

**Secure Data
Environment
Community
Workshop Report
by Connecting
Roma
June 2024**

Introduction

The workshop aimed to understand people's knowledge of the Secure Data Environment (SDE) and hear what the Romani Roma community think about how their data will be used. The workshop included a series of activities designed to assess and improve participants' understanding of SDE knowledge. Listening, sharing their views and thoughts. Participant responses to the workshop activities were key in evaluating their knowledge and effectiveness of the workshop as well as the input/opinion on the topic. The workshop explained the data saves lives strategy along with the national program and all information around SDE.

Participants

Participants were aged between 20 – 70 years old, all from the Roma background living across the Bradford District. They were paid in vouchers for taking part in the discussions, this was appreciated by the group to feel more valued for their input into this work. The workshop was held in a venue all participants were used to and felt comfortable to take part and feedback. The participants were able to talk in their first language which was translated back into English for the report but allowed for more natural conversations between participants.

Workshop Activities

The workshop began by explaining the SDE platform, what the workshop was going to focus on and incorporating the Data Saves Lives strategy so the group understood their input was going to be fed into regional and national work. Once the background information had been shared the workshop was an open discussion by asking questions and letting everyone take part in answering their thoughts. These activities were designed to be interactive and engaging, encouraging participants to apply the knowledge in practical scenarios and allowing them to share their thoughts, and views on SDE. The participants were provided with fruits snacks, water and pizza for taking part and a special Roma artist was asked to perform after the session.

Activity Highlights

- 1. Questions and answers:** Participants were asked a series of questions related to SDE concepts and strategies.
- 2. Hands on Exercise:** examples of real-life scenarios and challenges were provided to enhance the understanding of SDE programme.
- 3. Group discussions:** Facilitated discussions on the best practice and developments in providing secure data environment information to public and emerging technologies. Majority of these conversations were done in Roma, this allowed the participants to feel more comfortable and have more detailed conversations.



Participants Responses

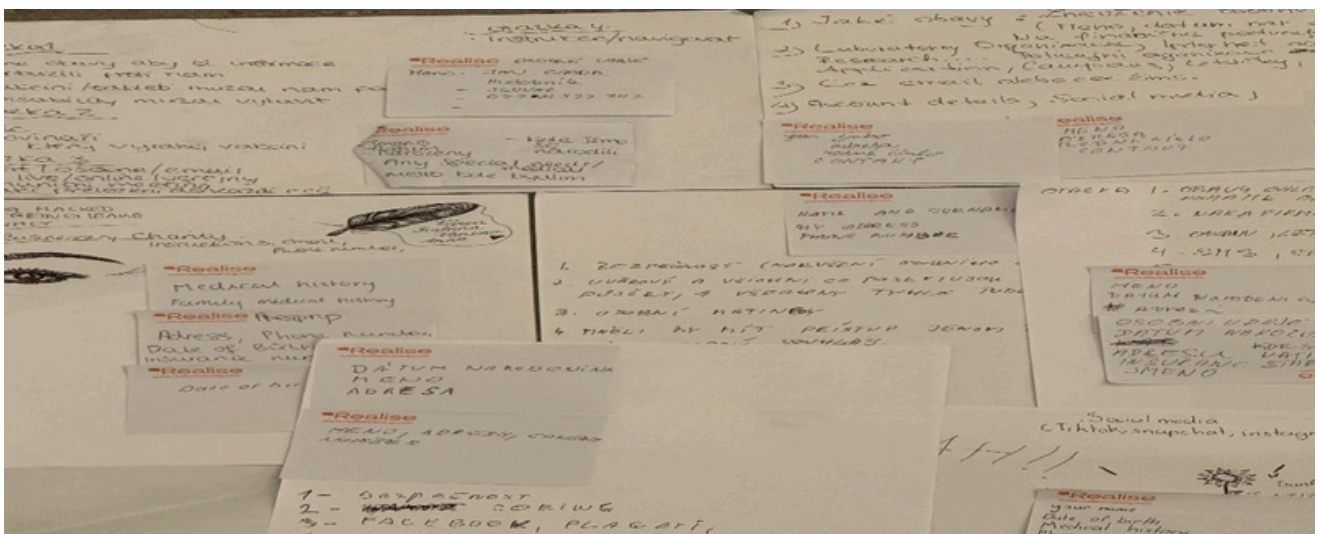
The quality responses from participants were notably high reflecting a strong grasp of the materials covered in the workshop below are some key observations:

Participants demonstrated a solid understanding of the fundamental and advanced SDE concepts programs and strategies.

The answers were well-articulated, showcasing the participants ability to think critically and apply their knowledge effectively.

The participants were asked if they would opt in or opt out of SDE, from this 40% said they would be happy for their data to be used while 60% chose that they would decide to opt out. The workshop significantly impacted their knowledge in SDE where they were able to make an informed decision.

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- Opted In: 40%
- Opted Out: 60%



Questions and answers exercise:

The questions and answers exercise were particularly well received, participants showed understanding in writing down their knowledge about SDE. They expressed their opinions and views around complex issues that SDE may pose. You can read more about the discussion further in the report.

Group Discussion

The group discussion revealed a collaborative spirit among participants. Many shared valuable insights, thoughts and experiences contributing to a rich, fun and informal learning environment.

Most of the participants within the group didn't know about SDE at all and it was their first time they have heard of it. They have also explained that if this was posed to them at a health appointment they wouldn't be able to fully understand what it is or what it involves and therefore wouldn't be sure if they should sign it.

The group felt that more Roma people need to be made aware of this and recommended:

To increase participation in future workshops it is recommended to:

1. **Increase awareness:** Promote benefit and opportunities of the workshop more broadly to potential participants.
2. **Participation:** involve in follow up meeting and kept updated in the discussion/work etc

For those who said they would have opted out, they felt they can't trust such as system, this was expressed this in one of the exercise during the workshop. The group named businesses/institutions that shouldn't be allowed to have access to such data such as profit making businesses, and still felt that they do not know enough about the protection of the system and who exactly would be allowed to access it.

1. Participants to be involved in identifying barriers to participation and areas for improvements, through more discussions/workshops
2. Evidence presented on relevant benefits to health due to SDE and more relevant evidence of good practice to be presented

Everyone also mentioned:

1. More information / promotion within the Healthcare Sector such as leaflets at the GPs
2. Understanding that Data Saves Lives and therefore it is important to participate, and share their voice
3. Gained more knowledge through this workshop and were grateful for the opportunity

Conclusion

The SDE workshop was a success. All participants showed a commendable level of engagement and proficiency in the activities provided. The high quality of responses indicated that the workshop effectively enhanced the participants knowledge of SDE main cores, aims and strategies. Preparing them for the future to understand the importance of a Secure Data Environment and the impacts of secure data.

Overall, the workshop demonstrated a split in the group between who would opt in and opt out. Both sides demonstrated and shared valuable arguments whilst both showing understanding of each other's opinion.

It was also clear that the Roma community lack knowledge about SDE but shown good understanding of data protection and the importance of data collection.

We feel the community would benefit from further information and perhaps translated materials that can be shared across the Healthcare Sector and further more be involved and kept consulted on this matter and it's ongoing progression.

Through the programme we have engaged with them on an individual and team effort to learn and understand the strategies in the SDE program and to understand the Data saves lives strategy. Every participant was given the opportunity to ask questions related SDE and data protection, on an individual basis. We know the participants are now more knowledgeable and more aware of data protection in the SDE.