West Midlands
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Summary Engagement Report

March 2025

What's in this report

Thank you for helping us get it right

When we began the journey to develop the West Midlands Secure Data Environment (SDE), we had a clear vision about the relationship we wanted to form with people living in our local communities.

Their opinions matter and we wanted them to know that. It was important to us that the involvement of local people was hardwired into the programme at every step.

The SDE presents a huge opportunity to save lives and improve care in our region. However, if we are to realise those benefits and do so in a way that is right for local people, we need their help. That means listening to them so they can tell us how to get it right.

That is why we are open about what we do and clear in how we talk about it. We believe in being transparent, and we welcome everyone in the West Midlands to be involved and to contribute to all aspects of the SDE.

With the help of local people, we have made tremendous progress since those early days. As we continue to grow the SDE, we would like to say a heartfelt thanks to all those who have taken the time to help steer our thinking so far. We very much appreciate your support and look forward to being able to share with you the health and care benefits the SDE will bring.

West Midlands SDE Programme Team

Health data saves lives

The West Midlands Secure Data Environment (SDE) will bring together people's health and care information from across the whole region to support research and improve care for everyone.

It will make it much easier for doctors, researchers and health and care service planners to learn from our health data, while keeping it safer and more secure.

Having a much better picture of the health of people in our region will mean researchers will be able to find new medicines, treatments and technologies. Health and care service planners will have a better understanding of whether services are still right for our local communities.

This report is about how we've talked with local people about the SDE, how they've been involved and how we've made sure their voice is heard at every level.

1 of 12
SDEs across England

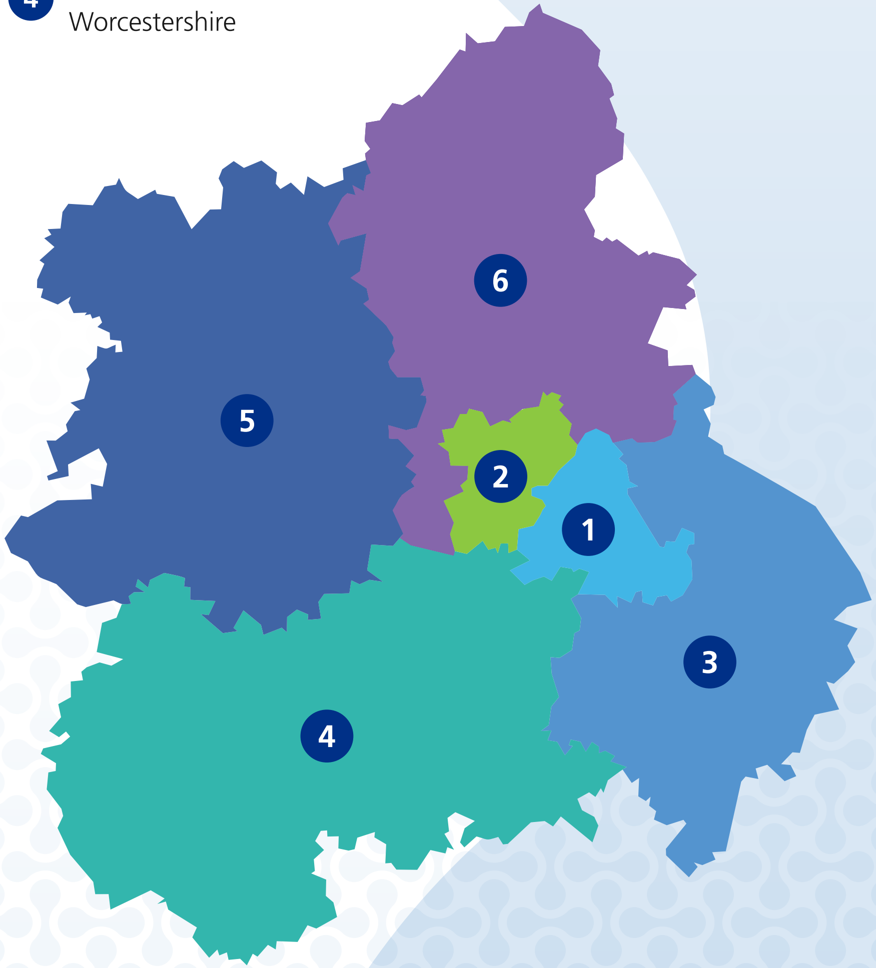
Owned and **run** by the **NHS**

Uses **strict** levels of **privacy** and **security**

Local people are widely involved

Areas covered:

1. Birmingham and Solihull
2. Black Country
3. Coventry and Warwickshire
4. Herefordshire and Worcestershire
5. Shropshire, Telford and Wrekin
6. Staffordshire and Stoke-on-Trent



What we've done

Everyone's views count

Before setting out to engage with people in our local communities, we wanted to be sure we were talking with the right people. It was important we heard even the quietest voices.

We carried out research to understand who lives in the region. We have since contacted more than 2,000 different cultural and health-related groups across the West Midlands.

Listening to local people

We held 64 meetings with diverse community groups, discussing the West Midlands SDE and hearing people's thoughts.

We also went along to large local events and busy places, where we talked with lots of people.

We ran a survey that was open to everyone in the West Midlands.

And our 'big discussion' day took the conversation a step further, bringing together people from across the West Midlands.

At the same time, we began working with the next generation, exploring opportunities for children and young people to get involved.

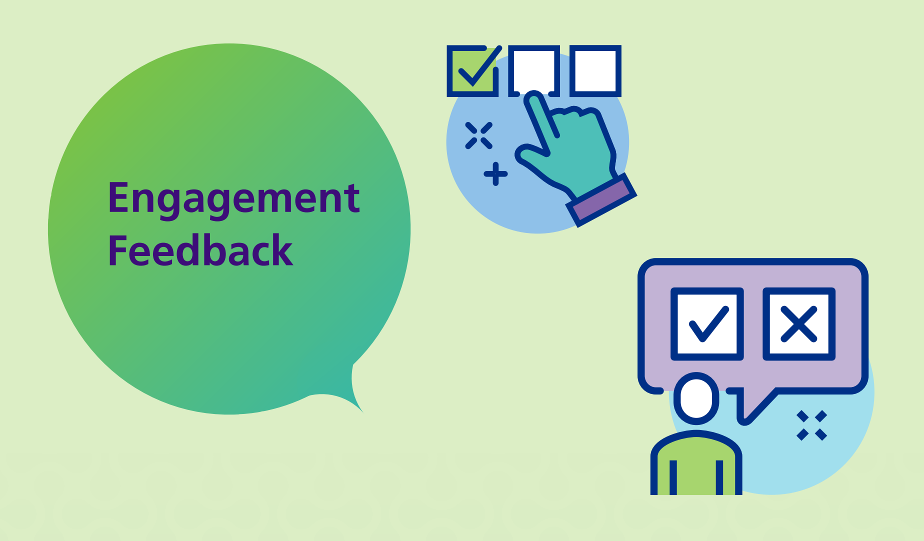
Engagement activity

Stakeholders

2,017 Stakeholder database contacts

14 Dedicated Patient and Public Advisory Group members

15 Dedicated Data Trust Committee members



Feedback from:

- Patient and Public Advisory Group
- Engagement with diverse community groups and questionnaires

Six high-footfall events: questionnaire

64 Organisations

525 Members of the public

Your voice at the centre

Throughout our engagement programme, local people have been at the centre of the secure data environment's day-to-day work.

Patient and public advisory group

Patient and public advisory group (PPAG) members have been invaluable, providing a patient view on many different aspects of the SDE. They meet together as a group, discuss the SDE with members of the leadership team, and review and give feedback on work important to the SDE's progress.

This has included being involved in the development of the ethics protocol – the document that describes the SDE and its purpose, along with setting out the moral principles and guidelines it will work to.

PPAG Members:

14 people recruited

Members described as:

12 Male

2 Female

Areas covered:

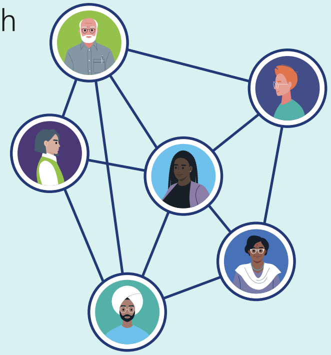
1 Birmingham (3)
2 Solihull (1)
3 Coventry (2)
4 Warwickshire (2)
5 Worcestershire (1)
6 Staffordshire (1)
7 Stoke-on-Trent (2)

Out of area:

8 Liverpool (1)
9 Sheffield (1)

Ethnicity:

8	White: English/Welsh/Scottish /Northern Irish/British
2	Black/African/Caribbean/ Black British: African
1	Asian/Asian British: Chinese
2	Asian/Asian British: Pakistani
1	Asian/Asian British: Indian



👤 = PPAG Member

Data trust committee

Members of the data trust committee (DTC) have played an equally crucial role assessing applications to use data for research through the SDE. They make sure only those projects that will genuinely benefit patients are approved. As with PPAG, these members of the public have been recruited from across the region. They give a patient and public view of how appropriate planned research is and how well researchers intend to involve and engage with the general public.

DTC Members:

15 people recruited

Members described as:

8 Male

7 Female

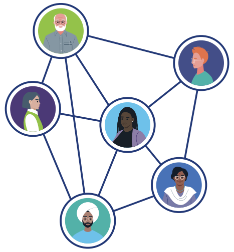
Ethnicity:

8 White: English/Welsh/Scottish/Northern Irish/British

4 Asian/Asian British: Indian

2 Asian/Asian British: Pakistani

1 Mixed/Multiple ethnic group



Data Trust Committee (DTC) public members review applications from research teams to access data held within the West Midlands SDE.

Public members of the DTC **advise** on the potential for public benefit, plus safe and responsible data use.

The DTC ensures that researchers' **access and use** of data is in the **public interest.**

The DTC includes:

- members of the public
- an independent chair
- experts as required

The DTC is responsible for making the **final decision** on each request to access data through the SDE.

Secure data environment workstreams

Members of PPAG sit on SDE workstreams and other groups in the governance structure to represent the voice of local people. They provide insight and opinion in areas such as commercial, as well as patient and public involvement, communications and engagement.

Telling the story of the West Midlands SDE

To support our engagement with people in the West Midlands, we created a website and communications materials.

These describe the reasons data is used for research and how it can help save lives in the West Midlands.

We understand that not everyone is keen to allow access to their data in this way. We wanted to make sure people living in our local communities understood their rights, so the website and materials explain how to opt out for anyone who does not want their health data used for research. A separate leaflet looks in detail at different opting out choices in the NHS.

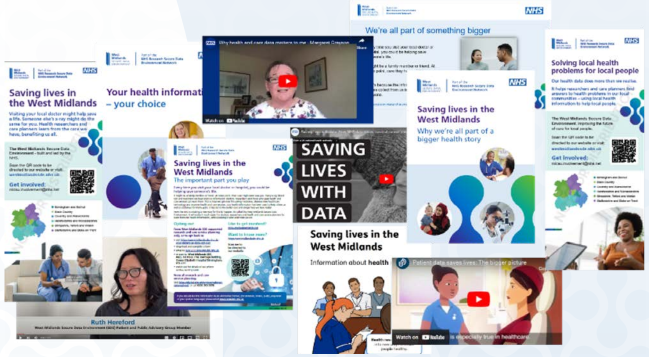
Alongside this, we ran a region-wide campaign, including social media adverts and outdoor advertisements on bus shelters and at other prominent sites. This helped us reach as many people as possible in the West Midlands.

We wanted to make sure we described the SDE in the way people found most helpful. So we carefully followed the results of research by Understanding Patient Data on the best words to use, and the guidance produced by PEDRI. We also worked closely with NHS colleagues nationally and in other regions to make sure our messaging was consistent with theirs.

The West Midlands Secure Data Environment is owned and run by the NHS to support research.

It is a safer and more efficient way for trained and approved researchers to analyse health and care data. It will help them develop new medicines, treatments, technologies and services that can improve health and care for everyone.

West Midlands SDE website:
www.westmidlandssde.nhs.uk



West Midlands SDE communications materials:
www.westmidlandssde.nhs.uk/resources

What Words to Use to Explain Secure Data Environments: Understanding Patient Data
www.understandingpatientdata.org.uk/what-words-use-explain-secure-data-environments

Good Practice Standards for public involvement and engagement in data research: PEDRI – The Public Engagement in Data Research Initiative www.pedri.org.uk/about-us/our-work

What you’ve told us

Meetings with community groups

Q **How would you feel about researchers using your health information for research through the West Midlands SDE?**

A Most people were happy but some had concerns on how security and access to data would be managed and communicated.

89%	felt it would be a positive move
58%	said it was important
18%	wanted conditions
12%	said they did not like the idea.

Q **What do you feel would reassure you and others and help people feel confident about their health data being available to use through the SDE?**

A **93%** suggested areas that would help reassure them:

32%	said a high level of data security
27%	said if it led to better health outcomes for the future
21%	said safe and secure IT systems
13%	said more information about the SDE, in ways that support all members of the community.
7%	said they would not trust any new system to store their health data and were not happy for their data to be used in this way.

Q How reassuring is it that the NHS is leading and managing the West Midlands SDE?

A Just over half of people were reassured the NHS was running the West Midlands SDE. Those who had concerns could not think of an alternative organisation they would trust more to do it.

52% of comments were positive

17% of comments were negative

11% had concerns or queries, mostly about data security and the NHS's ability to manage it appropriately.

Q What would you see as the benefits and disadvantages of data being used for research?

A People wanted more transparency. They also wanted assurances on the use of information and on governance around access to the system.

51% of comments were positive

31% were negative

8% could see no disadvantages.

Benefits

37% said research was important and would bring benefits

4% of respondents were from an Asian background who said the SDE would increase representation from their communities in research.

Disadvantages

22% of responses were concerns about data security, system failure and inappropriate selling of the data

Some raised concerns about potential disadvantages to people with mental health conditions.

Q **Do you believe patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?**

A Most said there should be patient and public representation but that training was needed. They also highlighted General Data Protection Regulation (GDPR) compliance and working to the Caldicott Principles as important, along with clear reporting processes.

71%	agreed there should be patients and public representatives
8%	did not agree
27%	generally agreed relevant professionals and public representatives should be involved but with conditions.

Q **Are you supportive of the SDE collaborating with partners such as academic researchers, commercial analytical companies, voluntary organisations and pharmaceutical companies in order to develop and innovate?**

A Many supported and understood the nature of collaborations. However, some were concerned profit-making organisations might want to access data for their own gain.

78%	of respondents said they supported collaborating with partner organisations in some shape or form
48%	were generally supportive of collaboration with partners but with considerations or concerns
6%	would not be happy with any collaboration
2%	wanted to keep the information in the NHS
20%	were concerned about data security
6%	were concerned about collaborators profiting from the data.

Q **What are your thoughts and feelings around charging organisations to access health information for research purposes?**

A More than half believed charges should be applied, particularly to profit-making organisations.

61% believed charges should be applied

16% of these suggested a sliding scale approach, based on data use, the number of records accessed and type of organisation

8% said only some partners should be charged, depending on type of organisation.

22% were unsure, did not agree with charging, or suggested a small charge or donation

5% were concerned about data security and confidentiality

38% made other points, including:

- funds should be used appropriately, either:
  - in the NHS **(24%)** or
  - to develop research **(3%)**.

5% said there should be transparency around data access, charges and profits

3% said organisations would be more responsible with the data if they had to pay for it

12% had other concerns, such as charging leading to increased distrust in the NHS.

Q **Should people who do not wish their health data to be used in this way be given the option to opt out?**

A Respondents strongly supported the choice to opt out.

92%	agreed or strongly agreed people should have the choice of opting out
5%	had no strong opinion
3%	disagreed.

Responses to questionnaire

What's important to you about the SDE?

96% said the SDE was important so that, working with the NHS, researchers could find ways to improve treatment and health

3% were not sure

1% disagreed

98% said it was important the West Midlands SDE would be used only by researchers and health and care service planners wanting to improve health and care

1% were not sure

1% disagreed

63% said it was important that organisations applying to access data through the West Midlands SDE should be charged to cover costs, with any surplus going to the NHS

29% were not sure

8% disagreed

94% said the SDE was important so that people who plan health and care services could learn if those services were still right for local people

4% were not sure

2% disagreed

96% said it was important data would be used only in secure and controlled settings

3% were not sure

1% disagreed

93% said it was important that people had the choice to opt out

4% were not sure

3% disagreed

What we've learned

Most people have told us the West Midlands Secure Data Environment is a good thing. The thought of better health and care services and new medicines and treatments is generally welcomed.

However, a lot of people are clearly worried about how safe their data will be. They want to know that, if their data is to be available through the SDE for research, it will be safe and used only by the right people, in the right way, for the right reasons.

People also strongly believe they should be able to opt out if they wish to.

Another thing we've learned is that many people do not think researchers should be able to use NHS data for free. Close to two-thirds (61% of people from the community groups we talked with and 63% of those who filled in our questionnaire) agreed there should be a charge. However, people did have different ideas about how charging should work.

There were also some people who were not sure about charging and others who thought it might cause problems.

What we recommend

1. The West Midlands SDE continues to communicate and engage with patients and the public to:
    a. promote further understanding, trust and appreciation, and
    b. ensure data available through the SDE is as diverse as possible to help address health inequalities.
2. PPAG and the DTC continue their important role.
3. The SDE engages further with young people and includes them in the research approval process as part of the data trust committee or by developing a youth forum.
4. The SDE keeps patients and the public informed about how their data is used.

As a general recommendation, we suggest patients and the public who have given their time to support the West Midlands SDE are kept informed on how their feedback has contributed to its development and progress.

For full details of the recommendations and topics to be considered for further engagement, please see the full report on the West Midlands SDE's website www.westmidlandssde.nhs.uk/resources/reports.

If you would like this information in an alternative format, (for instance, braille, audio, easy read or your spoken language) please email

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westmidlandssde.nhs.uk

IRAS number 333310