Yorkshire
& Humber
SECURE DATA
ENVIRONMENT

Part of the NHS Research
Secure Data Environment
Network

NHS

Secure Data Environment Community Workshop Report

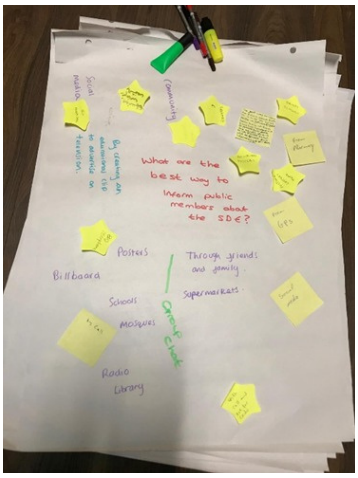
facilitated and
reported by
Bradford
Foundation Trust

Introduction

The Secure Data Environment (SDE) project is a major step in addressing the public concerns / thoughts about the safe use of patient data and data sharing around the SDE programme.

The project started to gather information from the 5 local grass root organisations to see what they think is an SDE and to get their thoughts. The grass root organisations working together Connecting Roma, Outloud, Bradford Foundation Trust and Abilities Together and Bradford 4 Better.

The aim for Bradford Foundation Trust was to find out what refugee, asylum seeker and those who would normally not engage with projects like this due to language, travel and other barriers.



The purpose of the engagement/workshop was to reach out to those that we have good relationships with, explain the project to them, personally call them and invite them to attend workshop as their views are important. The overall objectives were to understand the public understanding of Secure Data Environment & share insight to be part of regional and national feedback.

Funding

The SDE work was funded by Secure Data Environments PPIE scoping exercise; NHS England. Lunch and refreshments was provided for the participants that took part in the SDE workshops. Travel expenses were offered to participant's that needed it. The participants each received £20.00 vouchers as a way to thank them for taking part.

Participants Data

30 people attended, 25 female and 5 male

Postcode: BD1, BD2, BD4, BD5, BD7, BD8, BD9 and BD12 The language of the participants: 21 Arabic, 8 English and 1 Kurdish Age of participants ranging from 20-69 years old Ethnicity of participant: 2 Afghan, 4 British, 1 Iraqi, 1 Italian, 6 Moroccan, 1 Nigerian,
2 Pakistani, 12 Syrian and 1 Tunisian

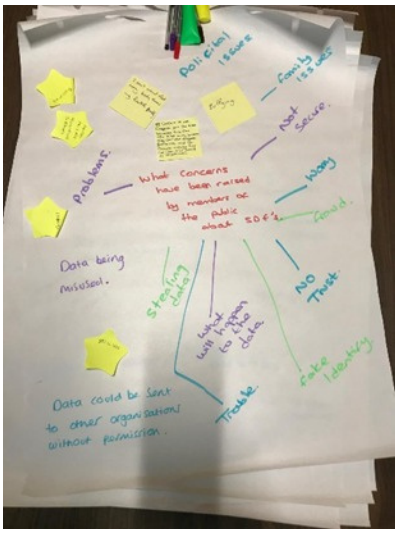
The status of the participant's: 3 Asylum Seeker, 5 British, 1 NRPF, 4 Leave To Remain and 17 Refugee's

We wanted to target refugee, asylum seekers and reach out to those who are the hardest to engage with. We invited around 20 people to each workshop and managed to get 75% of the participant's who attended the SDE workshops.

Method

(The where, when, what and how)

Before the workshop



We looked at the Bradford Foundation Trust database to see which participants would be interested in the SDE project that fitted the criteria of being refugee and asylum seekers, we called them over the phone using a interpreter to explain the project and explained to them that they will receive food/refreshments and £20 voucher for their time.

Then we created a list of the participants that wanted to take part and send them a text message of the date, time and venue. Few days before we called them again to remind them and make sure that they were still available and coming to the workshop and on the day of the SDE workshop we send a message out as a final reminder. We used different methods to tell people about the workshops such as face to face, telephone and sending message reminders through WhatsApp in their own language so that they understand. We had a interpreter at hand to answer any questions or queries that they had.

What worked well was that 30 out of the 40 participants attended the workshop that was recruited during June 2024, the food and voucher attracted the participants and having a interpreter attend the workshop really helped them to understand and take part. Some of the words used in the questions was hard for them to understand but we used examples to tried to break the questions down so that they had a better understanding of the questions.

The workshop

On the day of the workshop we setup the table and chairs so that they was all together, we used flip chart paper, sticky notes and coloured pens for them to write down their thoughts on each question. Before we started the workshop we got the group to have refreshments and we did a icebreaker so that everyone got to spend some time together to feel comfortable and relaxed. We started the workshop and give a lunch break half way through the workshop where we ordered food that they would like after asking them beforehand what they wanted on the day.

The session was an open discussion where we asked the question both in English and the language that they would understand, each person was given an opportunity to write down or say something about each questions asked, making sure everyone was equally involved and included into the workshop. We had some 1:1 discussions with those who needed extra support. The workshop took place at Bradford Foundation Trust on two Friday’s from 9.30am-1.30pm. We made sure all questions that were asked were explained and concerns raised were addressed so everyone left happy, we also took contact details so will keep them informed of the project and share the report once complete.

Findings (What did you hear & find out)

What concerns, conversations, questions the groups spoke about during the workshops:

What does secure data environment mean?

- Keeping data safe and secure
- Forming trust
- Providing clients with security so they feel confident with sharing information
- Keeping data private and confidential
- Maintaining privacy
- For the sake of own independence
- Active community engagement
- Accessing ones own personal information
- Confidentiality

What information should we share about the opt-out process?

- Speak to professionals face to face
- By phone calls
- Posters
- Text messages
- Emails
- Letters by post
- WhatsApp
- Inform people they have the right to opt out
- Confirm that you have opted out

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

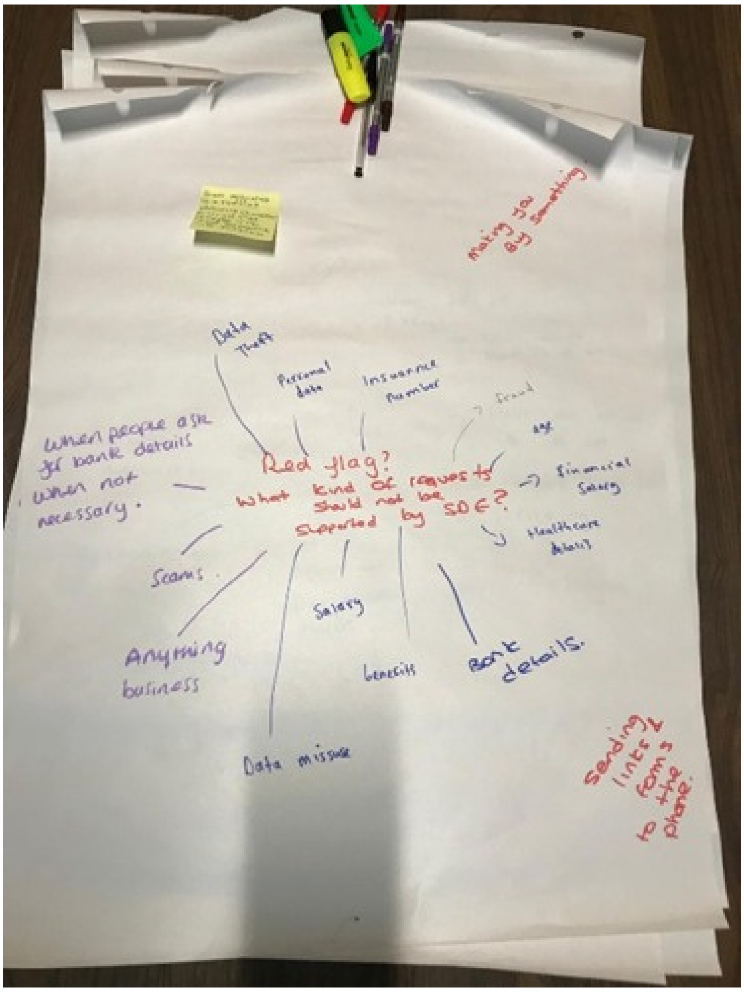
- DWP
- Citizens advice
- HMRC
- Home office
- Job centers
- Doctors/GP
- NHS
- Social workers
- Public
- Medical professionals
- Banks
- Police
- Anyone following policies/procedures of data protection
- Anyone who has undergone DBS checks
- Schools, colleges
- Mosques

What is the best way to organise an opt-out?

- Unsubscribe from emails
- Un follow commercial companies
- By emailing them that you want to opt-out
- By calling them and informing them you want to opt-out
- By letter
- Have an option to opt-out
- Talk to a trusted person to opt-out
- National data opt-out to avoid sharing healthcare records
- Screening

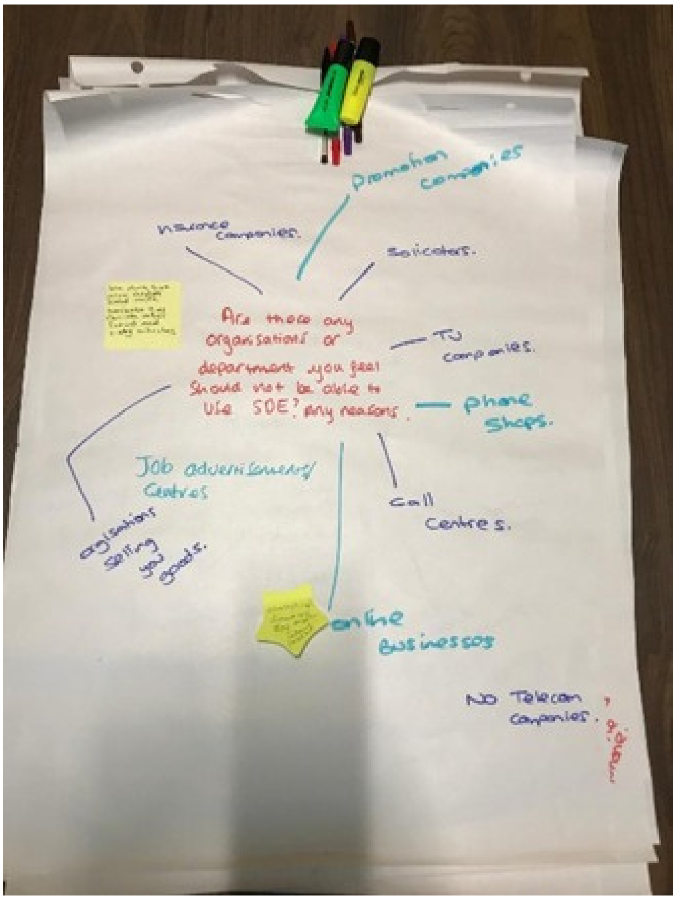
What kind of requests should not be supported by SDE?

- Data theft
- Personal data
- Fraud
- Age
- Financial salary
- Healthcare details
- Bank details
- Benefits information
- Data misuse
- Anything business
- Scams
- Insurance number



Are there any organisations or departments that you think should not be able to use SDE? Any reasons

- Insurance companies
- Promotion companies
- Solicitors
- Phone shops
- Call centers
- No telecom companies
- Online businesses
- Job advertisements/ centers
- Organisations selling you goods
- Online vendors
- Commercial companies
- Bitcoin
- Loan companies



If companies want to use data would that be okay?

- No
- If only it will benefit me
- Only for development of new treatment or medicine
- They should ask permission before using someone data
- No trust
- No sharing

What benefits do you see in having local health data available for researchers in a secure data environment?

- Can help with new resources being put into the community
- Can help with development of new treatment and medicine
- Help people

- Testing
- Finding from other communities
- Benefit specific communities

What kind of transparency or accountability measures would increase your trust in the Yorkshire and Humber SDE process?

- If they send letters
- Workshops
- Trust
- Consent forms
- Explain the process
- Agreement signed
- Keep us informed via letters

What are the best ways to inform the public about the SDE?

- Social media
- Creating a short educational clip on SDE to advertise on television
- Community
- Library
- Public posters
- Schools
- From pharmacy
- Letters being posted
- Through family and friends
- Group chats
- Radio
- Billboards

What makes you trust sharing your data with other people or companies for research?

- Only GP having access to data
- When a professional discusses with you why they need your data and how they will store it
- Hospitals having access to data
- Universal credit benefits or DWP
- No trust due to the pharmaceutical trade they may disturb people via emails
- NHS having data
- Obtain assurance
- Trusted relationships
- Police