACI Ltd, 2023) reveals that those with access to higher education (43%+ have a degree) and higher household income (above national average) are more likely to opt-out, compared to types which are more diverse families or student residences. It therefore suggests that opt-out of NHS data collection is something done by those with the means to do so. Acorn types with the highest opt-out in NENC are:
 - *1.C.7 Prosperous families in green-belt areas with substantial homes* (5.2% Opt-Out, 1.3% NENC population)
 - *2.D.12 Well-to-do empty nesters in detached houses* (5.0% Opt-Out, 2.4% of NENC population)

- 2.D.10 Well-off families in larger semis (4.9% Opt-Out, 2.6% of NENC population)
- 3.I.26 Younger couples & singles in flats (4.8% Opt-Out, 0.4% of NENC population)

The NECS report (2024) further investigates the attitudes towards sharing medical data, using Acorn data variables. The data shows that;

- Although <1% of the NENC ICB population combined, 3.F.18 Countryside retirees in spacious houses are much more likely than any other group to state that ‘Computers confuse me, I’ll never get used to them’, whilst 6.U.59 Students & sharers in multi-occupancy flats are most concerned about the lack of security of their online data.
- Types in group 5.P44-47 Tenant Living are more likely to have private medical insurance and less likely to have never used the internet (4.5% of the NENC ICB population).

Table: NENC (2024)

NENC Acorn Groups Funnel Plot Outliers Highlights of List Size LSOA Weighted National Data Opt-Out Rate						
Acorn Code	1.C.7	2.D.12	2.D.10	3.I.26	6.S.56	-
Acorn Type	Prosperous families in green-belt areas with substantial homes	Well-to-do empty nesters in detached houses	Well-off families in larger semis	Younger couples & singles in flats	Diverse young families in rented terraces & flats	UK
Opt-Out %	5.2%	5.0%	4.9%	4.8%	1.6%	5.4%
Opt-Out	2,300	3,875	4,280	635	665	-
List Size	44,185	78,005	87,550	13,410	40,980	-
Opt-Out Outlier	U95%	U95%	U95%	U95%	L99.8%	-
Adult in household has a degree	45%	51%	43%	45%	8%	22%
Just managing to make ends meet	15%	16%	19%	22%	31%	25%
Mean Gross Household Income	£79k	£66k	£68k	£58k	£27k	£48k
Computers confuse me, I'll never get used to them	13%	14%	24%	27%	27%	14%
I am worried that any personal information I enter online will not remain secure	72%	62%	61%	56%	57%	60%
Never used the internet	2.3%	1.8%	2.6%	1.2%	4.5%	3.0%
Has Private Medical Insurance	16%	11%	10%	17%	17%	11%

Population numbers in table rounded to nearest 5

Taken together, these reports demonstrate that within NENC there are some evident gender and age differences in terms of sentiment towards sharing data.

Females have been shown to have higher opt-out than males across most age bands and are more likely to express uncertainty about trusting their health data to be used for defined reasons only. This is supported in the Patient Experience Library's Literature Review which found that women are more likely to say that the NHS 'treating people's records as confidential' is very important (89% vs 85% for men).

Opt-out is highest amongst those age 30–39 years and decreases with advancing age. Furthermore, the street survey found that dissatisfaction and distrust with sharing health records in the SDE was notably higher amongst those aged 35-44 years. This age group also had the greatest reservations about data sharing with charities, universities, pharmaceutical companies and care agencies. It is thought 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 (Office for National Statistics, 2023).

Values and expectations around data sharing

The Great North Care Record Public Engagement Report (2020) reports on the values and expectations around sharing data, the foundation of all of these – respect.

- Reciprocity – citizens recognised the benefits of sharing data for improving health and social care for themselves and others in the community. Citizens said they would like to have access to data about them, both to see what is said about them and to add additional information like donor preferences.
- Fairness – citizens expected communication and decision making decisions about data sharing to be accessible to all regardless of class, education and literacy, disability, ethnicity or capacity.
- Agency/control – citizens said they want a say in how data is used about them, by whom and for what purposes. Control of information use and access was not only an individual issue, citizens expected to be involved in the oversight and governance of information sharing and the GNCR.
- Privacy – citizens expect their privacy to be maintained, except where they have specifically agreed to share personal information. Citizens wanted to know that data about them is secure and that their choices and preferences are upheld.
- Transparency/trust – citizens expected to be informed about how data about them is or may be used. Citizens expected institutions handling data about them to act in a trustworthy manner. Research institutions were felt to require more information to give clarity and lead to greater trust. Commercial and for-profit organisations the least trusted.

Surmising points and next steps

The purpose of this overview report is to support the development of a forward plan for communications and engagement for PPIE elements of the SDE programme. Insights will also provide a benchmark from which the NENC ICB can monitor ongoing public perception and tailor communications and messaging as the SDE is established, and support the development of the evaluation criteria that will be used by public members to review research applications.

Nationally, but more importantly regionally, the response to the SDE programme has been positive.

The latest insight from Stand (2024) found that 84% of the NENC population surveyed are very happy / happy to share their anonymous health records in the SDE. Conversely, 9% were not happy about their records being shared. Although lower than recently reported national figures (The Health Foundation reported this figure to be 1 in 5 people in 2023), it still raises concern about the quality and representativeness of SDEs if these people were to opt-out of their data being used in this way. This therefore creates challenge in terms of identifying who these people are and what would help them to reconsider their thought processes.

Furthermore, the research by Stand revealed that:

- 81% of NENC residents would be happy for their GP / other health services to share their anonymous health records directly with the SDE. Whilst 13% would like to manage this process themselves, and 5% would not be happy to share their records at all.
- Respondents expressed higher satisfaction towards sharing their anonymous health records data with NHS organisations. Although satisfaction levels was lower for organisations outside of the NHS i.e. universities, care agencies, pharmaceutical companies and local councils, there was still more support than objection. The lowest satisfaction was found for data sharing with charities with 61% very happy / happy.
- 85% completely trust / trust that their anonymised health records would be used for the described reasons of the SDE only, whilst 7% have little / no trust.
- 81% think there are definitely benefits to people sharing their health records 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 records, 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.

Understanding the population cohorts who are hold more negative views towards data sharing is key to not only informing the next stages of PPIE but the representativeness of the SDE. The results from the street engagement by Stand and the review by NECS provides insight as to the population groups who are likely to be more resistant to sharing their data in the SDE:

- Females
- Those aged 30-59
- Those who are more affluent i.e., those with higher household incomes and those with access to higher education
- Those living in more rural areas such as Northumberland, particularly in the areas of Morpeth, Cramlington and Hexham.

These findings suggest that opting-out of data sharing initiatives is something that is done, or able to be done, by those with a higher degree of privilege and stability in their lives.

The following summarises the identified barriers and enablers to patients / the public participating in sharing their healthcare data. It is important for these to be taken into account when planning future communications and engagement for PPIE elements for the programme. They should also be considered in the development of the of the evaluation criteria that will be used by public members to review research applications to the SDE.

Awareness and understanding	<p>Barriers</p> <ul style="list-style-type: none"> • Poor public engagement on related programmes (i.e. concerns about uses of the data & data privacy protections) • Uncertainty as to how the NHS is using the data it collects and the concept of data access for secondary purposes, including the processes involved i.e. data security • Lower satisfaction about data sharing with organisations outside of the NHS (specifically universities, care agencies, pharmaceutical companies and local councils) - particularly evident in the 35-44 year old age group in NENC • Misinformation e.g. Palantir’s [none] involvement with SDEs • Inconsistent terminology (i.e. SDE / TRE / Safe Havens) • Difficulties in meeting information needs relating to technical processes and terminology • Lack of awareness about ethics practices used in academia, resulting in concerns about how personal data is being used • Health professional influence (i.e. GPs)
	<p>Key considerations / enabling factors</p> <ul style="list-style-type: none"> • PPIE embedded throughout the SDE lifecycle - promoting reciprocity, fairness, agency, privacy, transparency and trust • PPIE representation and engagement of all population cohorts, with focus on those who are more likely to be resistant to sharing their data

	<ul style="list-style-type: none"> • The Five Safes Framework² has been broadly accepted as the overarching conceptual basis for educating the public about SDEs • Public information campaign with two overarching goals: <ul style="list-style-type: none"> ○ Highlighting the benefits of data use ○ Addressing concerns over data security and confidentiality, but also a range of other specific issues including data linkage and cloud-based storage. • Importance of providing better explanation of data use by organisations outside of the NHS (e.g. universities, care agencies, pharmaceutical companies and local councils), using tangible examples • Importance of distinguishing SDE from FDP/Palantir • Certain principles for communicating about SDEs have been highlighted as potentially effective: <ul style="list-style-type: none"> ○ Not assuming any prior technical knowledge ○ Using visual representations to show data processes ○ Demonstrating rather than explaining physical and logical controls by taking the public through the processes of data collection, access, handling and use ○ Consistent terminology ○ Highlighting the opportunity cost of not sharing patient data • Patient - professional relationships
Trust and transparency	<p>Barriers</p> <ul style="list-style-type: none"> • Lack of public faith stemming from historical events / poorly managed past programmes • Lower satisfaction about data sharing with organisations outside of the NHS (specifically universities, care agencies, pharmaceutical companies and local councils) - particularly evident in the 35-44 year age group in NENC • Key concerns amongst NENC residents relate to security of the SDE • In NENC, females are more likely to express uncertainty about their health data being used for described purposes only • Health professional influence (i.e. GPs) <p>Key considerations / enabling factors</p> <ul style="list-style-type: none"> • Building public trust about data sharing with organisations outside of the NHS specifically security of the SDE. • Ensuring the right processes are in place to manage trust <ul style="list-style-type: none"> ○ NHS to publish criteria for vetting potential partners ○ Publishing and maintaining standardised and accessible data use registers ○ Ensuring organisations accessing data do so in a trustworthy manner

² What is the Five Safes framework: <https://ukdataservice.ac.uk/help/secure-lab/what-is-the-five-safes-framework/>

	<ul style="list-style-type: none"> ○ Ensuring regular reviews are undertaken of the ‘Five Safes’ model ○ All accepted research proposals to demonstrate that they are in the public’s interest ● Consistently practicing proactive transparency about what sensitive data is being used, how, why and by whom and the distribution of any financial benefits to the NHS ● Patient - professional relationships
Relationships	<p>Key considerations / enabling factors</p> <ul style="list-style-type: none"> ● Patient - professional relationships are considered key to the success of the SDE. GPs are very powerful as data controllers with their personal and professional views likely to have a great impact on patients in their practices.

Next steps

The purpose of this overview report is to support the development of a forward plan for communications and engagement for PPIE elements of the SDE programme. It will also be used to support the development of the evaluation criteria that will be used by public members to review research applications to the SDE.

The research poses some key questions / considerations:

- Public awareness, understanding, trust and transparency play a key role in influencing perceptions about the sharing of personal data. These are important to consider not only for future communications and engagement but in the development of the evaluation criteria that will be used by public members to review research applications.
- How do we build public understanding and trust about data sharing with organisations outside of the NHS, where we know there is lower satisfaction / less trust? E.g. universities, care agencies, pharmaceutical companies, local councils and charities.
- How do we effectively involve and engage with the population cohorts who are more likely to express resistance to sharing of their personal data?

I.e. Females, those aged 30-59, those who are more affluent i.e., those with higher household incomes and those with access to higher education, those living in more rural areas such as Northumberland, particularly in the areas of Morpeth, Cramlington and Hexham.

- Recognising the key role of patient – professional relationships, how can we target and engage with GPs / other health professionals working within the areas / GP practices in NENC where we know there is higher opt-out and potentially will have greater resistance to the sharing of their personal data in the SDE.

Outputs / documents to look out for:

- Findings from NHS England's large-scale engagement events (spanning over 2024 and 2025, provider TBC). It is anticipated that the events will support implementation of the NHS Research SDE network and will be focused upon where public views can meaningfully shape decision-making.
- In late March / early April, Understanding Patient Data will be reporting upon a series of in-person and online workshops that are currently being undertaken to test existing resources and develop recommendations around communications in terms of language choice, resource type and style.

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