

Academic Health Science Network- Secure Data Environments

- Situational review

A report by Stand

January 2024



Introduction

In 2022, the Department of Health and Social Care (DHSC) committed to implementing Secure Data Environments (SDEs) as the default way to access NHS health and social care data for research and analysis purposes.

A significant volume of work has been ongoing to prepare for this and to understand public perceptions around the NHS sharing data with third parties. This desk report aims to provide a brief background to SDEs and an overview of the activity that has been undertaken nationally and locally within North East and North Cumbria (NENC) to understand public perceptions and support for the initiative.

[Stand](#), an expert organisation in patient and public involvement in policy, strategy, service design and transformational change programmes, were appointed to prepare this independent report. The first version of this report was made available in February 2023, with an updated version in January 2024.

This report has been carried out by reviewing every document made available by the programme team, in addition to further documents found as part of the research process. The document list and accompanying notes are included as Appendix one.

Background to Secure Data Environments and General Practice Data for Planning and Research

Secure Data Environments

In 2022, the DHSC announced plans to develop SDEs as part of the policy paper - 'Data saves lives: reshaping health and social care with data'¹. The benefits provided by an integrated, data driven approach to health care were recognised following the COVID-19 pandemic and DHSC wanted to apply that learning to the longer term.

SDEs are being developed nationally by NHS Digital to provide approved researchers and analysts with access to essential, anonymised health data to help inform research and deliver answers to vital health related questions. Funding was announced in March 2022 as part of NHS England's Data for Research and Development programme to accelerate work that was already being done to evolve the Trusted Research Environment (TREs, a form of SDE) which was created during the pandemic.

This is not the first time that government has wanted to take such an approach to sharing NHS data. In 2012, the government announced 'care.data' which aimed to extract data from GP surgeries into a central database to be used not only by health care researchers and NHS managers, but also academic institutions and commercial organisations. The cause of care.data's failure, and the focus of this report, being - public perceptions.

It is widely recognised that the public's faith in the NHS to keep their data safe has been damaged over the past decade. In the case of care.data people felt that the NHS had not gone to enough effort to inform the public that their data was being accessed, in addition to the lack of clarity around the option to opt-out of the system.

¹ DHSC; June 2022; Data saves lives: reshaping health and social care with data
<https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data>

In 2021, in preparation of the launch of SDEs, the Patient Experience Library undertook a literature review to identify some of the causes of public mistrust of the NHS. The following events were felt to have contributed to this;

- The Wannacry ransomware attack.
- The Royal Free Trust – who improperly shared the data from 1.6 million patients with Google.
- Bupa – who were fined £175,000 after a member of staff was able to extract the personal data of 547,000 customers and offer it for sale on the deep web.

It is against this background that we are working towards establishing SDEs allowing approved users to access and analyse data.

Following criticism about the lack of importance given to public engagement within the ‘Data saves lives’ strategy, the paper was updated in June 2022, with public awareness and engagement placed at the heart of the programme. The overarching aim is for someone who is using health and adult social care services to have confidence that their data is being handled properly, that they have good understanding of how it is being used, and that they have greater access to that data. They stated five ways that trust will be built on:

- By keeping data safe and secure.
- By being open about how data is used.
- By ensuring fair terms from data partnerships.
- By giving the public a bigger say in how data is used.
- By improving the public’s access to their own data.

In October 2023, the DHSC confirmed a shift from ‘data sharing’ to ‘data access as default’ through SDEs in its Data Access Policy² update (the next update is due to be published in early 2024). It is anticipated that moving to a system of data access will help to improve public confidence in secondary uses of NHS data. Evidence to support this is provided by the Boston Consulting Group’s (BCGs) Centre for Growth (2023) who found that a greater proportion of the general public are more comfortable with data access via SDEs, than data sharing.

As part of the strategy, NHS England have allocated £2million of funding for the delivery of large-scale engagement events in 2024 and 2025 (provider TBC). The feedback from these events will be used to support implementation of the NHS Research SDE network and will be focused upon where public views can meaningfully shape decision-making.

More locally, all NHS controlled SDEs are conducting patient and public involvement and engagement (PPIE) in designing processes and making access decisions, as well as engaging and informing people about how their data is used and the benefits. As part of this, NENC Integrated Care Board (ICB) have set up three governance groups with membership from both professionals and public members. This includes:

- SDE Steering Group.
- SDE Programme Group.
- NENC Data Access Committee.

² DHSC; Oct 2023; Data access policy update; <https://www.gov.uk/government/publications/data-access-policy-update>

General Practice Data for Planning and Research

The General Practice Data for Planning and Research (GPDPR)³ is a GP data collection system that has been in use since the 1st July 2021. The stated purpose of the system, according to NHS Digital, is that the data will be used 'for better planning of healthcare services and for use in medical research' and that the new system will be 'more efficient' at doing this than the previous General Practice Extraction Service (GPES) process.

Data from GP medical records has been used regularly in research for many years. In the past, making this information available has often been a manual process that needs input from individual GP practices. GPDPR aims to reduce this burden on individual practices by making it possible to transfer the data automatically and in bulk, rather than manually. The aim is to save time and free up GP practices to focus on looking after patients.

In order to keep the public properly engaged in the programme, the GP Data Patient and Public Engagement and Communications Advisory Panel⁴ was established in summer 2021. The aims and objectives of the panel are:

1. To act as advisors and consultants on the development and implementation of the four phases of the communication and engagement strategy.
2. To advise on who, how and when to engage patients and the public, to help shape the emerging communications content.
3. To ensure that all communications content, materials, and activities are informed by patient and public views during development, in order to build trust in the use of patient data.

Members of the panel include:

- Office of the National Data Guardian
- UseMYData
- Healthwatch
- Association of Medical Research Charities (AMRC)
- Patients and members of the public - known as lay members.

³ NHS Digital; General Practice Data for Planning and Research (GPDPR); <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research>

⁴ NHS Digital; GP Data Patient and Public Engagement Communications Advisory Panel; <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/gpdpr-assurance-groups/patient-and-public-engagement-and-communications-advisory-panel>

Public perceptions around secondary uses of health and social care data – a national perspective

The national response to the new SDEs has thus far been broadly positive, particularly as a result of how effective they were during the pandemic. Such an approach has long been advocated by HDR UK who say that they have “*so many benefits to the public, to the health and care sector and to clinical researchers*”. They are able to provide greater assurance that data is handled securely and only authorised researchers who have an approved project are able to make use of them without risking a person’s identity or privacy. Angela Wood, a Professor of Health Data Science at University of Cambridge has said that “*they provide a novel scale and depth of information (...) they produce results which have unquestionable generalisability across important subgroups.*” She also praised the speed at which researchers are able to gain access to the data they need, enabling researchers to tackle important policy related questions.

Digitalhealth (2022) has also sung the praises of SDEs, saying that they have enabled the democratisation of data during the pandemic, and that the healthcare sector has a responsibility to use the data effectively to improve outcomes for patients.

Cited in the ‘Data saves lives’ policy paper was a Citizens’ Jury exercise performed in 2021 by the National Institute for Health and Care Research (NIHR) in Greater Manchester regarding the sharing of health data. To surmise, they supported the decision to introduce health data sharing in the pandemic, and supported it continuing. Despite concerns about the lack of transparency, the majority were in favour of it continuing for as long as it was valuable. Interestingly, most believed that an independent body of experts and lay people should review the data sharing initiatives.

In 2021, the Patient Experience Library undertook a rapid literature review in conjunction with Ipsos Mori, where they identified a series of barriers and enablers for patients and the public participating in sharing personal healthcare data. The barriers identified were:

- Public understanding - people didn’t want their data used for profit by anyone other than the NHS. There is low public awareness around ethics practices in academia so people are concerned how their data is being used.
- A need for education and dialogue through public engagement - poor planning for public engagement was a root cause of the failure of care.data. Misinformation also needs to be considered, such as how people didn’t trust the Covid-19 app because it was run by Serco.
- Choice and control - people are concerned about why third-parties want their data, the security of which affects public perceptions.

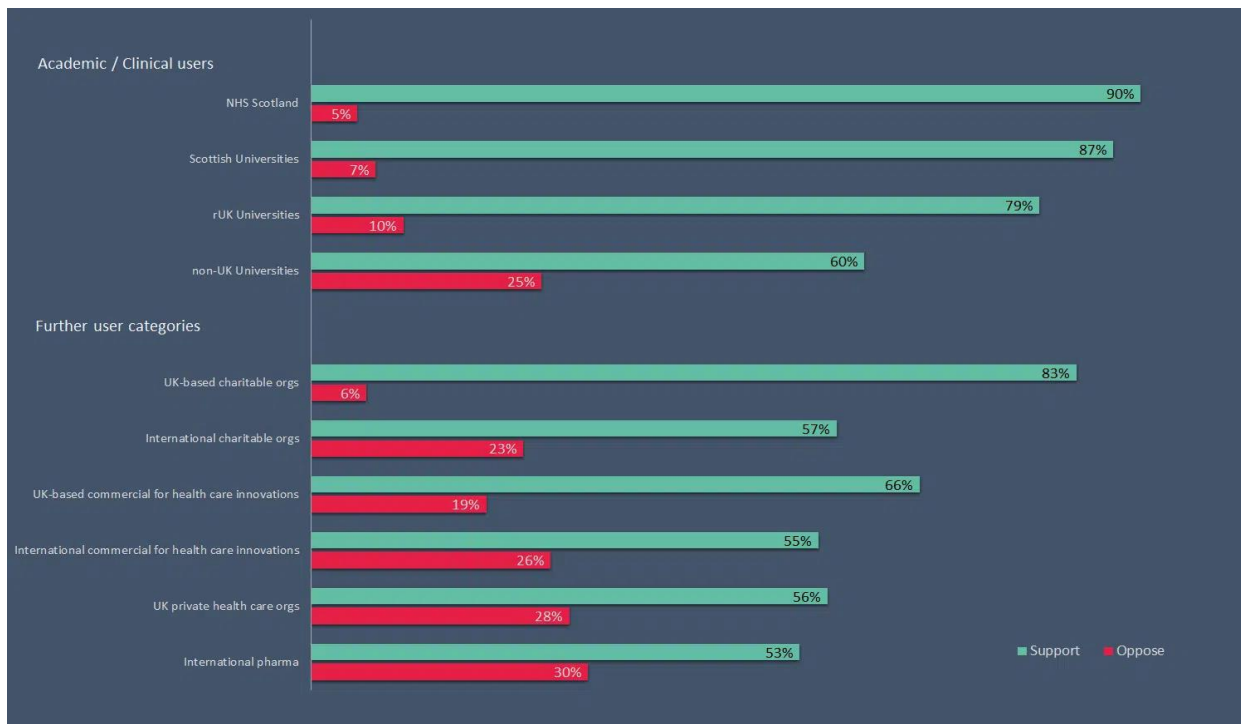
The enablers identified were:

- Trust - the DHSC found as part of their ‘Data saves lives’ initiative that 59% of people trust the NHS to use personal data ethically, more than any other organisation surveyed. However, this should not be taken for granted as it is conditional.
- Public benefit - the benefit does not have to be specific, but being clear about secondary uses with tangible examples is likely to gain more public support. Also highlighting the opportunity cost of not sharing the data may be beneficial.
- Relationships - patient/professional relationships will be key to SDEs being a success. This could also help in the shared decision making agenda.

In early March 2022, NHS England published a blog citing ‘deliberative engagement events’ conducted by One London as having provided a strong foundation for work going forward. For this report, only the recommendations for research will be investigated. The members of the public established the following criteria they wanted met, in order to feel comfortable with de-personalised data being shared:

- Benefits to be shared with the NHS such as shared IP, royalties, profits and outcomes.
- Benefits to be shared across to the NHS to avoid inequalities and to maintain the principles of the NHS.
- The NHS charging (not selling) for the use of such systems to recover maintenance/usage costs at a minimum. They also wanted a tiered charging system put in place, based on relative turnover, so as to make access to the data more equitable.
- NHS to produce a publicly available annual report (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.
- 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).
- Regular review of the ‘five safes’ model.
- No access granted to insurance companies.
- All research proposals to demonstrate that they are in the public interest.

In the same year, researchers from the University of Edinburgh conducted a study to understand public perceptions around different types of organisations making use of patient data (Dare UK, 2022). It concluded that there is a stark difference in perceptions between commercial use of data, and NHS/academic use of data. However, over half of respondents still supported the use of data by all the categories of organisations presented.



Respondents were also asked which conditions they would want to see in place before their data was shared. These included the removal of personally identifying information; strict rules that data could not be passed on to any other organisation; contracts put in place so data could only be used for agreed purposes, and data only being accessible in a secure IT environment.

In May 2022, Dare UK undertook a piece of engagement to establish what principles should be followed to make this programme a success. They published 'Building a trustworthy national data research infrastructure: a UK-wide public dialogue' which concluded that proactive transparency is essential, engagement should be inclusive and meaningful (linking to the establishment of the SDE governance groups in NENC), and that awareness needs to be raised about data security to improve public trust.

A second piece of research was published by the same organisation in August 2022 which set out the emerging findings and recommendations from Phase 1 of their 'Design and Dialogue' programme which aimed to establish the key challenges across the data research landscape and how we can overcome them. Their main finding for the purposes of this report was that trustworthiness needs to be demonstrated. They recommended that this be done in the following ways:

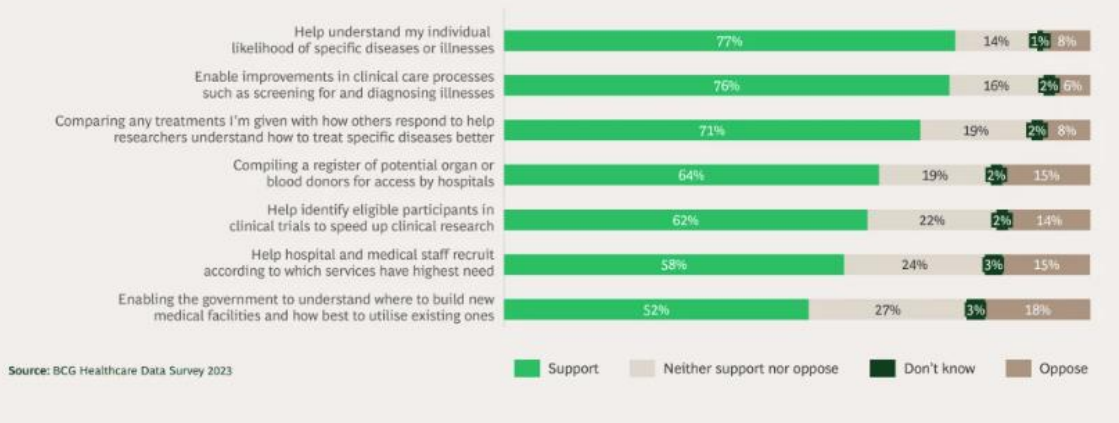
- Consistently practice proactive transparency about what sensitive data is being used for research, how, why and by whom.
- Conduct a UK-wide public information campaign to raise general awareness of how and why sensitive data is made accessible for research.
- Publish and maintain standardised and accessible data use registers.
- Drive a culture shift to recognise the crucial importance of public involvement and engagement and embed it throughout the sensitive data research lifecycle.
- Investigate the requirements for establishing an independent coordinating function for public involvement and engagement with sensitive data research, either as a new entity or as an offshoot of a relevant existing body.

A more recent survey by BCG Centre for Growth (2023) found that 90% of the general public surveyed are willing to share data with the NHS for any purpose. Whilst support was lower for data being shared with pharmaceutical companies (41%), central government (39%), academic institutions (38%), life science companies (33%), there was still much more support than opposition. The exception to this was tech companies (13% support vs 58% opposition). It is concluded that when the potential benefits are clearly communicated, and the right processes are put in place to manage trust, the public are supportive of allowing access to their data. The report makes recommendations for outcome-based use cases in the following areas: prevention, disease pathways, clinical trials and clinical care (Exhibit 2).

Furthermore, the BCG survey found that 66% of the public do not mind value or profits being generated from their healthcare data providing some of that value is reinvested into the health system and/or there are wider public benefits. When this happens, the level of support for profit-making from health data was more than double that of those uncomfortable with any profit-making.

There is majority support for data being used in all use cases

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used for this?



Similar findings were reported by The Health Foundation in 2023 who commissioned a survey of 7,100 nationally representative members of the public (aged 16 years+) to investigate their attitudes to uses of health technologies and data. In terms of sharing of health data, the key findings were as follows:

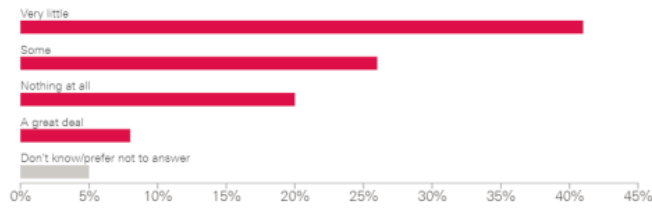
- Approximately two thirds (61%) were found to know 'very little' or 'nothing at all' about how the NHS is using the health care data it collects (Figure 4).
- Around two thirds trust GP practices (69%), local NHS hospitals/clinics (68%) and national NHS organisations (64%) with their health data, with trust lower for commercial organisations and charities and national / local government (Figure 5).
- The sample were generally happy for their data to be used for secondary purposes, with the greatest support for NHS data use. Support was slightly lower for use by health technology companies, pharmaceutical companies and universities (Figure 6). Notably though, for every scenario around 1 in 5 people were resistant to their data being used in any of these ways. This raises concern about the quality and representativeness of SDEs if these people were to opt-out of their data being used in this way.

The concept of sharing access to large-scale datasets for secondary purposes has been found to be a difficult concept for members of the public to grasp. This was stressed within a recent qualitative study by Baxter et al. (2023) who discussed how the members of the public they engaged with struggled to move beyond the concept of medical notes/individual health records being shared for the purpose of individual care. However, despite this uncertainty, those engaged with expressed a desire to know more about the data, in particular its purpose, how it is shared and used, in order to fully understand and be able to give an opinion on its use. This therefore highlights the need for improved communication about data for secondary uses to members of the public, which may potentially help those who are reluctant to share their data for any secondary use purposes.

Figure 4

Nearly two-thirds of the public know very little or nothing at all about how the NHS is using the health data it collects

How much, if anything, would you say you know about how the NHS is using the health data it collects?

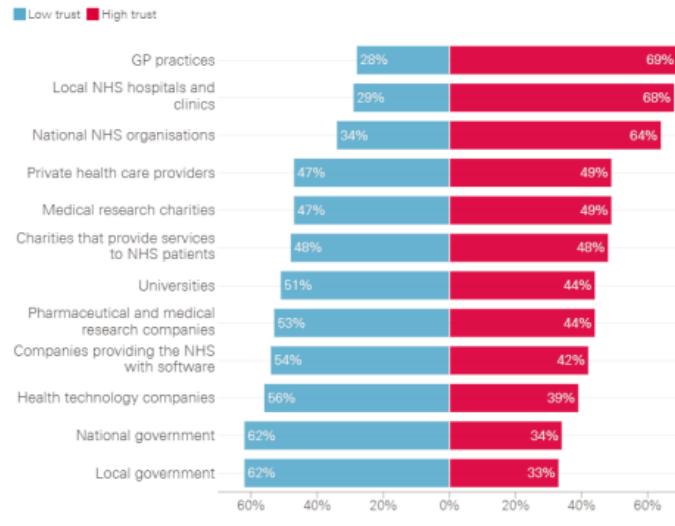


The Health Foundation © 2023
 Source: UK public survey fieldwork carried out online and by phone by Censuwide, 1-23 March 2023; total sample size 7,100 adults (85% from England, 8% Scotland, 5% Wales and 3% Northern Ireland); figures have been weighted and are representative of all UK adults (aged 16 years and older).

Figure 5

The public trusts NHS organisations the most with its health data

How much, if at all, do you trust the following organisations with your health data?

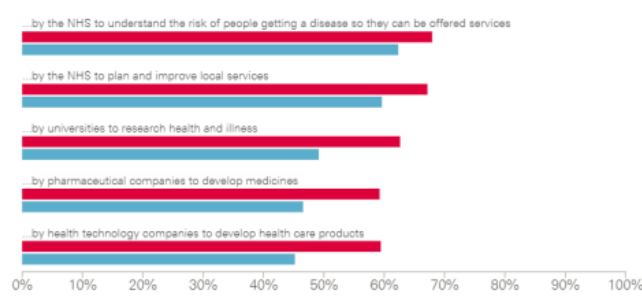


The Health Foundation © 2023
 Source: UK public survey fieldwork carried out online and by phone by Censuwide, 1-23 March 2023; total sample size 7,100 adults (85% from England, 8% Scotland, 5% Wales and 3% Northern Ireland); figures have been weighted and are representative of all UK adults (aged 16 years and older).
 * 'High trust' includes those who answered 'Trust a lot' or 'Trust moderately'. Low trust includes those who answered 'Trust a little' or 'Don't trust at all'.

Figure 6

The public is generally happy for its data to be used for secondary purposes, with the greatest support for NHS data use

I would be happy for my anonymous/identifiable health data to be used...



The Health Foundation © 2023
 Source: UK public survey fieldwork carried out online and by phone by Censuwide, 1-23 March 2023; total sample size 7,100 adults (85% from England, 8% Scotland, 5% Wales and 3% Northern Ireland); figures have been weighted and are representative of all UK adults (aged 16 years and older).

Federated Data Platform

In late 2023, it was announced that NHS England signed a £330 million contract with the US based organisation Palantir Technologies, to establish a Federated Data Platform (FDP) for Trusts and ICBs to share patient data between themselves, providing access for NHS staff who need to see it as part of their role only.

Palantir is a large company who specialises in big data analytics and prides themselves on their involvement with US defence and security agencies. The company was co-founded by a billionaire libertarian called Peter Thiel and who in the past has made comments about the NHS *“making people sick”*⁵. Furthermore, Palantir’s UK head, Louis Mosely has been quoted internally as saying that Palantir’s strategy for entry into the British health industry was to *“buy our way in”* by hoovering up smaller rival companies with existing relationships with the NHS in order to *“take a lot of ground and take down a lot of political resistance.”*⁶⁷

The announcement of Palantir’s involvement has therefore faced criticism from national and local campaigners who argue that Palantir’s lack of track record in healthcare and its murky links to US and UK spy agencies make it unfit to take on the job⁸.

Prior to Palantir signing the contract, in December 2022 NHSE published a heavily redacted version of its 586-page contract with Palantir, which blocked out significant parts of the content, including most of the information under the heading ‘protection of personal data’.

On the same day that the redacted contract was published, the Good Law Project said leaked emails showed Palantir had hired PR agency, Topham Guerin, to pay influencers to attack Good Law Project on social media. But Good Law Project noted that one of the non-redacted parts of the contract, covering ‘Publicity and Branding’, states that Palantir is not permitted to use the Authority’s name or brand in any marketing or publicise the contract without the prior written consent of NHS England.⁹

Since then, the Good Law Project have continued to critique the relationship between NHSE and Palantir, with NHSE agreeing to investigate whether Palantir has violated the terms of its contract.

Whilst the FDP is distinct from SDEs, there is confusion about the role (or lack thereof) of Palantir in the SDE initiative. This confusion has been exasperated by a recent tweet by the Good Law Project who stated that the NHS has just *“handed over medical information”* to Palantir. To mitigate this, they recommend that members of the public use the NHS national data opt-out.

⁵ The Telegraph; Jan 23; Britain’s affection for the NHS is Stockholm syndrome;

<https://www.telegraph.co.uk/news/2023/01/18/peter-thiel-britains-affection-nhs-stockholm-syndrome/>

⁶ Bloomberg; Sept 22; Peter Thiel’s Palantir Had Secret Plan to Crack UK’s NHS;

<https://www.bloomberg.com/news/articles/2022-09-30/palantir-had-plan-to-crack-uk-health-system-buying-our-way-in?leadSource=uverify%20wall>

⁷ openDemocracy; Oct 23; What you need to know about Palantir, the US firm in line for a £480m NHS deal;

<https://www.opendemocracy.net/en/palantir-nhs-federated-data-platform-peter-thiel-data-privacy/>

⁸ The National; Nov 23; SNP MP grills Rishi Sunak over Palantir’s NHS contract;

<https://www.thenational.scot/news/23956481.pmg-snp-mp-grills-rishi-sunak-palantirs-nhs-contract/>

⁹ Digital health; Jan 24; NHSE to investigate Palantir for possible breach of FDP contract;

[https://www.digitalhealth.net/2024/01/nhse-to-investigate-palantir-for-possible-breach-of-fdp-contract/#:~:text=NHS%20England%20\(NHSE\)%20will%20investigate,non%2Dprofit%20Good%20Law%20Project.](https://www.digitalhealth.net/2024/01/nhse-to-investigate-palantir-for-possible-breach-of-fdp-contract/#:~:text=NHS%20England%20(NHSE)%20will%20investigate,non%2Dprofit%20Good%20Law%20Project.)

Other sources (such as the Guardian¹⁰) have also added to the confusion, suggesting that the FDP will be used for research purposes, which is not the case.

This confusion therefore creates additional challenge for the SDE programme, in terms of raising awareness and providing reassurance about its distinction from the FDP and Palantir.

Public perceptions around secondary uses of health and social care data – a regional perspective

The following provides an overview of the work that has been undertaken to understand perceptions around sharing of NHS data, NENC ICB will build upon this to develop the terms and principles over who is given access to the data.

In May 2018, YouGov conducted a poll on behalf of Teesside University engaging with over 800 people from NENC. The study found that:

- After viewing a video about the Great North Care Record (GNCR) – 53% said that they would be happy to share their identifiable data with approved researchers and 46% agreed to the same with medical companies. It is important to note for that question “identifiable” meant that their data would be shared alongside their name and address, so that level should be treated as a baseline, as data shared through SDEs would not be accompanied by identifiable information.
- 86% believed that it was important to control their own privacy settings.

In 2019, NIHR conducted the Connected Patient (Leadgate) Project in NENC where they wanted to build a registry of patients, who had given their permission to be contacted by researchers from the NHS, universities, and commercial companies. Recommendations from the project, with relevance to the SDE programme are as follows:

- Additional work is required to explore the granularity of permissions and the rationale for choice.
- Overt commercialisation of the research process may hinder recruitment.
- Studies in primary care should be targeted at health promotion and chronic disease.
- Further work is required at a regional and national level to better articulate the role of commercial companies in NHS research.

Connected Health Cities worked with Teesside University and local Healthwatch groups in NENC to bring together citizens across the region (Great North Care Record Public Engagement Report, 2020). They conducted focus groups with people in the region that identified the following 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.

¹⁰ The Guardian; Dec 23; You may balk at giving your health data to Palantir but it could save your life; <https://www.theguardian.com/commentisfree/2023/dec/02/you-may-balk-at-giving-health-data-to-palantir-but-it-could-save-your-life>

- 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.

Variance between population groups

The sources reviewed share limited information as to whether any specific ethnic groups are particularly reticent to have their data shared in this way. For example, the Connected Health Cities Impact report (2020) from the Northern Health Science Alliance discussed how, as part of focus groups conducted by Teesside University, people in the north are concerned how the GNCR could affect people around them. They then investigated this further with ‘various ethnographic approaches’ and found that some groups in society have deep concerns about presenting to a doctor or allowing their information to be shared. Anxiety about patient/doctor confidentiality and concerns about data security was shown to push people away from health care. Unfortunately, they share no further specifics.

In terms of gender and age, the Patient Experience Library’s literature review (2021) 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). Furthermore, older people were happier to have their information shared between professionals involved in their care as it was difficult for them to remember everything, but 16-24 year olds were more confident that their data would be handled securely. Social status was also a factor, those better off are more likely to view the use of health data as being of benefit to society. C2DEs were uncomfortable with being targeted by specific messages.

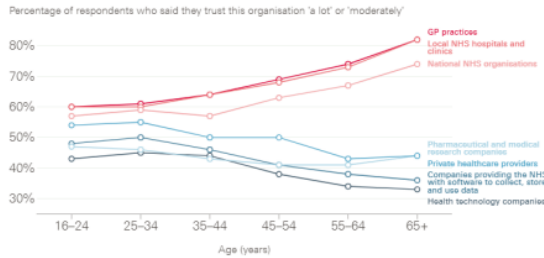
As part of the Connected Patient Project preferred mode of contact was explored to gauge public willingness to move towards digital communication (pre-pandemic). The response rate was consistent across age ranges, with women slightly more likely to respond than men. 61% gave permission to be contacted by at least one of the three organisations, this was based on a single GP practice, so this represents 15% of the practice population. It concluded that overt commercialisation would hinder further efforts, saying no to all three bodies was most common. Older people preferred letter, but generally people preferred text.

More recently, age differences were reported by the Health Foundation (2023) who found that younger people were significantly less likely to trust NHS organisations with their data than older people, but more likely to trust private companies and providers. Furthermore, younger people are more likely to feel in control of their health data, with over two thirds of those aged 65+ feeling they have little to no control (Figure 8 & 9).

Figure 8

Younger people are significantly less likely to trust NHS organisations with their data than older people, but more likely to trust private companies and providers

How much, if at all, do you trust the following organisations with your health data?

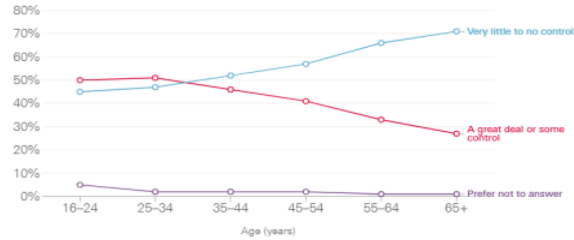


The Health Foundation © 2023. Source: UK public survey fieldwork carried out online and by phone by Censuwide, 1-23 March 2023; total sample size 7,100 adults (88% from England, 8% Scotland, 5% Wales and 3% Northern Ireland); figures have been weighted and are representative of all UK adults (aged 16 years and older).

Figure 9

Younger people are more likely to feel in control of their health data, with over two-thirds of those aged 65 years and older feeling they have little to no control

How much control, if any, do you think you have over how data about your health are being used by the NHS?



The Health Foundation © 2023. Source: UK public survey fieldwork carried out online and by phone by Censuwide, 1-23 March 2023; total sample size 7,100 adults (88% from England, 8% Scotland, 5% Wales and 3% Northern Ireland); figures have been weighted and are representative of all UK adults (aged 16 years and older).

Collation of key themes

Barriers for patients and the public participating in sharing personal healthcare data:

- Public mistrust stemming from historical events - poor public identified as root cause (i.e., care.data).
- Low public awareness and understanding about how the NHS is using the data it collects and the concept (and processes involved i.e. data security) with data access for secondary purposes.
- Low trust for organisations outside of the NHS (particularly pharmaceutical, medical research and health technology companies).
- Misinformation (e.g. Palantir's [none] involvement with SDEs).

Enablers for patients and the public participating in sharing personal healthcare data:

- Public benefit as the principal motivation using tangible examples to provide clarity (highlighting the opportunity cost of not sharing the data may also be beneficial).
- Inclusive and meaningful PPIE:
 - Promoting reciprocity, fairness, agency, privacy, transparency and trust.
 - Ensuring representation of all population cohorts.
 - Embedded throughout the SDE lifecycle.
- Public education and information to;
 - Raise general awareness of how and why sensitive data is made accessible for research.
 - To build trust and better articulate the role of universities, charities and commercial companies in NHS research.
 - Highlight and provide reassurance around data security / control procedures, for example:
 - Stringent criteria and process for vetting potential partners using an independent body of experts and lay people.
 - Removal of personal identifiable information

- Strict rules that data will not be passed on
 - Contracts put in place that data can only be used for agreed purposes
 - Data only being accessible in a secure IT environment.
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- Proactive transparency about who has accessed and used the data (and why), the impact of the analysis/research undertaken, and any distribution of any financial benefits to the NHS.
 - Patient / professional relationships – key role in shared decision making agenda.
 - Avoidance of misinformation.

Key questions / areas for further exploration

Some key areas that will be critical for further exploration include:

- Further demographic work to enable targeted messaging and engagement.
- Should part of the communications package be focussed on information governance and ethics practices in academia?
- How can we incorporate the message about data security?
- Do our organisations recognise the crucial importance of PPIE for this project- public involvement and community engagement was intended to be embedded at every stage of planning delivery and development of the Applied Research Collaboration's strategic aims? Has this happened?

Appendix one

Name	Date	File name	Document purpose	Notes
National Institute for Health Research North East and North Cumbria	12/07/2019	The Connected Patient Project: Report (connectedhealthcities.github.io)	Reporting the results of the Connect Patient Project	
Northern Health Science Alliance-Connected Health Cities Impact Report-2016-2020	May 2020	86a089_bb3031f66a974501a2f4437bc3c3c631.pdf (usrfiles.com)	Providing a report on the benefits of the connected health cities to improve health and social care services for patients across the north of England with a specific section dedicated to NENC	<ul style="list-style-type: none"> ● 10m people now have connected health and care records ● During this, 3000 conversations were had with citizens on what principles should apply to the use of their data: <ul style="list-style-type: none"> ○ Agency ○ Reciprocity ○ Fairness and lack of exploitation ○ Privacy ○ Transparency and trust ● Focus groups in our region, they expressed clear value and expectations around sharing data, including respect. Analysis identified: <ul style="list-style-type: none"> ○ Reciprocity ○ Fairness ○ Agency/control ○ Privacy ○ Transparency/trust ● These have become part of the national narrative ● Mentions the YouGov poll from the EOI

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				<ul style="list-style-type: none"> • Researchers from Newcastle Uni considered the finding from the focus groups that people are concerned how the GNCR could affect people other than themselves. They engaged nine groups and organisations in Teesside, working directly with marginalised groups. • The findings highlighted how member of some groups had deep concerns about presenting to a doctor or allowing their info to be shared, with anxiety about patient/doctor confidentiality and concerns about data security were shown to push people away from health care. • Work continues with the Leadgate project to work out what questions and systems need to be developed to allow members of the public to take control of their data sharing preferences
NIHR Applied Research Collaboration NENC	March 2021	NIHR-ARC-NENC-Public-Involvement-and-Community-Engagement-Strategy-March-2021.pdf	Sets out the aims and objectives of Public Involvement and Community Engagement in the delivery of Applied Research Collaboration NENC strategy	<ul style="list-style-type: none"> • Embed PICE in the planning, development and delivery of the ARC strategic aims at every stage. • Opportunities for the public to influence and be involved in the governance of ARC • Research is both informed by and designed to deliver on public priorities and needs
NIHR- Citizens' Juries on Health Data Sharing in a Pandemic	May 2021	ARC GM Projects (nihr.ac.uk)	Reported on a citizens jury exercise conducted in	<ul style="list-style-type: none"> • A majority were in favour of all the data sharing initiatives continuing for as long as they were valuable (potentially beyond the pandemic and for non-COVID-19 uses), with support ranging from 58% for the NHS COVID-19 Data Store and Platform to 87% for OpenSAFELY across the three juries.

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			Greater Manchester	
NENC ICS- TREE Strategy	May 2021	https://north-eastnorthcumbria.nhs.uk/media/hguly/nenc-tree-strategy-v1-0-final.pdf	Outlining the ICS' strategy to unlock the value of data in the region to improve and sustain better health and well-being outcomes in the region	<ul style="list-style-type: none"> ● One of the strategic outcomes is “developing public and partner trust and assurance on use of data through a transparent, safe and effective capability” ● The use of patient identifiable data will be reviewed for applicable future projects, ensuring the right governance ● Transparency in outcomes for organisations, governance and public groups ● Part of the first theme of the NENC digital strategy is “respecting the rights of our citizens” ● Public groups are included as regional partners (such as a Citizens Forum) ● The TREE case for change includes: The TREE will provide increased understanding of how data can be safely used to deliver new and innovative health and care services and treatments. The capability will provide transparency on data sources, how the data is used and what outcomes it leads to. It will empower our public through their representation in its governance and by using individual preferences for data-sharing through interacting with tools such as MyGNCR ● Public preferences from tools like MyGNCR will be used to identify and recruit cohorts of potential consenting participants for regional and national research and trials
British Association of Social Workers- What Influences Parents and Practitioners' Decisions to Share	July 2021	Smart%20et%20a%202021%20What%20influences%20parents%20and%20practitioners'%20decision%20to%20share%20perso	Local research about what makes people willing to share their data	<ul style="list-style-type: none"> ● Key themes in participants' accounts include the degree of need for help and support; the importance of trusting relationships; stronger and structured joint working practices; and understanding how information is shared

Name	Date	File name	Document purpose	Notes
Personal Information within an Early Help (Social Care) Context? Implications for Practice in Sharing Digital Data across Sectors		nal%20infor mation%20fi nal%20versio n.pdf		
Patient Experience Library- Public perceptions of NHS data use: Rapid literature review	July 2021	Public+perce ptions+of+N HS+data+use +- +rapid+litera ture+review %20(1).pdf	Providing a literature review around current public perceptions of the NHS using their data	
Digitalhealth- TREs in the NHS- how health data sharing is saving lives	May 2022	TREs in the NHS – how health data sharing is saving lives (digitalhealth .net)	Looking at the NHS' development of a TREE	<ul style="list-style-type: none"> ● It has enabled the democratisation of data ● There is a responsibility to use this data effectively for improving care
Dare UK- Building a trustworthy national data research infrastructure:	May 2022	DARE_UK_Bu ilding_a_Trus tworthy_Nati onal_Data_R esearch_Infr astructure_P	Summarising a public dialogue to explore views as to how the UK's data	<ul style="list-style-type: none"> ● Proactive transparency should be practised. Clear understandable and engaging information should be brought into peoples lives through proactive channels to raise general awareness

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A UK-wide public dialogue		public_Dialogue_May-2022.pdf	research infrastructure could work in a more joined up way	<ul style="list-style-type: none"> ● Engagement should be inclusive and meaningful. The public should be involved in initiatives, requiring proactive and targeted outreach. The public's input should be sufficiently informed so as to be meaningful ● Raise awareness of data security processes to improve public trust ● A unified process should be agreed with multiple members of the public from each nation ● Sensitive data should be used where it is in the public benefit
DHSC- Data saves lives: reshaping health and social care with data	June 2022	Data saves lives: reshaping health and social care with data - GOV.UK (www.gov.uk)	Providing a brief on what the policy means practically	<ul style="list-style-type: none"> ● Opt-out systems will be simplified ● Five principles have also been set out to realise the benefits of the system: <ul style="list-style-type: none"> ○ Any use of NHS data, including operational data, not available in the public domain must have an explicit aim to improve the health, welfare or care of patients in the NHS, or the operation of the NHS ○ NHS data is an important resource and NHS organisations entering into arrangements involving their data, individually or as a consortium, should ensure they agree fair terms for their organisation and for the NHS as a whole. ○ Any arrangements agreed by NHS organisations should not undermine, inhibit or impact the ability of the NHS, at a national level, to maximise the value or use of NHS data. NHS organisations should not enter into exclusive arrangements for data held by the NHS, nor include conditions limiting any benefits from being applied at a national level, nor undermine the wider NHS digital architecture ○ Any arrangements agreed by NHS organisations should be transparent and clearly communicated in order to support public trust and confidence in the NHS and wider government data policies. ○ Any arrangements agreed by NHS organisations should fully adhere to all applicable national level legal, regulatory, privacy and security obligations
Dare UK- Paving the way for a coordinated	August 2022	DARE_UK-Paving_the_way_coordin	sets out the emerging findings and	

Name	Date	File name	Document purpose	Notes
national infrastructure for sensitive data research		ated_national_infrastructure_sensitive_data_research-Aug2022.pdf	recommendations so far from Phase 1 of the DARE UK programme – ‘Design and Dialogue’ – which began in July 2021	
Dare UK- How can trusted research environments support researchers outside of academia? Public engagement, governance and training to support safe use of data	14/11/2022	https://dareuk.org.uk/how-can-trusted-research-environments-support-researchers-outside-academia/	Outlining the public perceptions of different types of organisations accessing sensitive data for research in Scotland	
ICB Non-executive Director briefing	22/12/2022	NED briefing v0 5 2022 12 21	Outlining the update that was provided to ICB Directors	<ul style="list-style-type: none"> ● NENC will be one of 11 ICBs to receive funding as part of NHS England’s Data for Research and Development programme. ● A key part of the programme is the establishment of a single Data Access Committee (DAC) with patient and public representation in 2023.

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				<ul style="list-style-type: none"> In 2023 we will re-constitute the existing SDE governance to include the DAC and will have re-purposed many of the dataflows currently held by NECS for research and development purposes.
The Health Foundation – Exploring public attitudes towards the use of digital health technologies and data	Nov 23	https://www.health.org.uk/sites/default/files/pdf/2023-11/Exploring%20public%20attitudes%20towards%20the%20use%20of%20digital%20health%20technologies%20and%20data.pdf		<ul style="list-style-type: none"> Survey of over 7,100 nationally representative members of the public to investigate their attitudes to uses of health technologies and data, and the key factors affecting their views.
Baxter et al. - Sharing real-world data for public benefit – a qualitative exploration of stakeholder views and perceptions	Jan 2023	https://bmcpublikealth.biomedcentral.com/articles/10.1186/s12889-023-15035-w		<ul style="list-style-type: none"> Study to gain an in-depth understanding regarding the potential to unlock real world data that was held in individual organisations, to better inform public health decision-making. This included sharing data between and within health service providers and local governing authorities, but also with university researchers. Methodology comprised of online workshops and interviews with senior level decision makers / service leads, researchers, data analysts, those with a legal and governance role and members of the public. The report makes recommendations of the changes that need to be actioned at a number of different levels, both internal and external to organisations (Summary of priority areas for action at different levels derived from the final workshops).

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Boston Consulting Group's Centre for Growth	July 23	https://www.bcg.com/united-kingdom/centre-for-growth/insights/towards-a-healthier-wealthier-uk-unlocking-the-value-of-healthcare-data	To understand public perceptions around access and use of healthcare data	<ul style="list-style-type: none"> BCG conducted a survey with a representative sample of the public.
Great North Care Record Public Engagement Report	July 2018	https://www.greatnorthcarerecord.org.uk/wp-content/uploads/2018/09/GNCR-public-engagement-report-FINAL.pdf		

