

SDE PAG July meeting notes 29/07/26

Updates:

- PAG F2F meeting on Saturday 22nd August
- AI workshop scheduled for September 26th at Bradford Arts Centre – will be sending times for the workshop.

Communications planning introduction:

Honey introduced communications work, explaining our approach to audience targeting and messaging strategies, and presented examples of word clouds and communication channels.

Warm up activity:

We started with a warm-up exercise asking participants to rewrite a description of Yorkshire's secure data environment in more public-friendly language. *"The Yorkshire & Humber Secure Data Environment is a secure space for approved research and innovation. The data is de-identified: no information, like your name or personal details are shown to the researcher."* (This is on the website front page)

The team discussed improving the website's front-page messaging for the Yorkshire and Humber Secure Data Environment (SDE). The importance of visual elements and proper colour contrast, suggesting the use of NHS's blue and white colours, was emphasised, as well as ensuring the Y&H SDE acronym is included, to familiarise people with that. Feedback was provided on terminology, with recommendations of "safe space" instead of "secure space" and "handled with care" when discussing data de-identification.

Campaign planning:

The team discussed a campaign titled "Your data can help shape your community" that was previously discussed in March, focusing on media campaigns, arts and visuals, and success stories targeting specific demographics. We suggested keeping key messages between three and five to maintain focus. The discussion covered using Slido for audience engagement and planning to address risks and considerations for the campaign implementation.

We explained that the Yorkshire & Humber SDE team needs to be more explicit about being an NHS organisation rather than being associated with companies like Palantir, due to negative media coverage around health data. The team discussed the need to clarify their NHS housing and legitimate purposes to address public concerns. The meeting then transitioned to a brainstorming session about target audience, key messages and risks and considerations via Slido.

Target audience:

- Communities where trust in health systems has eroded
- Men
- Range of different demographics - but each clearly segmented
- Elderly
- People inclined to withdraw consent from sharing of data
- The sceptics
- Mothers and new parents

What will your key messages be

- Reassure regarding platform providers
- Not selling data
- Not lining pockets of 'fat-cats'
- Your data. Your community. Better health
- No hidden agenda...Just research
- Together, your data can make a difference
- Importance for validity that data comes from all communities as may address inequalities in health etc
- This can benefit YOU!
- Healthier communities
- Reduce inequalities
- Research benefits the public

What are the risk and considerations of this campaign?

- If the messaging is not specific and too theoretical, it loses impact. Real life examples and benefits provide “proof” it works
- Data breaches are relatively frequent. This causes lack of trust. Need a response if a breach hits the news when a campaign is in play.
- We need to be transparent - what data is used, who can access it, why it's used, how privacy is protected, what choices people have

- We need to consider the fact that trust may already be fragile
- Audiences' communication is most sought with may access 'go to' digital means less ... other means need to be considered.
- Sceptics can be difficult to convince and may launch their own counter-campaign on social media using emotive statements and ignoring facts
- We need to have thought about the types of concerns our community may have, and to be ready to respond
- Getting enough data from the required demographic due to fear or misunderstanding
- For community-based campaigns, the community leaders will set the tone, and the risk is we don't understand their position before the campaign - so they do not endorse the SDE
- Could we include some real-world case studies to show how healthcare can be improved? It needs to be something tangible
- Agree about the use of established trusted voices e.g. community leaders
- Measuring public understanding
- Need to provide truthful, authentic reassurance only.
- We need to make sure that 'trust' is given the same profile as 'data' in our messaging
- Risk of running a campaign which is low cost, of necessity, but which is not targeting the community it seeks to. Example is digitally illiterate (eg some of the elderly population) where social media would have no reach.

Brainstorming:

Target audience

The group discussed communities where trust in health systems has eroded, with clarification that these are primarily marginalised communities experiencing health inequities, including ethnic minorities, people with limited English ability, and those with disabilities. A PAG member provided specific statistics showing worse health outcomes for ethnic minorities in maternity care and mental health, emphasising the diversity within ethnic minority groups and the need for creative communication approaches. The group agreed to use examples of known health system failures as an index for identifying distrustful communities, with plans to move on to key messages after this discussion.

Key messages

The team discussed strategies for engaging ethnic minority communities in health data collection initiatives, focusing on key messages about data validity and community representation. One suggestion was using mass media channels like radio, TV, and billboards, while emphasising the importance of translating messages into community languages and working with community leaders. It was noted that it is important to speak to communities first and co-produce messages with them, so we understand their concerns and make it a more meaningful development of a campaign, and to ensure community values are considered for communities to feel more respected.

Another recommendation was to target specific age groups through appropriate channels like hospitals, community centres, and social media platforms relevant to different demographics. For example, if we are targeting mothers then present campaigns in waiting areas, maternity wards, hospital canteens, and contact other health departments in communities to see how they present campaigns. An important question was raised about whether certain groups are more likely to withdraw consent for data sharing, which the team agreed to investigate further with data analysts.

Another PAG member suggested integrating health data education into school curricula to prepare future generations for the digital world, but some of the PAG advised against involving children directly and proposed obtaining information through paediatric doctors instead. We discussed our presence on social media platforms like LinkedIn and X, noting declining engagement on X. The conversation ended with a discussion about targeting ethnic minority communities with key messages, focusing on building trust in health systems.

Risks and considerations

The team discussed risks and mitigation strategies for a healthcare data campaign targeting communities that have lost trust in healthcare services. One suggestion was to involve community leaders and using clear language to communicate the importance of health data, particularly using maternity health disparities as a compelling example of how data collection leads to better outcomes and government interventions.

There might be a risk of the same people engaging, how do we mitigate that?

Language was another risk identified and to mitigate that we would communicate with the community link/ community champion, preferably someone that has a health background that can translate what we are wanting to achieve.

One PAG member raised concerns about potential incentives and the risk that increased awareness might lead to people withdrawing their data participation, though the group agreed that transparency about data usage was essential.

Next steps

- Explore, with the help of SDE data analysts, whether there is evidence showing which groups are more likely to withdraw consent for data sharing, and bring findings to a future meeting.
- Review and revise the website homepage text and visuals for the Yorkshire & Humber Secure Data Environment, incorporating feedback from the meeting (e.g., language simplification, use of NHS colours, improved visuals).
- Write up the meeting notes and send them to all attendees, inviting them to highlight any omissions.
- Plan and confirm arrangements for the AI workshop on 26th September at Bradford Arts Centre and communicate details to attendees.
- Consider and develop a communications campaign targeting communities with eroded trust in health systems, using the key messages and audience insights discussed, and bring proposals to a future meeting.