Yorkshire
& Humber
SECURE DATA
ENVIRONMENT

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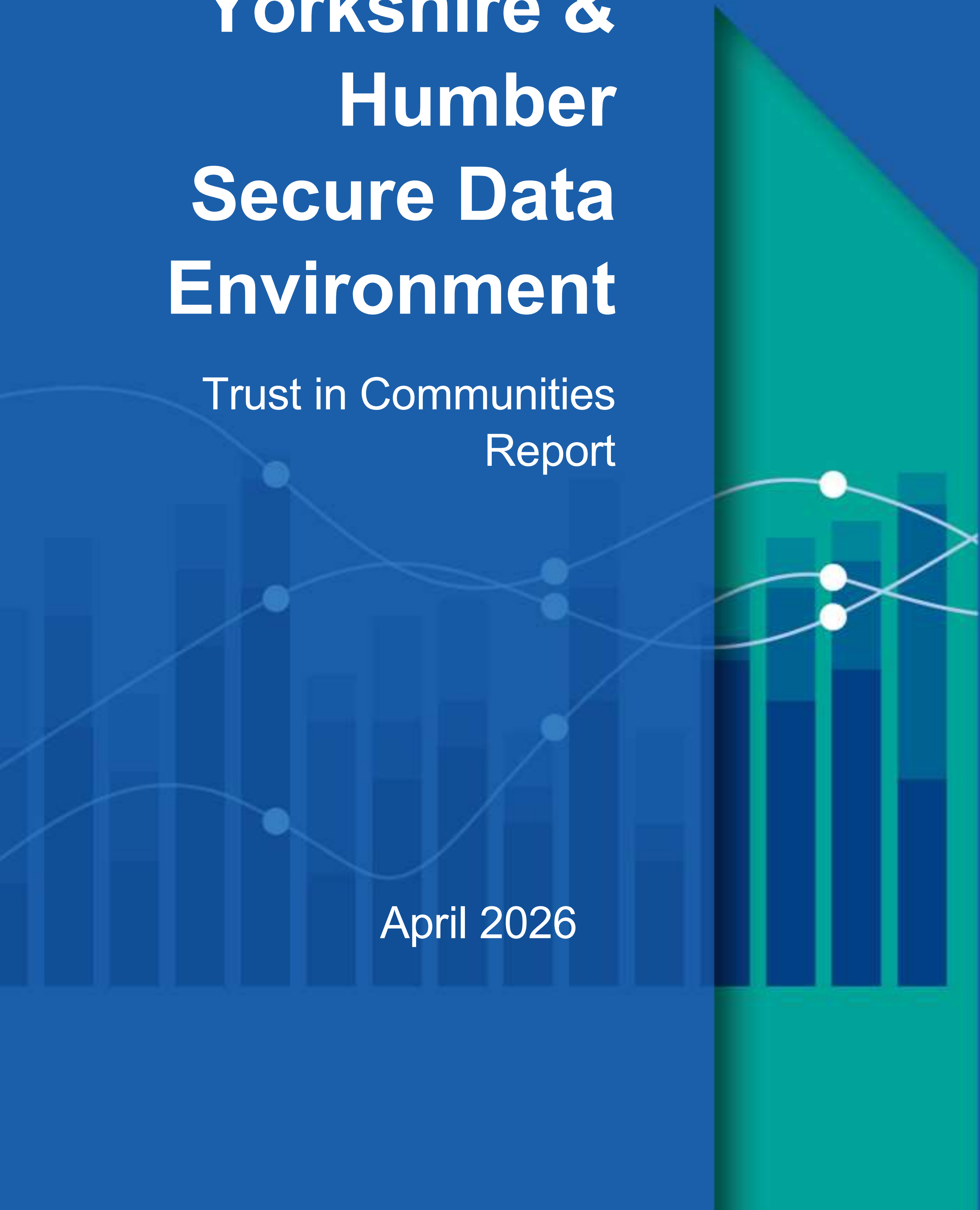
Yorkshire & Humber Secure Data Environment

Trust in Communities Report



April 2026

Contents:

Background

The Yorkshire and Humber Secure Data Environment (YHSDE) is a secure NHS data system, health and care data is safely and securely analysed by approved users without the data leaving the environment.

Overview

The purpose of this session was to gather public insights on public trust within various communities and explore why there is a lack of trust around data and data sharing. The aim was to help us understand how we can better engage with various communities, through a variety of medias.

For this session we had a discussion with our Public Advisory Group (PAG), who advocate on behalf of the wider public and help to provide diverse perspectives for the Yorkshire and Humber Secure Date Environment (YHSDE) team to gain valuable insights into the needs and concerns of various communities. We met up in Leeds to discuss the topic of trust around data sharing and communication within communities regarding Secure Data Environments (SDEs)

The main focus points were to discuss:

- What trust means to them?
- Why there is a lack of trust with various communities?
- What can we do to build a better trusting relationship with these communities?

The image below shows the initial thoughts and recommendations on the topic of trust by the PAG.

WHAT IS TRUST?

- Authenticity
- Delivery
- Consistently built overtime
- Identify yourself in what is being delivered/ promised.

TRANSPARENCY

- Easy to access information
- QR codes
- Debunk misinformation, tackle issues/ concerns
- Use the English language and other languages for various communities
- Create examples of data use and its impact

DATA CONCERNS

There is a caution around digital systems and online data security.

Reassure:

- Security
- No SDE breaches of personal identified data
- Anonymisation

Focus on:

- How the YHSDE is being used
- It's potential

PUBLIC PARTICIPATION

- Invite engagement mechanisms to capture a degree of support/ comments via online platforms.
- Recognise, answer and tackle issues and promise it.

The public needs to identify and see themselves, people who are of a similar age, ethnicity and background.

Concerns

This section summarises the key themes of concern, commonly raised by our public members. These themes reflect the issues of the wider communities, including lived experiences or cultural concerns around data and how lack of trust has an impact on communities.

Data use and transparency

Data use and transparency was a concern commonly reflected on throughout the session, with public members expressing an uncertainty around how health data is used, as well as a lack of clarity on who can access the data. Many public members stated that there was confusion around the opt-out systems, expressing that there are no clear confirmation, or proof, that you have opted-out. They questioned what it was that people were opting-out of.

This creates a lack of trust for the wider community as, if they don't feel there is transparency within SDEs and not enough awareness and reassurance around how the data will be used, then there will be an unwillingness to engage.

Organisational trust issues

There is a perception, from the wider public, that GPs lack clarity around who is receiving the data and they do not know how the data will be used. This ultimately creates patient uncertainty and reduced confidence in the whole system. Due to organisations not providing clarity on data usage, there is a reluctance around sharing data, as communities are unsure on how the data is actually being used and if the data is being used for good reasons.

Data safety and risk

During conversations with our public members, on behalf of the wider public from the Yorkshire & Humber region, they expressed worries around data breaches. This was mainly due to online media, and the stories around misuse of sensitive information. It was also expressed that there is a lack of clear communication on what happens when breaches occur, as well as how the public is informed and reassured. This was considered important when building trust and being transparent with the community.

Disconnected systems

Public members commonly expressed, due to their own personal experiences, concerns around Primary and Secondary Care records not being linked up. It was thought that this creates a burden for patients to reshare or update information, which creates uncertainty and mistrust towards organisations. Concerns were also expressed around the continuity of medical records when moving or attending other practices.

Historical and generational mistrust

During discussions public members commonly expressed that there is a long-standing mistrust of organisations, not just healthcare services, due to generational knowledge being passed down, as well as negative experiences and stories circulating within various community groups. This can impact the wider community and lead to many members of the public distrusting organisations. There is also a fear of what the potential risks or consequences will be, as a result of sharing their data, due to some communities wanting to protect their data, personal information or family name.

Cultural sensitivities

Many communities provide strong emphasis on:

- Privacy
- Family reputation
- Protection of their personal information

Some communities also perceive health and data as being private and taboo subjects.

Perception Risks

There was strong emphasis on the communities' fear of being exploited for research, due to historical factors. As well as this, AI and data language creates anxiety and misunderstanding.

Impact of low trust

As a result of communities' lack of trust towards data, due to cultural and historical factors, as well as their own personal experience, ethnic minority groups are underrepresented in datasets. This can lead to biased research outcomes and missed health improvement opportunities.

The image below presents an overview of the concerns from the public's perspective.

There were significant concerns regarding how health data is managed, communicated and used. Overall, a consistent lack of transparency and trust from the wider public shapes public attitudes and willingness for them to engage.

Data Use and Transparency

- Public understanding of how health data is used, collected and accessed is limited.
- There is confusion around opt-out systems, including uncertainty on what it involves ad wheter preferences are actually recorded.
- Lack of clarity undermines confidence and reduces public willingness to engage.

Organisational Trust Issues

- There is the perception that healthcare professioals, for example GPs, lack clear knowledge on where patient data goes and how it's used.
- This creates reluctance for public and patients to share their personal information as it's questioned whether their data is being used appropriately or for beneficial purposes.

Data Safety and Risks

- Fears around data breaches and misuse of sensitive information as a result of media coverage.
- Lack of transparent communication around what happens when breaches occur and how the public are informed.
- Clear communication and reassurance was identified as essential to building trust.

Disconnected Systems

- Lack of merging between primary and secondary care records create frustration and mistrust within communities.
- Patients often needs to update their health records, which creates concerns about its continutiy when moving between providers or regions.

Historical and Generational Mistrust

- Long-standing mistrust of institutions, beyond healthcare, plays a major role.
- Often shaped by generational experiences, shared community narratives and past negatvie encounters.
- These contribute to ongoing caution and concern about the risks and consequences of sharing personal data.

Cultural Sensitivities

- Privacy, family reputation and protection of personal information are highly valued across many communities in Yorkshire & Humber.
- Health and data-related topics are considered private or taboo to some communities, reinforcing hesitation around data sharing and engagement.

Perception Risks and Misunderstanding

- Concerns about exploitation, partucularly fears of being "tested on" for research purposes.
- Complex terminology, especially around AI and data can create anxiety and misunderstanding, further distancing communities from engagment.

Impact of Low Trust

Low levels of trust have substantial consequences. Underrepresentation of certain groups, particularly ethnic minority communities, leads:

- Biased datasets
- Less inclusive research outcomes
- Missed opportunities for improving health quity

Recommendations

PAG members made a number of recommendations. These have been separated into two sections: *"What builds Trust?"* and *"How do we build trust?"*

The core message during the discussions was **Your Data. Your Community. Our Future.** There was a lot of emphasis on how health and data are a collective and by sharing experiences and data, communities can better shape health outcomes, for themselves and for future generations.

1. What builds trust?

Start with people, not data

Many PAG members recommended that it is important to start with open conversations and then build trust from that, as well as building on shared experiences and real stories from those communities. It is also important to recognise that community engagement is ***"not a one size fits all"*** and that each community communicates, trusts and engages differently.

Build trust through understanding

It was recommended to directly ask communities:

- What builds your trust?
- What concerns you about data?

Show clearly how data is used and who benefits from that data

Provide real-world impact and benefits from members of the community that show the positive outcomes made that are driven by data.

Avoid tokenism, as providing community members with incentives may feel dismissive to some community groups. This reiterates that community engagement is ***"not a one size fits all"*** approach.

Honesty about risks

PAG members recommended we acknowledge past misuse and current risks around use of data. They recommended we clearly explain the safeguards in place and described what happens when things go wrong. This would help reassure the wider public.

Consistency over-time

It was commonly stated that trust is typically built though repeated, consistent engagement and not something that only happens once. It was also recommended that there needs to be visible actions to prove that communities are being listened to and not just messaging being put out on social media. Authenticity is the key when building trust with the wider communities within Yorkshire & Humber, ***"Be authentic, they don't go by what you say, but what you do."***

The image below presents an overview of the recommendations of "what builds trust?" from the public's perspective.

The group emphasised on building public trust, particularly in data use across diverse communities in Yorkshire & Humber, requires a people first, transparent and sustained approach. Trust is not achieved through one-off initiatives, but through meaningful, consistent engagement grounded in understanding and authenticity.

WHAT BUILDS TRUST?

Start with People, Not Data

- PAG members highlighted the importance of beginning with open conversations rather than technical explanations.
- Building trust should be rooted in shared experiences, real-life stories and genuine dialogue.
- Crucially, engagement must be tailored, recognising that different communities have distinct ways of communicating, trusting and engaging. **"A one-size fits all approach does not work."**

Be Honest about Risks

- Transparency about both past data misuse and potential risks is crucial.
- Acknowledging these openly, alongside clearly explaining the safeguards and processes for handling data breaches can help build credibility and reassurance.
- Honesty was seen as a necessary foundation for trust.

Build Trust Through Understanding

- Actively listening to communities is essential. Asking direct questions such as "What builds your trust?" and "What concerns you about data?" helps shape more responsive and inclusive approaches.
- The importance of clearly demonstrating how data is used, who benefits and showcasing substantial real-world outcomes was stressed.
- Authentic examples of positive impacts within communities can also strengthen confidence.
- Avoiding tokenistic engagement is key, as incentives alone may feel dismissive to some groups.

Consistency Overtime

- Trust develops through ongoing, visible action rather than one-off communication efforts.
- It was emphasised that consistent engagement, follow-ups and demonstratable change are essential.
- Communities are more likely to trust organisations that show they are listening and acting on feedback, rather than just simply delivering messages.
- Authenticity, demonstrated through actions rather than words was identified as a core principle for building lasting relationships.

What should we do to build trust?

Effective engagement approaches

PAG members recommended the use of Community Ambassadors and trusted local figures within communities, such as faith leaders and pastors. Community Ambassadors could be trained to lead conversations on data topics. They would help build trust as they already have an established relationship with their wider community.

It was also suggested to meet members of the community within their trusted local groups, for example, faith groups, elderly groups, community centres and forums. Workshops should be held with community leaders to gather feedback and to ensure ongoing communication with the community.

Another way that was recommended was to engage the community by using arts-based approaches, for example:

- Poetry and spoken word
- Exhibitions in community spaces, museums or online
- Short plays/ skits

These options were favourable, as creative outputs from conversations are immediately visible and it reflects community voice more authentically. It also creates collective recognition and validation that signals stories are worth listening to, as well as building emotional trust from the wider communities as it has the capacity to reach a variety of audiences.

Use stories to show impact

Many PAG members favoured using personal journeys when discussing how data is used. This helps demonstrate the impact previous research has had on health , as well as showing how prior research can impact the future.

Another suggestion was to create a storyboard showing what would happen if research did not happen and what the outcomes would be both now and in the future.

They felt it is important to highlight success stories from similar areas to the communities we are engaging with. This can help people understand better and negate the negative experiences being circulated around communities.

Education and awareness

The group felt that education and awareness was important for engaging various communities and recommended the promotion of data literacy in schools. It was thought this would help young people understand the concept of data and its importance for the future, as well as encourage conversations at home with parents/carers. Raising awareness this way would help people understand why sharing data is important.

Depending on the impact in schools, they also recommended working with education systems to embed data literacy into the school curriculum.

Myth-busting was recommended to address misinformation directly. Sharing of misinformation causes confusion within the community as well as reluctance to share health and care data.

Be honest about limitations

It is important to be transparent about any limitations the SDE may face. The public need to understand that ***"there is no perfect dataset"*** and that sometimes there will be gaps in the data. This is often due to incomplete demographic forms which ultimately leads to inequality within datasets. The public need to be made more aware of the work being done to improve the quality of this data.

Messaging and accessibility

PAG members agreed simple and clear language should be used, avoiding jargon, especially when covering topics around AI and data systems. Key messaging information needs to be understood by the public.

A multi-channel outreach approach would include:

- **Social media posts:**
  Ensure visuals, colours and images are included in information posters, creating short explanation videos to put online and using real life stories and examples. This is needed to engage the public, targeting a variety of learning styles.

- **Radio adverts:**
  This will help engage and provide awareness to a variety of people at any time.

- **In-person events:**
  To help understand how communities work together, delivering tailored workshops and messaging.

These must focus on using real stories that follow a relatable narrative for each community. The group also came up with some messaging that could be used for social media posts that may help to further engage community members across Yorkshire & Humber:

- ***"Your data can help shape your community"***
- ***"We can change the future for so many people"***
- ***"Data is the future"***

It was recommended that when engaging with communities where English may not be their first language, to communicate with them in their 'mother language'. This would support the Community Ambassadors when conducting in-person events or sessions and ensure messages are translated.

The images below present an overview of the recommendations of "how do we build trust?" from the public's perspective.

Effective engagement with communities relies on building trust through existing relationships, communicating clearly and transparently and making information accessible and relatable. Approaches should be community-led, culturally sensitive and inclusive, using creative methods to bring data to life. Strengthening education and awareness, while addressing misinformation and limitations, helps foster long-term understanding and confidence in data use.

BUILDING TRUST THROUGH COMMUNITY RELATIONSHIPS

A central recommendation is to work with community leaders/ trusted local figures, such as:

- Faith leaders
- Pastors
- Community representatives

In order to create Community Ambassadors.

Local figures already have established relationships with their communities, making them well-positioned to lead conversations and build trust.
Engagement should take place within existing trusted spaces, including:

- Faith groups
- Elderly groups
- Community centres and forums

PAG members suggested a process that is essential for sustaining engagement and trust within communities:

Workshops with community leaders → **Consistent follow-ups** → **Ongoing communication from us**

CREATIVE AND ARTS-BASED ENGAGEMENT

Arts-based approaches were strongly encouraged as a way to engage communities in a more inclusive and expressive way. For example:

- Poetry and spoken word
- Exhibitions (community spaces, museums, online)
- Short plays or skits.

These methods allow community voices to be expressed authentically and visibly. This fosters:

- Collective recognition and validation
- Emotional connection and trust
- Engagement across diverse audiences

USING STORIES TO SHOW IMPACT

Story-telling is recognised as a powerful tool for communicating the value and importance of data. Showing personal journeys can help to demonstrate:

- How data is used
- The real-world impact of research.

For example, showcasing research from past, present and future and how each stage has had an impact on health.

Additional approaches include:

- Storyboards that shows scenarios with and without research that presents the impact of communities for both.
- Highlighting success stories that represent individuals from various backgrounds to improve relatability.

This helps counter negative narratives and promotes a more balanced understanding of data use.

EDUCATION AND AWARENESS

Improving health and data literacy is key to long-term engagement.
Suggested actions include:

- Promoting data literacy in schools to encourage conversations between young peopke and their families
- Exploring opportunities to embed data literacy into the school curriculum.

Addressing misinformation through myth-busting is crucial to:

- Reduce confusion within communities
- Build confidence in data sharing

TRANSPARENCY ABOUT LIMITATIONS

There needs to be honesty about the limitations that the SDE may face. With this communities should understand that:

- There is no perfect dataset
- Gaps exist due to missing or incomplete information

It is also important to clearly communicate ongoing efforts to improve data quality and to also reduce inequalities.

CLEAR MESSAGING AND ACCESSIBILITY

Effective communication requires:

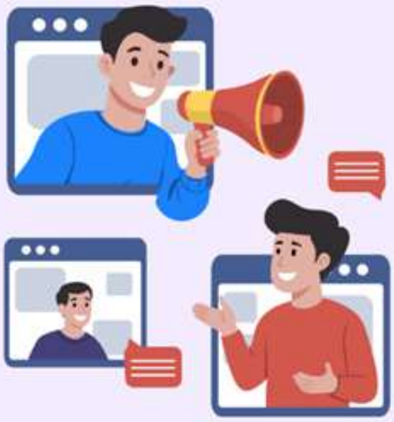
- Simple, jargon-free language
- Clear explanations of complex topics, for example, AI, Data systems)

A multi-channel outreach approach was also recommended, this includes:

Social media: Visual content, short videos and real-life stories
Radio: Broad and accesible awareness
In-person events: Tailored workshops and direct engagement with communities

Messaging should reflect real, relatable stories and cater to different learning styles.
To improve inclusivity:

- Provide translations where needed
- Support Community Ambassadors/ Community representatives to communicate in community members' first language.



PAG group plans

The group was split into two groups, with each group choosing to focus on what plans and recommendations they would like to map out.

The groups frequently brought up their lived experiences in relation to the topic of trust and as a team, so it was useful for members to map out what the programme should do.

The first group focused on mapping out how the SDE programme should communicate to the public to fully engage with them.

The second group focused on mapping out a plan for Community Ambassadors, looking at their role and which organisations should be engaged. They also worked on the messaging and a communications action plan.

The images below show more details in what the groups had planned.

MEDIUM OF INFLUENCE

WHAT TO DO IN THE PROGRAMME:

- Understanding the issues relating to incomplete datasets
- Influencing GPs to listen to the public and consider a new way of the sharing of patient data
- Helping the GPs understand the SDE and how it can benefit their patients
- Making the link between data sharing and policymaking
- Explaining GP hesitancy to share their patients' data
- Challenging other areas who pay GPs for patient data, is this ethical?

HOW TO COMMUNICATE WITH THE PUBLIC:

- Storytelling - How has the sharing and use of data benefited the public/ community/ groups
- Narration
- Musical form
- Facts and figures included in the storytelling
- Festival of storytelling
- Relatability - this encourages different levels of communication to each other and to the message.

OUR HEALTH IS OUR WEALTH

AMBASSADORS FROM DIFFERENT COMMUNITIES:

- Different racial/ ethnic groups
- Intersectional characteristics such as gender and sex
- Knowledge and experience
- Credibility
- Advantage if they have a health background
- Incentive for time, energy, knowledge and experience
- Cultural understanding requirement (Sensitivity, Awareness, Competence)

GROUPS AND ORGANISATIONS:

- Health groups
- Community centres
- Religious institutions
- Schools and universities
- Businesses (community hotspots -barbers, hair/ beauty salons)
- Local pharmacy
- Local businesses
- Community leaders (Unity, migration groups)

MESSAGING AND COMMUNICATION:

- Tailored messaging, avoiding onesize fits all
- Where possible, layperson language and avoid jargon
- Translate where possible
- Relatable examples
- Case studies
- Creative ways to circulate information
- Work with communications teams
- Bringing different communication teams together
- Breakdown data (what data is, types of data)
- Benefits of data
- Provide a GDPR Understanding

Conclusion

In conclusion, trust is the key issue that shapes how communities engage with us around the topics of health and care data. Concerns around:

- Transparency
- Use of data
- Safety
- Public's own lived experiences,

have led to uncertainty and reluctance to share data, particularly where communication is unclear, or systems feel disconnected.

To address this, engagement must focus on building relationships and not just about sharing data. This should include:

- Working with trusted community figures
- Being open about the risks and limitations
- Clearly showing how data is used and how it benefits communities

Ultimately, trust is built overtime, through consistent, honest and visible actions. The SDE must demonstrate, not just communicate that it is listening and acting in the best interests of the various communities in the Yorkshire & Humber region.

The image below presents an overview of the conclusion from the public's perspective.

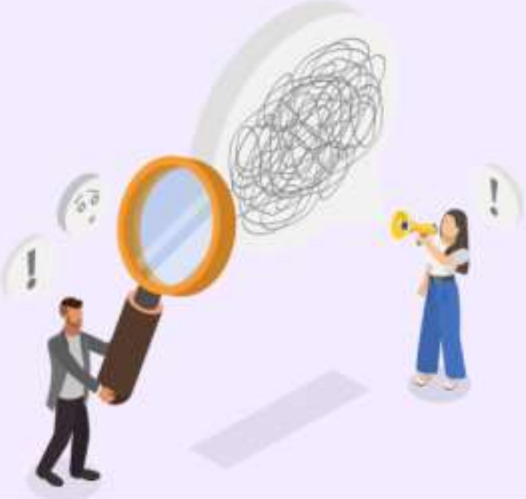
Trust shapes how communities engage with topics of health and care data. We need to show it, not just say it - trust comes from actions, not just words.

WHY IS TRUST LOW?

Concerns include:

- Transparency
- How data is used
- Data Safety
- Personal and community experiences

This leads to uncertainty and reluctance to share data, especialy when communication is unclear or systems feel disconnected.



WHAT NEEDS TO HAPPEN?

Focus on building relationships, not just wanting them to share data:

- Work with trusted community figures via the Community Ambassadors
- Be open about potential risks and limitations within the YHSDE
- Clearly show how data is used and how it benefits communities

HOW IS TRUST BUILT?

- Trust is built overtime, not just through one-off efforts.
- Through consistent, honest and visible actions
- By listening and responding to communities

Glossary

Acronyms/ Phrases	Definitions
YHSDE	Yorkshire and Humber Secure Data Environment
SDE	Secure Data Environment
PAG	Public Advisory Group
Primary Care Records	Detailed records that include a patient’s medical history, medications, allergies, and visits to healthcare providers like GPs, dentists, pharmacies, and opticians.
Secondary Care Records	Medical records created when a patient receives treatment from specialist services, such as hospitals or consultants, mental health services, rather than from a GP.
Data	Information or facts that are collected and used for understanding, decision-making, or analysis.
AI	Artificial Intelligence
Community Ambassador	A trusted person who helps share information and connect organisations with their community
Data System	A way of collecting, storing and using information so it can be organised and accessed easily