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SECURE DATA
ENVIRONMENT

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Secure Data Environment Community Workshop Report by OutLoud

June 2024

Introduction

OutLOUD is a creative education and training organisation based in Bradford, with extensive experience working in the south part of the city, particularly in Holme Wood. We have a proven track record of delivering numerous successful community engagement and research projects on a variety of themes and subjects. These projects have been delivered in partnership with Born in Bradford (BiB), the Bradford Institute for Health Research (BIHR), and the Centre for Applied Education Research (CAER).

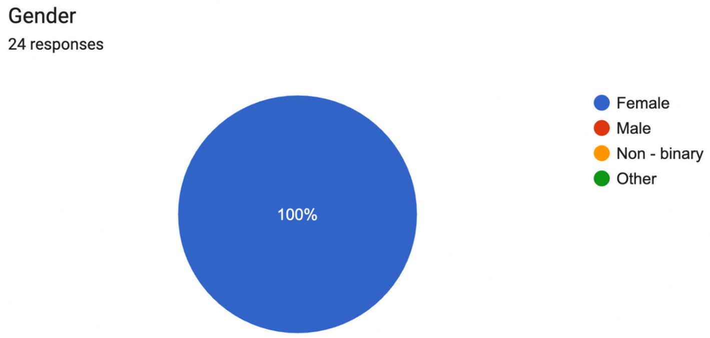
This report shares the findings of a recent project we conducted exploring the new NHS secure data environment (SDE). The overall aim of this project was to gauge the public's understanding of the SDE and to identify any concerns they may have about this new platform. We focused on targeting residents within the Bradford South area, with a particular emphasis on those living in Holme Wood, BD4.

Funding

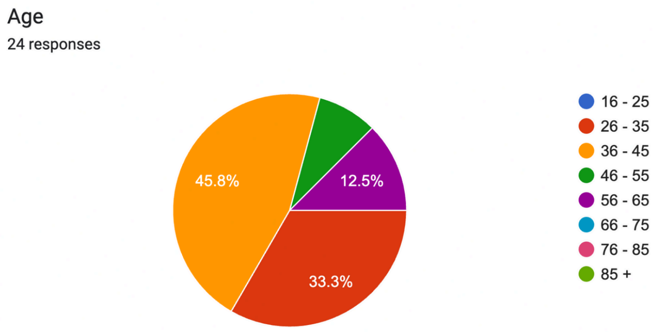
This project was funded by the NHS SDE Project. We made food a central part of our event, knowing from experience that it always draws people in. We provided Caribbean cuisine at our events, which was new to many of the attendees. All participants received a £20 shopping voucher to thank them for their time and participation.

Participants

A total of 24 people attended our workshops. All participants spoke English as their first language and resided in the Bradford South area, with 97% living in Holme Wood, BD4. Below is additional demographic information and data about the participants.



100% of our participants were female. Engaging men in our research projects has always been a challenge, and we are continually seeking new strategies to improve our outreach to the male population. Although we had five males registered for the workshops, none of them attended.



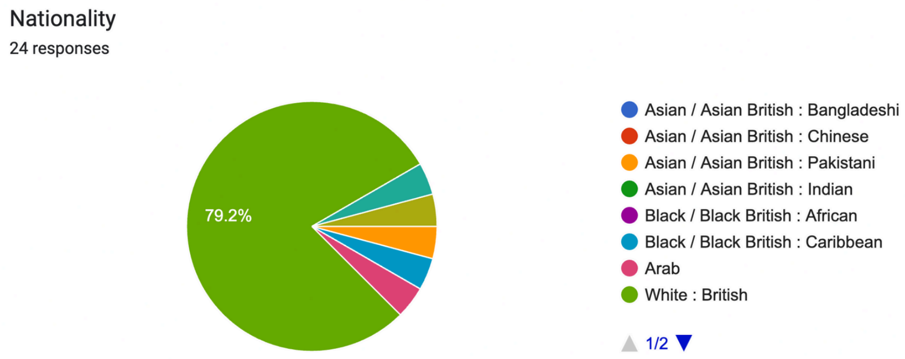
We had a varied age range in attendance. The exact breakdown of these age ranges is as follows.

8 participants were aged 26-35

11 participants were aged 36-45

2 participants were aged 46-55

3 participants were aged 56-65



The majority population in Holme Wood is White British and our participant data reflects this however we did have a number of other nationalities represented. The exact breakdown is as follows.

19 participants were White British

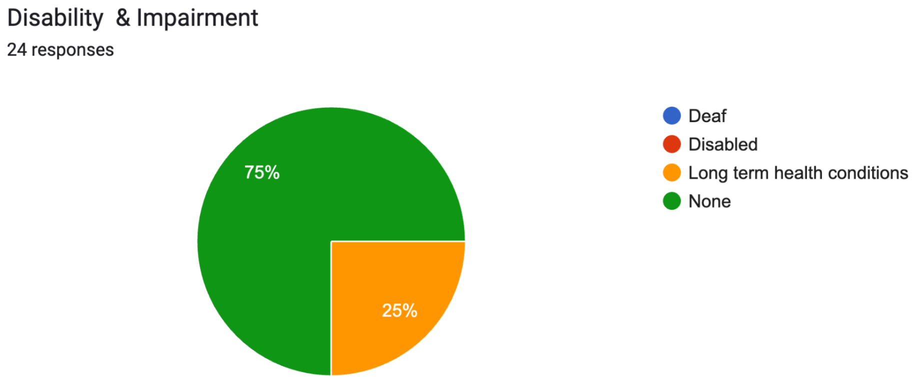
1 participant was Asian/Asian British:Pakistani

1 participant was Black British:Caribbean

1 participant was Arab

1 participant was Kashmiri

1 participant was Mixed Race



Method

Our workshops were delivered face-to-face, with two interactive sessions held during the day and one in the evening to accommodate both working and non-working individuals. We promoted the workshops through various channels, including social media, posters, and word of mouth, encouraging attendees to bring a friend, work colleague, or neighbour.

A total of 33 people registered for the workshops, with 24 attending. We recognise the need to engage more males and plan to target male-specific projects and groups for future promotions, potentially considering gender-specific workshops to achieve a more balanced gender representation.

During the workshops, we employed a range of tools and methods, including whole group discussions, small group discussions that reported back to the larger group, presentations, and individual activities. We aimed to make the workshops as interactive as possible, using methods to engage different learning styles.

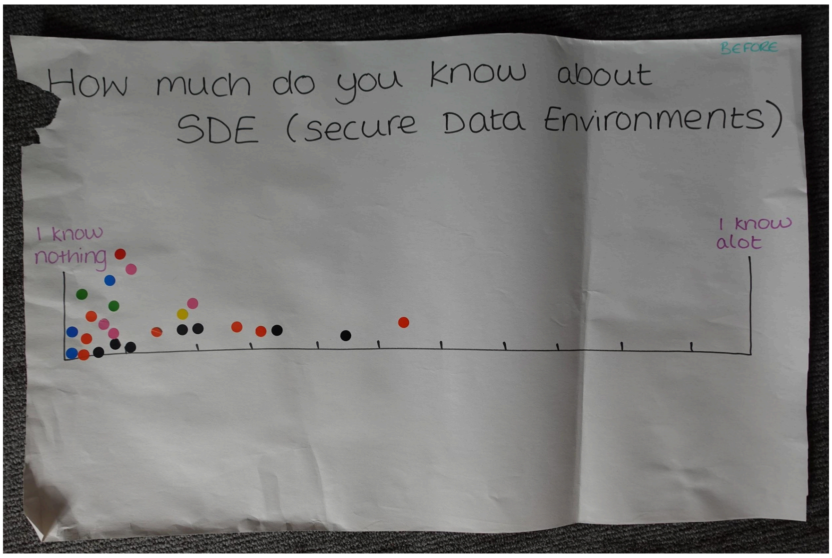
This included visual cues, activities where participants could write down their views and ideas, and the use of sticky dots for responses to certain questions. To ensure unbiased feedback, we provided each group with a blank sheet, preventing the views of one group from influencing another.

Our workshop, titled "Understanding SDE," lasted two hours, including a break and time for food. The structure of each workshop remained consistent to ensure uniformity in the flow of information and questions presented. We began with an icebreaker and introductions to help participants feel comfortable. Before providing any information about SDE, we asked attendees, "How much do you know about Secure Data Environments (SDE)?"

We followed this with a short presentation on what SDE is and showed a video that explains the platform in more detail. This provided participants with a good understanding and foundation for the discussions during the workshop.

Findings

We began by using a sliding scale to gauge participants' existing knowledge of SDE. At the start of both workshops, none of the participants knew what SDE was or what it meant. We asked the same question at the end of the workshops, and all participants reported that their understanding and knowledge of SDE had significantly increased.



Who does your healthcare data belong to?

We felt this question was important to ask as we began discussing SDE and the use of people's data and information for this platform. Participants provided various answers, with the majority stating, "My data belongs to me." Some said, "My data should belong to me" or "Me, but..." These participants elaborated that while they believe their data should solely belong to them, they don't think it does in practice. Other responses indicated that participants felt their data belongs to the NHS, health professionals, and GPs.

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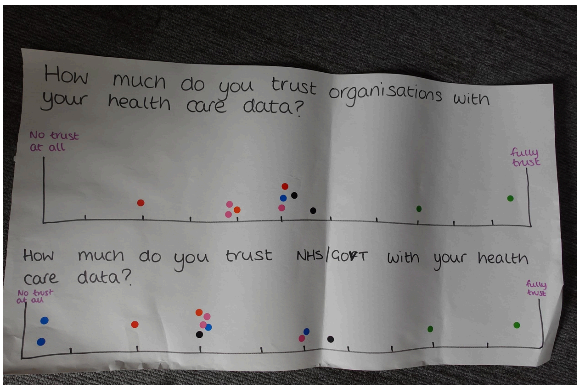
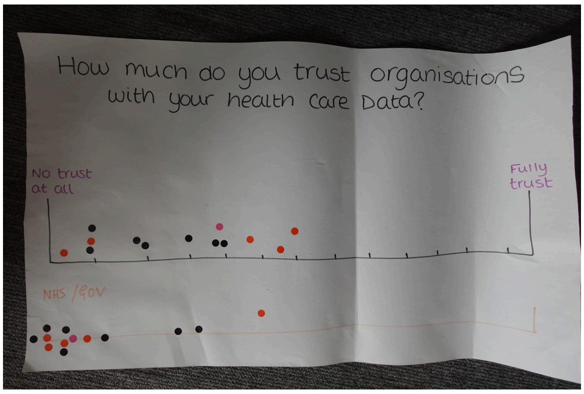
How much do you trust organisations with your health care data?





We used a sliding scale to address this question, as shown above. Some participants asked which organisations we were referring to, so we clarified that they should consider all organisations, both public and private. Following this, we asked how much they trust the NHS/Government with their data. Out of 24 participants, only 2 placed their stickers towards the "Fully Trust" end of the scale. Most participants positioned their responses at various points on the sliding scale, predominantly towards the "No Trust at All" end.

Who should be able to see your records in SDE?

We provided participants with a list of organisations and asked them to work in small groups to discuss and categorise each organisation into "Yes" or "No" columns regarding access to records in the SDE.

In both workshops, all groups unanimously agreed that the NHS and GP practices should have access to the records. Meanwhile, all groups firmly stated that Google, Facebook, Amazon, Apple, and store loyalty card programs should not have access.

There were mixed opinions on whether universities, health apps, local councils, insurance companies, and banks or building societies should be granted access and participants said it would depend on the circumstances.

What advantages and disadvantages do you see in having local health data available for researchers in SDE?

Participants answered this question in small groups, spending time discussing their thoughts and answers before sharing their conclusions with the rest of the group. Both groups identified a range of advantages and disadvantages, as listed below.

Advantages	Disadvantages
Data to be made available for research to help changes to be made. Help people who are studying Help develop science, advance medicines, improve housing, roads and reduce pollution. Data will help get a bigger picture and deeper understanding of an issue or problem to help solve problems	Data and information going to the wrong people Not everyone wants their data to be included Is it really secure??? Used from wrong purposes like scams, telemarketing and sales.

Would help understand a city or place better	Become a police state
Could help community groups to develop new projects or gain access to funding	Could be used to penalise certain groups
Data could help to enhance good practice or to scale and build on good practice from other areas	Could be used to stereotype
It might help to get additional funding into certain areas that need it the most both geographically and subjects/themes	Could result in funding cuts

What should your health data be used for?

We asked participants to answer this question individually by placing sticky dots under the headings below: Help plan the best services, Help people stay healthy, Help find cures for diseases, General research for the public good, Commercial research, and Anything else?

All participants agreed that health data should be used to help people stay healthy and to find cures for diseases. The majority of participants said no to using health data for general research for the public good and commercial research. There was a mix of yes and no responses for using health data to help plan the best services. In the "Anything else?" section, one participant suggested that the police should be able to access health data to assist people affected by crime.

How do you feel about companies using your health data?

This question was discussed by the group as a whole. All participants agreed that if companies requested access to this information, it should be used exclusively for health research, with some specifying that it should be limited to healthcare-related companies only. The consensus was that SDE data should not be used for marketing purposes, sold for financial gain, or used by non-healthcare entities, except for medication and treatment development by registered pharmaceutical companies. The data should only be used to improve the NHS and health outcomes, advance or improve medications and treatments, and should only be accessible to well-established companies.

What are the best ways to inform public members about SDE? - For example what it is, what benefits it will bring etc

During a group discussion, participants suggested various ways to disseminate information effectively. They proposed sending an official NHS letter to ensure everyone receives the information, as other methods might not reach everyone. Additionally, they suggested putting up posters in doctors' surgeries, using social media, TV adverts, and buses, and holding information sessions or workshops similar to the one they attended. They also recommended informing people face-to-face through NHS services.

Is an automatic opt-in OK?

We asked participants to individually respond to this question using a sticky dot to indicate YES or NO. Out of the 24 participants, 20 answered NO, and only 4 answered YES. We then informed the participants that SDE would be an automatic opt-in, which raised concerns among many. The primary concern was that participants should be notified about the opt-in so they can make an informed decision about their participation. One participant also suggested that they should have the option to choose which specific information they consent to include.

What is the best way to organise an opt-out? (if you didn't want to be involved how could we opt you out)

The majority of participants were not comfortable with the SDE being an automatic opt-in. They suggested that an opt-out option should be offered to everyone through an official NHS letter, the NHS app, and during visits to doctors or other NHS services. Additionally, they recommended that the opt-out option be communicated multiple times to ensure everyone is informed about the SDE and can make an informed decision about their inclusion.

Who should decide which researchers or organisations can access patient information through the SDE?

This question was posed to the entire group for discussion. Initially, some participants felt they should make the decision themselves. However, after further exploration, the group agreed that this wasn't practical. They suggested that the decision should be made by professionals and some trusted, vetted members of the public forming a decision-making panel. They emphasised that the decision should never be made by just one person, but by a group, to ensure security and due diligence in the process.

Should researchers ever have access to fully identifiable data or should this only ever be anonymised data?

This was a collective no, participants felt very strongly about this and stated this data should always be anonymised and never fully identifiable.

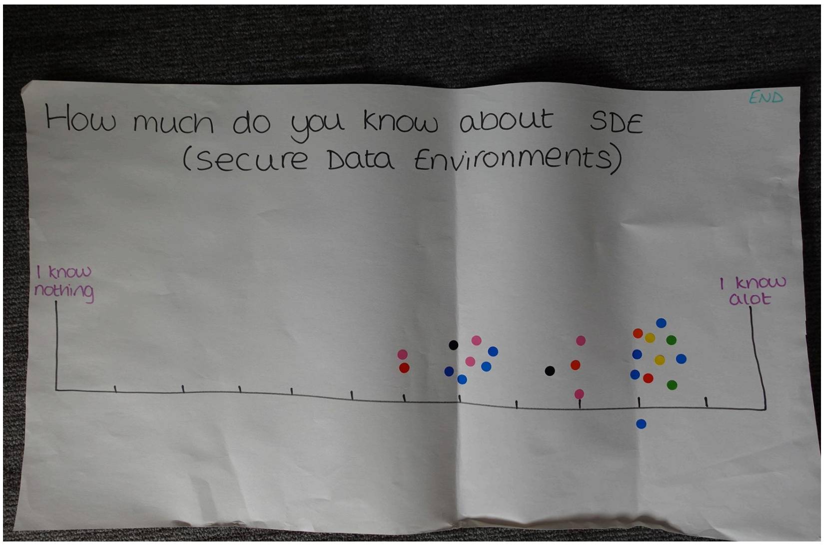
What concerns do you have about your records being used for SDE?

The main concern among participants was the safety and security of the data, ensuring it didn't fall into the wrong hands or get used inappropriately. Some participants questioned the security implied by the name "Secure Data Environment," finding it somewhat ironic. Despite the data being anonymized, all participants emphasised the need for careful consideration when granting access to companies and individuals for research purposes.

Additionally, participants stressed the importance of considering how the data is stored once access is granted and suggested that the duration of access should be limited based on the specific research being conducted.

How much do you feel you know about SDE after today?

As you can see all participants reported an increased level of knowledge and understanding about SDE after the workshop.



Conclusion

In conclusion, participants expressed gratitude for the opportunity to learn about this new service and were highly engaged with the subject. Their knowledge of the SDE increased significantly. Throughout the workshop, they identified several advantages and disadvantages of the service and raised various concerns, which have been detailed in this report. Overall, participants felt valued and appreciated the chance to participate. Many mentioned they would share this information with friends and family, helping to spread awareness about the SDE.

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