

North East and North Cumbria – federation workshop

1. Executive Summary

Overall, the workshop showed that public members understood and identified a range of benefits to the proposed federated Secure Data Environment (SDE) model. These include the ability to analyse larger datasets and compare findings across a greater geography, and these findings could improve public health, improve health outcome and inequalities.

The group was very conscious that the greater size, brings greater complexity.

However, there are a range of concerns which programmes looking to link SDEs would need to address. Whilst overall support for federation reduced during the workshop session, the concerns raised are in line with general concerns raised by the general public in our street surveys of 2024 about data sharing and SDEs. Their concerns included the technical accuracy of data, security, trust, how governance would apply and how their voice would continue to be heard in the development of the programme. They would need to be addressed before the programme federates data.

2. Background and Purpose

The workshop took place on 27 November 2025 with 15 members of the North East and North Cumbria (NENC) Secure Data Environment (SDE) Patient and Public Involvement and Engagement (PPIE) group.

The aim of the session was to explore the public member's views, feelings, benefits and concerns about federating data between the three northern SDEs. The three SDEs included in the discussion were:

- North East and North Cumbria
- North West
- Yorkshire and Humber

The workshop was required as part of a wider piece of work commissioned by DARE UK. University of Sheffield is leading a project on behalf of the three northern SDEs

as part of the DARE UK Early Adopter Programme, aimed at transforming how sensitive health and public data is accessed and used for research in the UK.

The project – called PANORAMA project (Pan-North Data Research Advancements for Multi-Domain Access) is a collaboration between NHS organisations and universities in the North of England covering a population of 15 million.

The project is divided into four distinct work packages:

1. Leadership and federated governance
2. Federating infrastructures
3. Linking federated outputs
4. Professional, patient and public involvement

This workshop fits in the final work package.

Yorkshire and Humber have already completed a citizen's jury in March 2025. This explored the public's view around a range of topics but included federation.

In the NENC region, there has previously been no engagement or involvement activity about federation so there are no current insights for us on this subject.

As the work in Yorkshire and Humber is gold standard patient and public involvement, and with limited timescales available, the project team took the decision to use the same materials, questions and prompts as Yorkshire and Humber. Using the NENC public member group did mean that there was less ground work to do in relation to helping them understand what an SDE is.

The key question we explored was how supportive the group members were about their own healthcare data being used in a federated SDE project.

The objective of the session was to compare the findings with Yorkshire and Humber, and to allow for the North West to run the same session as NENC, so results across the three areas can be combined and a recommendation made as part of PANORAMA for future SDE-linking projects.

3. Methodology

The workshop took place during one of the public member's standard monthly meetings. They operate on an alternating schedule of online and offline, so this workshop took place on MS Teams.

It took place on Thursday 27 November 2025 and following standard programme and PPIE programme updates, the session took place at 10am.

Extensive work by the PPIE programme team previously means that the sample of people in the group is representative of the local population in terms of age, ethnicity, income, and geography. Whilst not all members of the group attended the meeting, 15 of the 19 did join the session.

The approach we took was using the same presentation, questions and discussion prompts as the Yorkshire and Humber citizen jury – whilst recognising that we were much more limited with time than their group.

We explained to the group that, although the discussion sessions were recorded, this was solely for transcription purposes and no individual would be identified in the report.

We also introduced additional safeguards: public members were polled anonymously during the session to ensure they did not feel pressured to ‘please the project team’.

The PPIE group holds a wide range of views, and we wanted to ensure that no one felt they would be unfairly judged or treated differently by the programme team if they did not support federation.

The workshop format was broken down into these sections:

1. Welcome and presentation (15 mins) Programme team

- Overview of PANORAMA
- What we must deliver
- Why federation work is taking place.
- What federation means
- Summary of key concepts
- Clarify task for public members.

2. Clarification questions (10 mins) Programme team

Open Q&A to ensure all participants understood the proposal before discussion.

3. Anonymous poll shared in the chat on MS Forms link

Participants completed the poll there and then, although some updated after the meeting.

Question:

“You have heard about the proposal to enable research and planning across the three Secure Data Environments in the North of England so that researchers can access health and social care data from three regions: North West, North East and North Cumbria, Yorkshire & Humber.

Based on what you have heard, how do you feel about this proposal to enable research and planning across the three Secure Data Environments in the North of England (The Northern Secure Data Environment Partnership)?”

Response options:

1. Very supportive
2. Fairly supportive
3. Neither supportive nor unsupportive
4. Fairly unsupportive
5. Very unsupportive

4. Breakout discussions (40 mins)

The programme team facilitated discussions in three separate breakout rooms. Rather than having one large group, the public members were randomly split into smaller groups to give everyone an opportunity to speak. The sessions were recorded and transcriptions generated.

There were two main questions posed to the breakout groups:

1. What are the main benefits?
2. What are your concerns?

This was an open discussion, and all participants were encouraged to share their views.

5. Anonymous poll shared in the chat on MS Forms link

The poll after the main presentation was repeated to see if there was shift in how people felt about their healthcare data being used in this way. This was on a new MS Teams link and again was shared and completed anonymously.

6. Wrap-up and next steps (5 mins) Programme team

The programme team brought all participants back together and to wrap up and give the participants a chance to raise any final points. Recordings from the breakout sessions would be analysed and all the benefits and concerns would be grouped together and combined across all breakouts.

4. Findings / Key Themes

Anonymous polling results

We polled all the public members straight after the presentation, once they knew some basic information about what federation is and had the opportunity to ask any clarification questions.

Options	Before Discussion	After Discussion
Very supportive	3	2
Fairly supportive	6	2
Neither supportive nor unsupportive	2	2
Fairly unsupportive	1	4
Very unsupportive	1	1
No response	2	5
Total	13	11

These findings indicate a drop-in support for federation among our public members once they had a chance to consider and think in more detail about the implications. With 9 of them going from very to fairly supportive to just 4 after the discussion.

Likewise, 2 public members were either very or fairly unsupportive before the discussion, with 5 feeling that way after the discussion.

Note that not all participants completed the survey and fewer people completed the second follow up. We could imply from this, that people were unsure about how they felt about the proposal.

Workshop discussion results

The discussion sessions broke into three smaller groups. Here the group focused on what they saw as the benefits and concerns in relation to their data being used in a federated way.

These discussions were transcribed and have been themed below:

Benefits

1. Improved population-level insights

- Ability to see patterns across a larger area, especially for people who live or receive care across different regions.
- Supports population health management by enabling comparisons between similar communities (e.g. coastal, rural, isolated areas).
- Strengthens understanding of health inequalities and their links to wider determinants such as housing or environment.

2. Better support for rare conditions

- Federated datasets create larger sample sizes nationally.
- Enables more meaningful research on rare conditions that a single region cannot analyse alone.

3. More comprehensive research and innovation

- Researchers can access richer, more complete datasets.
- Potential for national-level insights and interventions rather than small, siloed studies.
- Supports the development of more effective and transferable solutions.

4. Easier data flow and technical efficiency

- A federated model could streamline how data is accessed, shared and linked between SDEs.

- Helps avoid repeated, separate applications for similar datasets across different regions.
- It could mean that the costs for researchers to access the data reduces.

5. Future potential for concierge-style coordination

- If implemented well, a centralised coordination model could simplify multi-SDE applications.
- Could help researchers navigate datasets more easily and reduce duplication of effort.
- A single front door and one application form would simplify the researcher process.
- Potential financial benefits for the wider research community
- Greater knowledge and sharing of best practice, especially with complex applications.

A summary of the concerns of federation identified by the groups are:

Concerns

1. Governance, approval processes and control

- Lack of clarity on who has final authority in a federated model — particularly if another region's DAC approves access to data from NENC.
- Strong desire for transparency and reassurance about how governance would work.
- Concern that the existing national “concierge” idea is unclear, immature, or inconsistently applied.
- Concerns raised that public representation in other regions works differently to NENC.

2. Loss of local oversight and public voice

- Worry that local PPIE views may not “travel” with the data.
- Each SDE has different public panels and approval processes; people want assurance that local concerns and values will be retained.

3. Data expansion and ‘creep’

- Strong concerns about linking too many types of data (e.g. police, environmental, benefits, local authority).
- Fear that broad data pooling could become “a monster,” increase risks, or lead to uses that feel uncomfortable or intrusive.
- Anxiety linked to wider political discussions such as digital ID cards, privatisation of the NHS and the Federated Data Platform provided by Palantir.

4. Trust, privacy, and security risks

- Concern about broader access and the potential for misuse, commercial exploitation, or data being “sold to the highest bidder.”
- Concerns about data leaks and uncertainty at who would be responsible if something goes wrong.
- Perception that NHS data feels more secure and trustworthy than other public sector datasets such as local authority or government departments.
- It could be more vulnerable or attractive to cyber criminals.
- Moving data between SDEs perceived as risky.

5. Need for clear boundaries and safeguards

- Desire for clear rules on what can and cannot be included.
- Need for assurance that the federation will not be used to expand data purposes without consent or public debate.

6. Operational complexity

- Risk of overwhelming systems and people if roles, responsibilities and escalation routes are unclear.
- Training and support would be needed across all federated partners to ensure consistency.
- Harmonisation of data and risks of not comparing like with like and the possibility of errors or mistakes in the data leading to incorrect conclusions.

7. Variation across regions

- Differences in maturity of SDEs (e.g. Northern Partnership vs. others).
- Concern that federation may expose local data to inconsistent standards or processes.

7. Complexity and confusion for the public

- Risk of confusing people by changing the narrative from “your data stays in NENC” to “your data may be used across wider regions.”
- Concerns about losing public trust if messages become too technical or change too often.
- Clear preference for simple, consistent public-facing explanations.

7. Conclusions

Many participants were comfortable with their data being shared across regions for research, as long as it is done in an open, transparent, honest and respectful manner.

People felt that sharing data across larger areas could help generate stronger evidence and enable researchers in other regions to answer important questions.

The group unsurprisingly valued strong public involvement, clear communication, and robust safeguards, and they emphasised the importance of testing and careful implementation.

If data is handled and analysed correctly, combining datasets could provide a more complete picture of health needs, supporting better planning and services.

There was some variance across the three breakout groups with some having greater comfort with the proposed federation than others.

In conclusion it's not a blanket approval for people's data to be federated. The groups were very clear that there are many benefits to researchers and the wider public, all groups identified a range of similar benefits. However, all groups identified a range of concerns that would need to be addressed.

Governance and accountability were a key concern for the groups, which is no surprise given this group's role in data access governance in NENC.

Our group are more informed than the general public due to their involvement with the programme, but most are broadly in favour and advocates for research and the benefits this brings them and their wider community.

The PANORAMA project, or future federated SDE programmes would need to address and unpack the technical, governance and data quality issues.

A wider concern for the group is the overall motivation of those behind this work. As with other work in this area, trust and transparency are overarching issues to address.

There are concerns that the SDE space is already highly complex, that this is adding further complexity that our group may not feel comfortable with at this point in time.

What was clear from the two anonymous polls was that support for federation reduced as the group considered it more. Whilst this shouldn't prevent this work going ahead, it highlights a list of concerns that would need to be addressed and overcome before the public in our region would be supportive of this change.

8. Recommendations

Further work with members of the public in the NENC region would be advantageous. Any further developments in federated ways of working would need the public voice to continue to ensure the governance and controls around the use of data are aligned with public opinion.

The findings of the citizen's jury in Yorkshire and Humber need to be combined with NENC and NW smaller workshops to get a clear picture of people's views across the whole of the North of England.

The development of a public charter – or a list of pledges of what we will and won't do with NHS data may also help give some assurances and help build trust in this area.