Yorkshire & Humber
SECURE DATA ENVIRONMENT

Part of the NHS Research Secure Data Environment Network

NHS

# Secure Data Environment Implementation in the Yorkshire and Humber Region: Workshop Insights

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# 1. Introduction and background

Secure Data Environments (SDEs) are a safe space where approved researchers can look at NHS healthcare data for important studies. However, protecting people's privacy is very important and therefore all personal details like names, addresses, and NHS numbers are changed to fake information through a process called pseudonymisation. This means researchers can study medical data without seeing any real details that show who the patients are. The SDE is part of a bigger network and follows strict rules to make sure the data is used safely and correctly.

The research enabled by the SDE can lead to better understanding of diseases, improved treatments, and advancements in medical knowledge that ultimately benefit public health. It can also support evidence-based policymaking, monitoring of health trends, and more efficient collaboration among researchers. However, the implementation of SDEs raises important questions about data privacy, security, and public trust.

# 2. Purpose

A series of workshops were organised to gather public opinions on the implementation of a Secure Data Environment in the Yorkshire and Humber region.

This project's aim was to get the public's views to help ensure that SDEs are created and managed in a responsible and ethical manner that addresses public concerns.

By gathering input from a diverse range of individuals from Bradford, it can help understand the public's views, identify potential problems, and develop guidance, processes and protocols to protect individual rights while reaping the benefits of SDEs.

# 3. Participants

The workshops included members of the public from diverse backgrounds, with a nearly equal balance of men and women. Participants were invited from across the Bradford district.

# 4. Method

The participants that attended were from broad areas of Bradford and from various ethnicities. The sessions started with an overview of the workshop plan. The discussions were structured around the following questions:

1. What does "Secure Data Environment" mean?
2. What benefits do you see in having local health data available for researchers in a Secure Data Environment (SDE)?
3. What are the best ways to tell the public about the Secure Data Environment (SDE)?
4. What makes you trust sharing your data with other people or companies for research?
5. If companies want to use data, would that be okay? When would it not be okay? What should they be allowed to use it for?
6. Are there any groups or departments that you think should not use the Secure Data Environment? Why?
7. What kind of requests should not be supported by SDE?
8. Who should decide which researchers or organisations can access patient information through the Secure Data Environment?
9. What kind of transparency or accountability measures would increase your trust in the Yorkshire & Humber SDE process?
10. What is the best way to organise an opt-out?
11. What information should we share about the opt-out process?

A slideshow was used to present each question. The workshop employed a variation of the “brain-writing” to ensure that all participants, including those who might be more introverted, had an equal opportunity to contribute their ideas. Participants were presented each question followed by a short explanation, example and/or clarifications where required. They were then given a three-minute time limit to write down their initial thoughts on a card. This approach allowed everyone to formulate their ideas without the pressure of immediate verbal response, encouraging a more diverse range of perspectives.

Following this individual reflection time, the group engaged in open discussions about their answers. This initially started by swapping cards and asking participants one by one to read out what was written on their card. This allowed opinions from those more introverted members of the group to be heard and discussed. Following the first two or three questions the groups became more comfortable with each other and discussions became more natural, with members feeling more confident to share and discuss their opinions directly. This method proved particularly effective in drawing out views from less vocal participants, ensuring a more comprehensive representation of community perspectives.

The informal setting and structured yet flexible format encouraged open and honest communication. Participants were able to share their views freely, leading to rich and interesting dialogues among the group.

All written responses and verbal discussions were analysed for common themes and key insights. This comprehensive approach to data collection allowed for a thorough understanding of both individual and collective viewpoints on the implementation of the Secure Data Environment in the Yorkshire and Humber region.

# 5.Key findings

## 5.1. Benefits of having local health data available for researchers in an SDE

Participants identified several potential benefits:

- Efficient and effective allocation of funding to the areas with the greatest need.
- Identification of patterns in health outcomes across different communities, helping to reduce health inequalities.
- Analysiswillallowinsightsintohowlifestyle,environment,andother factors affect health outcomes in different areas.
- Helpinformpolicydecisions:forexample,ifdatashowshighasthma rates in areas with poor air quality, it could lead to targeted pollution reduction policies.
- Aid in identifying correlations between health conditions and socio-economic factors, allowing the development of more holistic approaches to public health.
- Data could improve allocation of NHS resources to where they are most needed.
- Data analysis could help identify early warning signs of diseases, leading to earlier and more effective interventions. It could also lead to more effective preventive health strategies.

## 5.2. Best ways to inform the public about the SDE

Suggestions included:

- Providing clear,honest information about theSDE,its purposes, and safeguards.
- Face-to-face discussions and workshops in community centres, allowing for direct engagement and the opportunity to address concerns in person.
- Accessible information in multiple languages and formats, ensuring that information is available to all community members, including those with disabilities or language barriers.
- Use of social media and digital platforms: Creating engaging, easily digestible content to explain complex concepts that can be shared easily to increase delivery to a wider audience. Involvement of respected community figures and “Influencers” to help explain and promote the SDE concept. Partner with local groups to disseminate information through established networks.
- Multiple approaches to reach diverse demographics: Recognising that different groups may prefer different communication methods.
- Use of traditional media: Ensuring information is available through TV, radio, and newspapers for those who prefer these channels.
- Direct communication via text messages and emails: Using personalised methods to reach individuals directly.
- Leveraging the NHS website and official channels: Utilising trusted, official sources to provide credible information.

## 5.3. Factors that increase trust in sharing data for research

Participants emphasised:

- Clear explanations of how data is protected from breaches and unauthorised access.
- Clarity and transparency on who has access to the data and why they require access. Information on potential benefits to the public from sharing the data.
- Clear information on how privacy is maintained through pseudonymisation.
- Assurances that the data will not be used for profit or exploitation. Strict regulations and accountability measures: Implementing and communicating about robust governance structures.
- Clarity on what information is shared when people consent to sharing their data.
- Explanation of approval process for organisations which will be allowed access to the data.
- Assurances that researchers only see the data they need for their specific study.
- Regular updates on how data is being used by providing ongoing communication about research projects and findings.

## 5.4. Transparency and accountability measures to increase trust in the Yorkshire & Humber SDE process

Key suggestions included:

- Disciplinary action for misuse of data. Penalties to be given and publicised for organisations who misuse data or experience data breaches.
- Creation of a diverse board to have oversight over the SDE's operations and use.
- Need for a diverse panel of experts to decide on data access, including doctors, IT, data and cyber security specialists, legal experts, statisticians, and patient representatives.
- Strict ethical guidance for appropriate data use. Implementation of ongoing checks to ensure compliance with all regulations.
- Clear information on how long data will be stored by the organisations and when it will be destroyed.
- Clear criteria that organisations must meet before being approved for access to the SDE.
- Individual access to see what data is held about them and who has accessed it.
- Some participants likened this to how they are able to see who accessed their credit report via products like Credit Expert by Experian or ClearScore.

## 5.5. Best way to organise an opt-out process

Participants recommended:

- Use various media formats to inform people on their right to opt-out and how to opt out.
- Opt-out information should be simple and easy to understand for all community members.
- Creating materials that are accessible to people with different literacy levels and/or disabilities.
- Using GP surgeries and other healthcare settings to share opt-out information.
- Ensure access to face to face support for those who need help understanding or opting out of sharing their data.
- Utilise trusted local figures to help communicate information about opting out.
- Communicate the positives and negatives of opting out in a simple way.
- Offering multiple, frictionless ways to opt out, such as online, SMS, email, or phone.

# 6. Conclusion

The workshops provided valuable insights into the ideas, concerns and expectations of the public regarding the implementation and use of a Secure Data Environment in the Yorkshire and Humber region.

Attendees showed a keen interest in the potential positives of SDEs. However, they also expressed important concerns about data access, security and privacy. They suggested several solutions as discussed above to help improve trust in sharing their data with a SDE.

During the workshops there were some interesting discussions which revealed the complexity involved in sharing their data. Attendees understood both the individual and public benefits of sharing their data. However, they expressed valid concerns about data security, privacy and potential misuse of the data by organisations.

The workshops helped emphasise the importance of transparent communication, ensuring effective governance structures and a well communicated and simple opt out process to help build public trust in SDEs.

The findings from these discussions can help inform the development of policies and communication strategies to ensure that the implementation of the SDE is transparent, trustworthy, and beneficial to the community.