

Public Advisory Group (PAG) Service Design session

May 2026

Introduction

In April, partners from across the region and the Yorkshire & Humber Secure Data Environment (SDE) programme team, came together to:

- Define a shared vision for the Y&H SDE service
- Identify what it will take to build and run the service at scale
- Begin shaping a single, unified regional service rather than separate local offers.

The focus of this work was on the future, considering what a long-term sustainable service should look like and how we move towards that vision.

Following on from this, in May we brought together our Public Advisory Group (PAG) to review and evaluate this direction. The group acted as *“critical friends,”* helping to ensure that the developing SDE service reflects public expectations, priorities and values.

Overall, members of the PAG reflected positively on the session, highlighting both the depth of work undertaken and the increasing clarity around how the SDE will function in practice.

This report details the feedback received, outlines some of the themes and forms a conclusion from the day.

Feedback

Many PAG members noted that the session helped make the SDE *“feel more tangible and real”*, moving beyond a conceptual model to something more concrete and understandable. The opportunity to explore approaches to developing the Secure Data Environment (SDE) as a service, alongside considerations of brand positioning, user profiles, was seen as both reassuring and encouraging, with one PAG member stating, *“It makes the SDE more tangible and easier to consider the practical questions, concerns and reassurance which the public would seek.”*

PAG members also welcomed the opportunity to act as critical friends, contributing to shaping the service design and long-term vision. One PAG member stated, *“It was particularly valuable to come together in person with a diverse group of individuals*

who each brought different professional, personal and community perspectives to the discussion, ensuring that a broad range of voices informed decision-making. It is often rare to be in spaces where lived experiences and co-production are at the centre of decision-making processes.” Several reflections emphasised this point on how rare and important it is to be part of a space where community voice, lived experience and diverse perspectives are genuinely central to decision-making.

There was also strong appreciation for holding the session and for the efforts of the wider Y&H SDE team in creating an inclusive and engaging environment. The day was described as *“productive, insightful”* and overall worthwhile, with a shared sense that different elements of the SDE are beginning to come together more coherently. Members expressed a desire to better understand the user journey for data applicants, saying they were *“Looking forward to seeing what the actual interface for data applicants would look like and the service experience design.”*

Key discussion themes

Commercial model and access

PAG raised important questions about how the commercial model will operate. This included:

- Whether organisations accessing data will pay.
- Whether contributors of data will receive similar services.
- How fairness will be maintained.

Concerns were expressed about the potential imbalance, such as whether organisations providing more funding may receive greater attention or influence when accessing data within the SDE.

There was concern on how pricing models might differ between user groups, such as senior academics and upcoming researchers, with senior academics paying less than an upcoming researcher. Members were also interested in who was leading the development of the commercial model and with this emphasised the importance of public involvement in shaping the model, suggesting there should be dedicated engagement sessions on this.

Financial sustainability and planned direction

The importance of ensuring that the SDE is financially sustainable was strongly emphasised. Members were interested in where Y&H SDE is currently positioned on its roadmap and how it plans to balance demand for data with availability.

There was also focus on identifying regional strengths. Members of the PAG suggested that Y&H SDE should clearly define what it does well and use it as a key 'selling point' to the programme.

Equity, risks and safeguards

Members explored potential risks of imbalance within the system and asked what safeguards are in place to mitigate these challenges. There was also recognition that having multiple SDE platforms across England may offer benefits in terms of resilience and risk management, stating, *"it is better that there are different platforms across the country, as if one platform gets compromised then other ones won't as it's a separate system."*

Public transparency and engagement

Transparency and trust were key themes during this session. Members asked about what has been done to demonstrate to the public how data is being used and how Y&H SDE operates. There was an interest in ensuring that information about ongoing and upcoming projects is visible and accessible, particularly via the Y&H SDE website.

The importance of clear user journeys was also highlighted, to ensure people understand how data is accessed, used and translated into outputs.

Members additionally raised questions about whether individuals can opt-out of specific aspects of data use.

Data processes and standardisation

Challenges around data standardisation were discussed, particularly variations in how GP data is coded. Some members suggested that a regional approach could be a practical starting point, for example, increasing the proportion of GP practices in Yorkshire & Humber using consistent coding systems.

There was also interest in progress towards a standardised application process for researchers requesting access to data in the SDE.

Learning from other models

It was asked whether the Y&H SDE is drawing learning from similar initiatives in other countries. It was suggested that understanding different international approaches and health priorities could help to inform local development while remaining context specific.

Service design principles discussion

To conclude the session, there were discussions around the 11 main principles:

The SDE is

1. Designed and built for its users and solves their whole problem
2. Providing a single experience for its users across all routes and channels
3. Simple to use, minimising duplication for everyone who uses the service
4. Safe (to use), protecting privacy and security of everyone
5. Operating reliably and consistently
6. Delivering once where it makes sense to do so
7. Local, where relationships matter
8. Harnessing local expertise and innovation
9. Applying consistent, recognised (data/ tech/ other) standards, frameworks and artefacts
10. Adopts and adapts – 80/20. 80% standardisation with 20% customisation for variations
11. Working in collaboration, not competition.

There was strong support for recognising and valuing patient data, with a clear emphasis on delivering public benefits.

There was a request for clarity on how specific principles, for example the 10th principle (Adopts and adapts – 80/20. 80% standardisation with 20% customisation for variations) are being put into practice.

PAG members recommended to strengthen the co-design approaches, ensuring that communities are actively involved through user testing and engagement at all stages.

The importance of flexibility within the principles, was noted, to allow the programme to adopt as it evolves.

There was also a consideration of how principles align with decisions about where and how data is stored, ensuring consistency between the values and implantation.

Next steps

The feedback and recommendations provided by participants will help shape future activities. The following next steps outline how these views will be taken forward.

- Demonstrate how PAG feedback has directly influenced decision-making through regular "You Said, We Did" updates
- Define and communicate the programme's distinctive regional strengths and areas of expertise
- Establish opportunities for PAG members to review and test service developments
- Involve public contributors in user journey mapping and interface design activities
- Develop case studies and examples demonstrating how secure data access can improve healthcare, research, and patient outcomes
- Develop simple visual explanations outlining how data moves through the SDE and how safeguards operate
- Provide clear information regarding data opt-out arrangements and any relevant choices available to individuals

- Develop prototype user journeys for researchers and data applicants
- Regularly review the principles to ensure they remain relevant as the programme evolves
- Provide accessible explanations of privacy, security and governance safeguards

Conclusion

Overall, the session was viewed as a significant and positive step forward and members of the PAG left with increased confidence in the direction of the Y&H SDE. The session highlighted key areas where continued engagement, transparency and co-production/ co-design will be essential throughout the SDE programme.