West
Midlands
SECURE DATA
ENVIRONMENT

Part of the
NHS Research Secure Data
Environment Network

NHS

Engagement findings report

March 2025

The feedback received from all questionnaires and engagement events has been minimally edited, proofed or annotated for the purpose of clarity of response.

What's in this report

IRAS number 333310

1. Foreword

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.

To help make this possible, we have carried out extensive patient and public involvement.

- We have made real and successful efforts to reach people who are part of our diverse community groups, as well as those in the wider population.
- We have been joined by a group of enthusiastic individuals who make up our Public and Patient Advisory Group (PPAG), ensuring we hear the public voice throughout.
- We have an equally dedicated Data Trust Committee, made up of members of the public who make the final decision on whether requests to use the SDE for research projects should be approved – saying yes only to those truly in the public interest.

We have supported this work with communications explaining how the SDE can make a difference to people in the West Midlands. Our PPAG members have been instrumental in ensuring these communications work for everyone.

We are now also holding conversations with children and young people from our communities. Inspiring the next generation to engage with research is a responsibility we take seriously.

The research we conduct today will shape their future, so it is crucial to ensure their voices are heard.

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

2. Executive summary

2.1. Introduction

The information collected from us by doctors and nurses every time we have care can save lives – our own and those of other people too. So when the NHS in England started to develop secure data environments (SDEs), the aim was to make better use of that data to improve care for everyone.

The West Midlands SDE brings together people's health and care information from across the whole region, keeping it safely within the NHS. Having such a large amount of knowledge will help researchers learn more about the health conditions that affect lots of us and the less common ones suffered by just a few.

Everyone living in the West Midlands stands to benefit from what the SDE can bring, but it has to be done in the right way. For that reason, people living in the region are essential to informing decision making for the SDE.

By understanding right from the start how patients and the public in local communities felt, the SDE could be created to reflect their views.

That meant giving local people every chance to get involved and listening to what they had to say.

This report details the programme of communications and patient and public engagement carried out to make sure people were not only informed, but could also get involved and have their voice heard at every level.

The West Midlands SDE programme team commissioned NHS Arden and Greater East Midlands CSU and NHS Midlands and Lancashire CSU Communications and Engagement Service to coordinate the independent analysis of the feedback from the engagement and to produce this report.

2.2. The process

Before setting out to engage with people in local communities, we wanted to be sure we were talking with all the right people. It was important we heard even the quietest voices, so we began by producing an equality impact assessment.

This in-depth evaluation of the West Midlands and its communities looked at the potential equality impacts of the SDE. What we learned from this analysis led to our wide-ranging communications and engagement campaign:

- the building of a database of more than 2,000 different cultural and health-related groups across the West Midlands to support the engagement
- face-to-face meetings with 64 community groups across the region
- a questionnaire resulting in 186 responses
- attendance at six high-footfall events to hear people's views
- a 'big discussion' day with people from across the West Midlands, at which to take the conversation a step further
- working with the next generation, exploring opportunities for children and young people to get involved
- a website, communications materials, social media and outdoor advertising to inform as many people as possible and encourage involvement
- alignment of our communications and engagement with best practice guidance.

At the same time, the SDE's governance structure was developed in a way that would ensure transparency and build the public voice into each stage of development. This included:

- **Patient and Public Advisory group (PPAG)** – the SDE's patient group, which informs, reviews, challenges, and endorses the activities and developments of the SDE.
- **Data Trust Committee (DTC)** – public members review applications from researchers requesting access to data held in the West Midlands SDE. The DTC ensures researchers' access and use of data is in the public's interest.
- **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, and PPI, communications and engagement.

2.3. Response to the engagement campaign

At every engagement meeting held with community groups, we asked a series of questions. The feedback we received will influence the development of the West Midlands SDE and its use for research and care planning. As will responses to the questionnaire, along with comments and opinions from the high-footfall events, our big discussion day and conversations with children and young people.

A more detailed set of community group and questionnaire results can be found in sections five to eight of this report but, in summary:

Community groups

4% of comments about the benefits and disadvantages of health data being used through the SDE for research were from people of an Asian background. They felt the SDE was important to increase representation of their communities in research.

89% of respondents felt positive about their data being used for research through the West Midlands SDE.

93% suggested ways to help reassure people about their data being used.

52% found it reassuring to have the NHS leading and managing the West Midlands SDE.

51% were positive about the benefits of their data being available through the SDE.

71% agreed there should be patient and public representation on the SDE assessment panel for data access requests.

78% were supportive of the SDE collaborating with partner organisations.

48% were generally supportive, with conditions, of the SDE collaborating with partner organisations.

61% believed organisations should be charged to access health information for research.

92% agreed or strongly agreed people should have the choice of opting out.

Questionnaire

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

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

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

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

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

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

2.4. Points for consideration

By far, the greatest concern voiced throughout the engagement was that of data security.

- On the question of how people would feel about allowing their health data to be used by researchers, 18% said they would agree to do so on condition they could be assured it was '100% safe and secure' and that the data would remain in the UK.
- When it came to the benefits and disadvantages, 22% of respondents expressed concerns about data security, system failure and inappropriate selling of the data.
- On collaborating with partners, 20% said they were concerned about data security.
- Regarding feelings about the NHS leading and managing the SDE, 11% had concerns or queries, mostly about data security and the NHS's ability to manage it appropriately.

In respect of the NHS charging for access to data, more than 60% said it was the right thing to do. However, some people were either not happy, or undecided.

- Among community groups, 22% said they were unsure, did not agree with charging or suggested a small charge or donation.
- 12% of respondents had other concerns, including whether charging would increase distrust in the NHS.
- 29% of questionnaire respondents said they were 'not sure' whether researchers should be charged to access data.

Other themes arising from respondents' comments included:

- wanting to be told what information from their data would be used, by whom and for which projects
- providing wider community reassurance through the availability of information about the SDE in different languages and formats
- being told how the SDE would be funded and for how long
- concern for those with mental health conditions, including whether some might not have the capacity to opt out
- wanting reassurance the SDE would lead to quicker diagnosis and development of new medicines and treatments.

2.5. Conclusion

From this report it is clear the majority of people are positive about the development of the West Midlands Secure Data Environment. Most welcome the benefits it can provide for the region's population.

However, there are clear concerns about data security. People require the reassurance that, if their data is to be used through the SDE for research, it will be safe and free from exploitation. There is also a strong belief that people should be able to opt out if they wish to do so.

Close to two-thirds (61%, community groups and 63%, questionnaire respondents) agree with charging for access to health data held by the NHS, although there are differences of opinion on what this should look like. Others are undecided or see it as a potential issue.

2.6. Recommendations

The recommendations of this report are:

- the West Midlands SDE continues to communicate and engage with patients and the public to:
  - promote further understanding, trust and appreciation, and
  - ensure data available through the SDE is as diverse as possible to help address health inequalities
- PPAG and the DTC continue their important role
- 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
- 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 on the recommendations and topics to be considered for further engagement please see section 9 of this report.

3. Background to the West Midlands SDE

The overarching aim of the West Midlands SDE is to improve the quality of healthcare delivery to people, in a system that is efficient and ensures equitable access to care. The SDE will give authorised, trained researchers the ability to analyse health and social care information from the region to find ways to improve care for everyone.

The West Midlands Secure Data Environment (SDE) enables researchers to use health data in a better way to find new medicines, treatments and healthcare technologies.

It brings together people's health and care data from across our region, offering researchers a large amount of information to study. It is a more efficient and effective way of carrying out health and care research.

The COVID-19 pandemic helped us develop better ways to access and use data to save lives. Tracking the spread, identifying those most at risk, and the fast development of effective vaccines were just some of the ways health data was used to help fight the virus.

Secure data environments were created to build on what was learned from this, so we can continue to gain the benefits of life-saving research and treatments.

The West Midlands SDE will help researchers learn more about different health conditions. Working with health and care staff, they will also be able to discover ways to help people living in areas of our region where health is poorer and lives are shorter.

The West Midlands SDE is owned and run by the NHS and uses strict levels of privacy and security to protect people's information and keep their personal details confidential. Local people are widely involved with the SDE to make sure this happens.

The areas involved in the West Midlands SDE are:

- Birmingham and Solihull
- Black Country
- Coventry and Warwickshire
- Herefordshire and Worcestershire
- Shropshire, Telford and Wrekin
- Staffordshire and Stoke-on-Trent

Universities, hospitals and other health and care-related bodies from the six integrated care systems (ICSs) in these areas are working together on the SDE to bring together the health data they hold. An ICS is the partnership of health and social care-related organisations in each local area. In the West Midlands, there are 848 of these organisations across the six ICSs, looking after the health and care needs of 6.2 million people that make up a widely diverse population.

1 of 12
SDEs across England

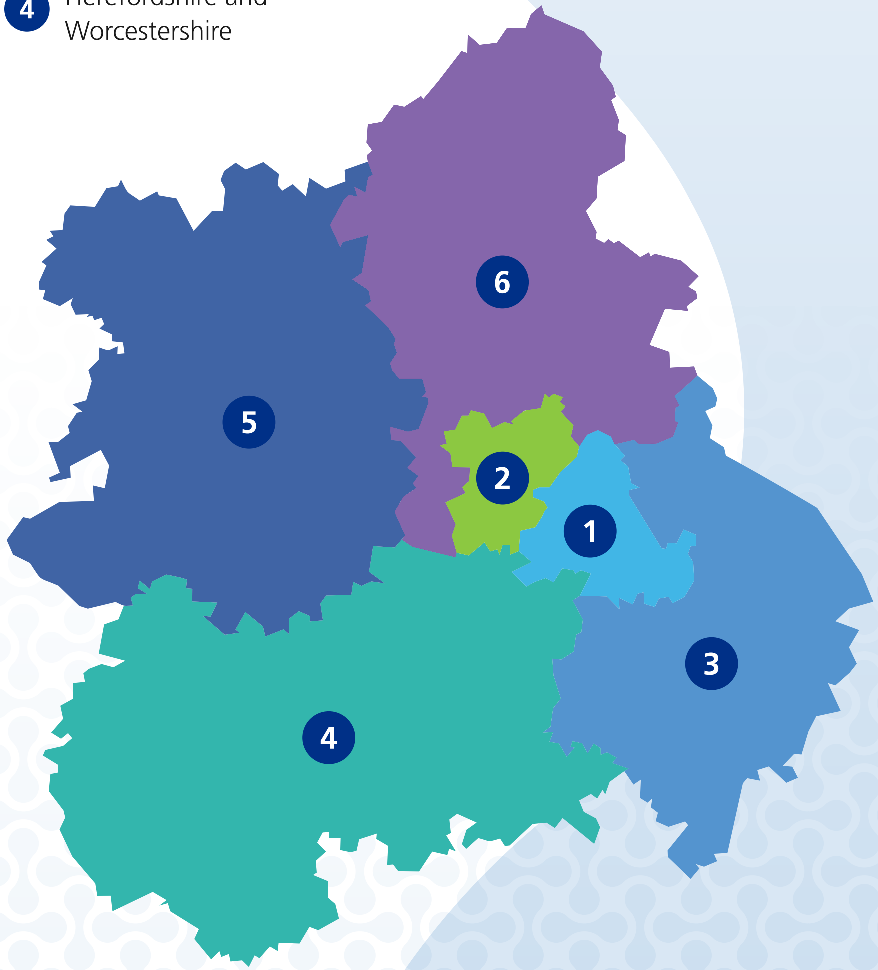
Owned and **run** by the **NHS**

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



4. Methodology

4.1. Equality impact assessment

A vital step before engaging with local people to hear their views on the West Midlands SDE was to understand the region's population and map engagement activity to make sure even the quietest voices were heard.

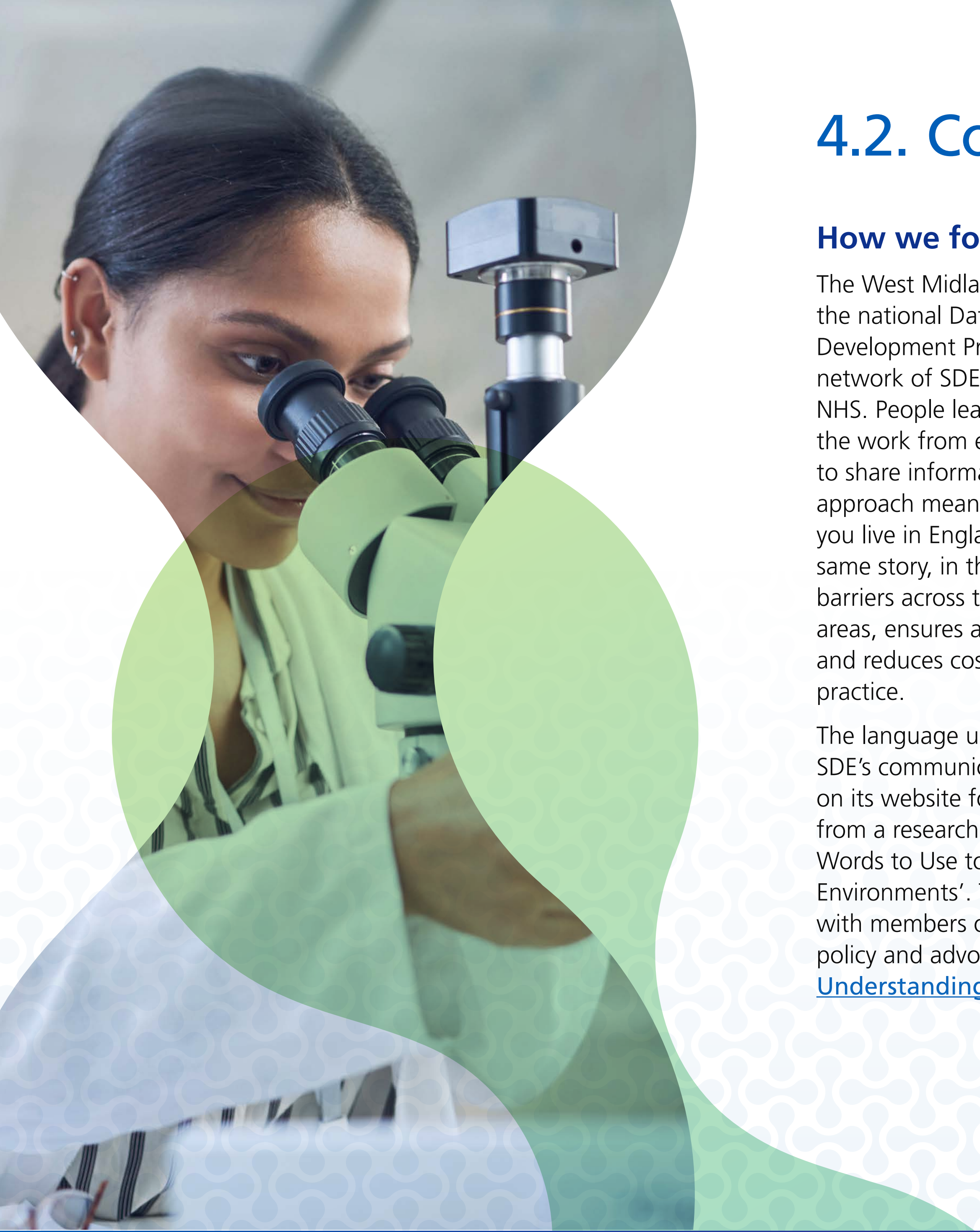
We achieved this through an in-depth evaluation of the region and its communities. We looked at the potential equality impacts of the SDE and used the findings of this analysis to inform our engagement programme.

For the success of the West Midlands Secure Data Environment, it was essential to incorporate voices from the region's diverse community groups. The purpose was to:

- address the queries and perspectives of community members
- build relationships based on trust
- encourage the availability of more diverse and representative data for research.

The end result was 64 invaluable meetings held with a wide range of community groups across the West Midlands. These provided a wealth of important feedback to help influence the SDE's development and operation. They also played a significant role in informing people about the SDE, what it means for them and their rights in terms of the use of health data for research.

By considering the insights gained from the equality impact assessments when developing our engagement and inclusion plan, the secure data environment was better positioned to achieve fair and comprehensive participation. This approach has not only enhanced the SDE's overall effectiveness but also supports its commitment to being socially responsible. What's more, it aligns with the SDE's broader goal of building relationships with a diverse pool of people for future engagement.



4.2. Communications

How we follow best practice

The West Midlands SDE operates within the national Data for Research and Development Programme and is part of a network of SDEs owned and run by the NHS. People leading on different parts of the work from each SDE meet regularly to share information and ideas. This joint approach means that, no matter where you live in England, you will receive the same story, in the same way. This reduces barriers across the different geographical areas, ensures an equal understanding and reduces costs by sharing best practice.

The language used in the West Midlands SDE's communications materials and on its website follows the findings from a research project called 'What Words to Use to Explain Secure Data Environments'. This work was carried out with members of the public by research, policy and advocacy organisation, Understanding Patient Data.

In addition, we have worked hard to align communications and engagement for the West Midlands SDE with the Good Practice Standards for public involvement and engagement in data research. These were designed by PEDRI – The Public Engagement in Data Research Initiative – working with the public and professionals.

The West Midlands' communications, engagement and PPI approach is a blend of national and regional activity, ensuring all messaging and methods are appropriate for our population.

- 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/

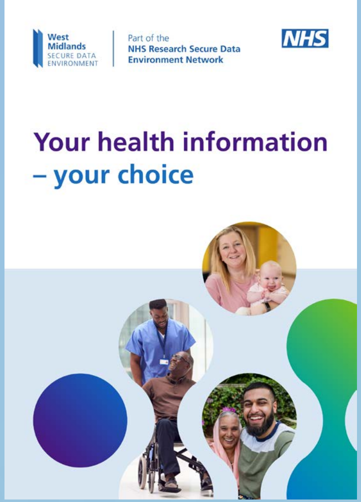
Resources

The West Midlands Secure Data Environment has [a website](#) and a suite of [communications materials](#) to ensure information about the SDE is widely available to members of the public.

These resources promote awareness and understanding of the West Midlands SDE while also supporting the extensive programme of engagement.

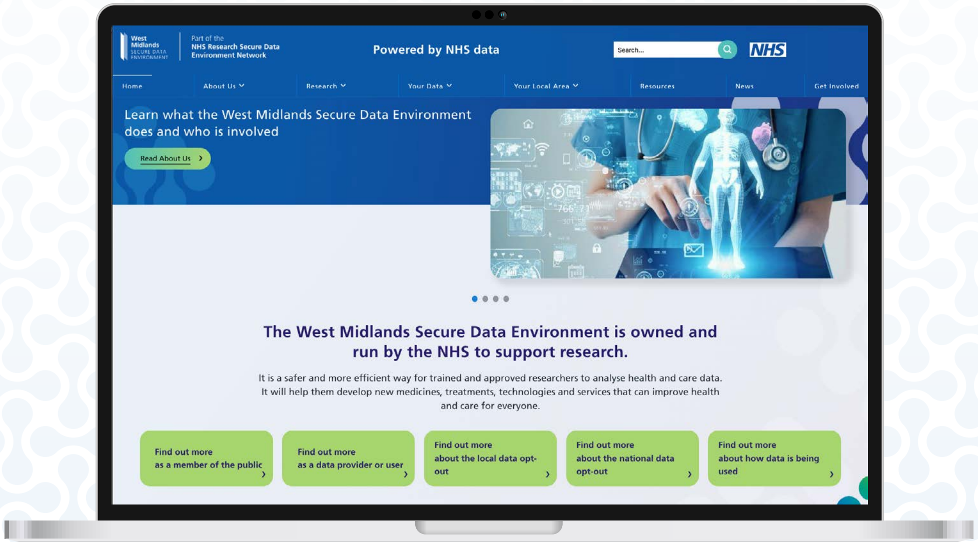
The public-facing communications materials focus on how health data saves lives, aligning to the national campaign approach. They describe the reasons data is used for research and the benefits this can bring to people living in our local communities.

To ensure patients and the public are aware of their rights, the website and materials include details of how to opt out for anyone who does not want their health and care data used for research. There is also a separate leaflet that looks in detail at different opting out choices in the NHS.



Your health information – your choice

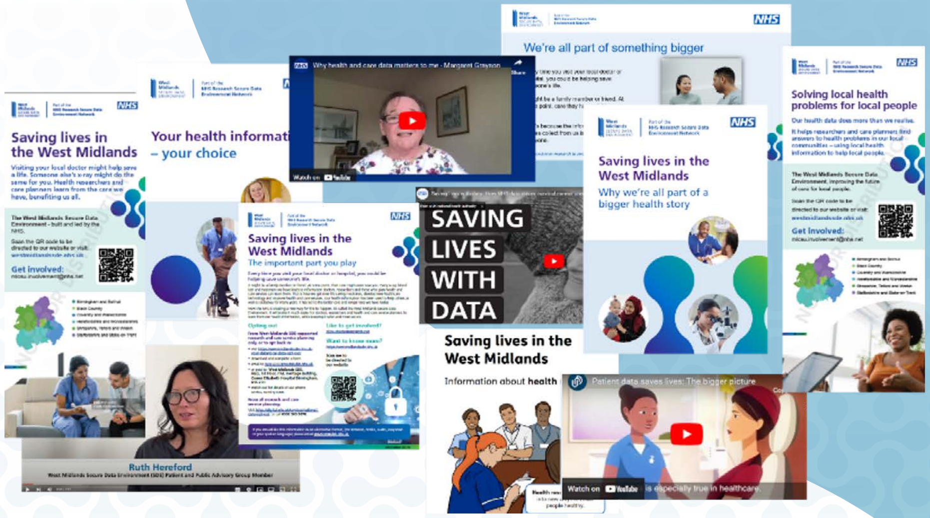
West Midlands SDE website: www.westmidlandssde.nhs.uk



Learn what the West Midlands Secure Data Environment does and who is involved

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 communications materials: www.westmidlandssde.nhs.uk/resources/

Distribution

The leaflets, posters and a presentation have been widely used at engagement events and face-to-face meetings, along with pull-up banners. Several engaging videos and animations are available to watch on the SDE website and have also been shown during community group presentations. The website has a resources section to host the materials and make them available for all to download.

Communications toolkits made up of the public-facing materials and an article for use on websites and in newsletters have been distributed to health and care organisations across the West Midlands region, bodies such as Health Innovation West Midlands, Healthwatch and West Midlands Combined Authority. They have also been shared with 1,000 community and charity organisations. All have been asked to support by sharing the materials through their communications channels and with their patient and community groups.

Transparent and accessible

From the very beginning, it was important to the SDE team to be open about what the SDE does and to be clear in the way it was described. Wording throughout the patient and public materials is in plain English to ensure it can be easily understood. An easy read leaflet was also produced to reach those who might find it useful.

Images in the communications materials reflect the diversity of the West Midlands population, while the leaflets, posters and website have all been accessibility tested.

To make sure the communications work for as many people as possible, the SDE's patient and public advisory group (PPAG) reviewed and gave feedback on the website and draft copies of the materials.

Social media and outdoor advertising campaign

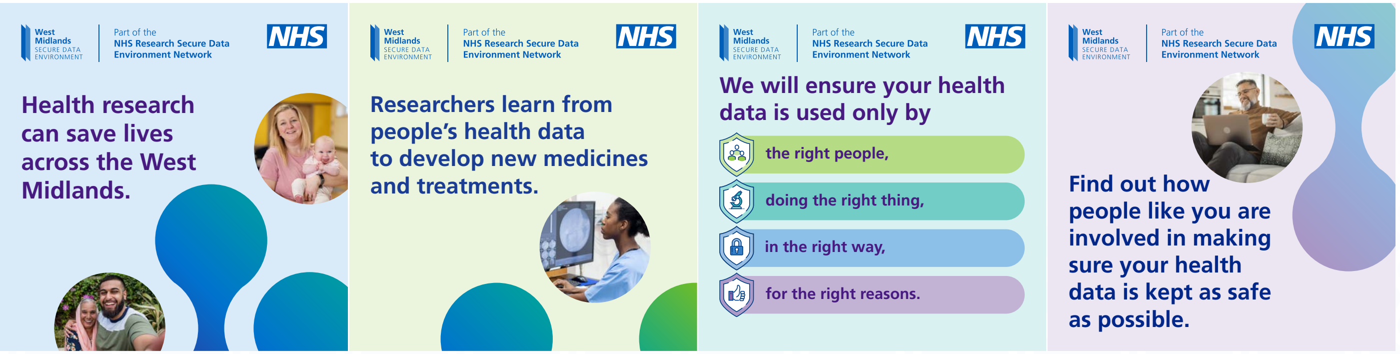
To raise awareness of the SDE with as many people as possible in the region, a further campaign was carried out through social media and outdoor advertising.

A series of adverts was run using Meta social media accounts, along with large poster advertisements on bus shelters and supermarket walls as well as other prominent sites.

The story told in both parts of the campaign mirrored that of the public-facing communications materials – health data saves lives. Here again, the SDE's PPAG members played an important role by commenting on the campaign artwork.

Web links and QR codes on the posts that accompanied the social media adverts, as well as on the outdoor adverts, directed people to the SDE website for more information.

Social media advert 1

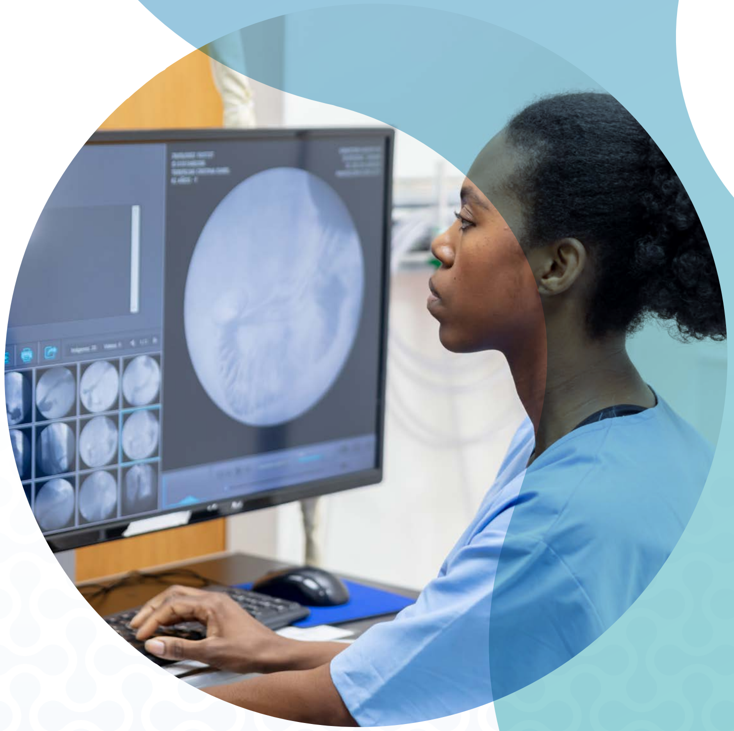


Social media advert 2

How and where

The social media adverts appeared on some of the region’s integrated care board (ICB) Facebook and Instagram accounts for six weeks in September and October 2024. They were also carried on accounts belonging to organisations such as Healthwatch and Health Innovation West Midlands.

The large outdoor adverts each ran for two weeks at different times between September and December 2024. They were placed at sites across all six West Midlands integrated care system (ICS) areas, in high-footfall areas of the region to capture those most likely to walk or use public transport.



Outdoor advertising

West Midlands SECURE DATA ENVIRONMENT
Part of the NHS Research Secure Data Environment Network
NHS

We need researchers to keep finding new, life-saving medicines and treatments, especially for big problems such as cancer and dementia.

The West Midlands Secure Data Environment is a better way for this to happen. Find out how data can save lives.
Visit www.westmidlandssde.nhs.uk

West Midlands SECURE DATA ENVIRONMENT
Part of the NHS Research Secure Data Environment Network
NHS

Every visit to your doctor or hospital could contribute to important discoveries about health conditions that affect lots of us.

Find out how your health data can help save lives in Staffordshire and Stoke-on-Trent.
Visit www.westmidlandssde.nhs.uk

4.3. Patient and public involvement

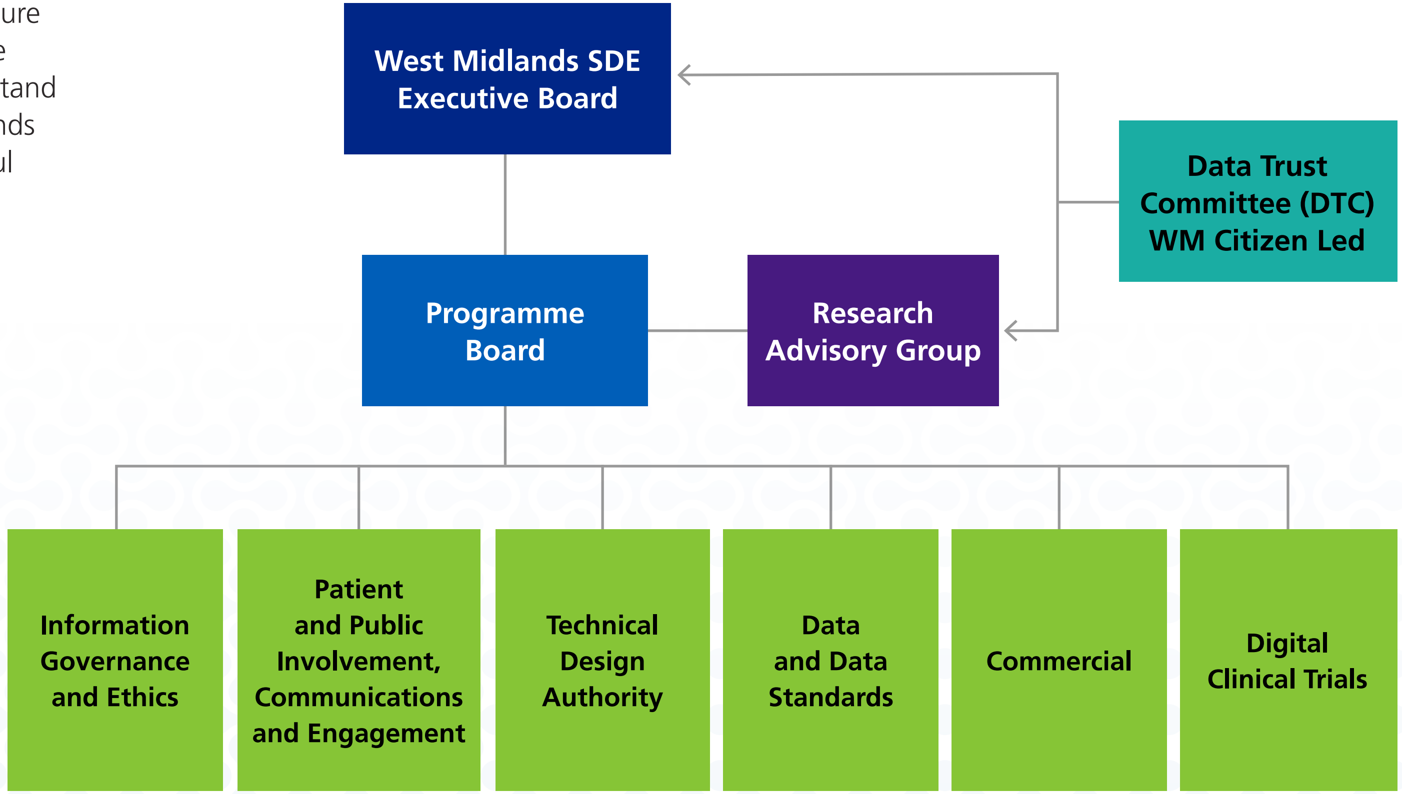
4.3.1. The West Midlands SDE governance structure

The West Midlands SDE governance structure was developed in a way that would ensure transparency. This allows people to understand the process of developing the West Midlands SDE and enables them to make meaningful contributions.

Public contribution throughout meant the public voice was built into each stage of the West Midlands SDE development.

Patient and Public Advisory group (PPAG) – the SDE's patient group, which informs, reviews, challenges, and endorses the activities and developments of the SDE.

Data Trust Committee (DTC) – public members review applications from researchers requesting access to data held in the West Midlands SDE. The DTC ensures researchers' access and use of data is in the public's interest.



West Midlands SDE Executive Board

Data Trust Committee (DTC) WM Citizen Led

Programme Board

Research Advisory Group

Information Governance and Ethics

Patient and Public Involvement, Communications and Engagement

Technical Design Authority

Data and Data Standards

Commercial

Digital Clinical Trials

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, and PPI, communications and engagement.

Transparency

Public contribution throughout

The public have the final say

Develop proportionate review

Direct and inform the programme

Developing proportionate review Members of the Patient and Public Advisory Group were involved in the development of the ethics protocol that has informed, and will continue to inform, the development of proportionate review. This is a faster review process for research projects that are low in ethical risk.

Directing and informing the programme Patient and public involvement has directed and informed the West Midlands SDE – through the governance structure and the wide patient and public communications and engagement activity.

4.3.2. Setting up the Patient and Public Advisory Group

The aim of the West Midlands SDE Patient and Public Advisory Group was to bring together volunteers with a strong passion for research, the healthcare data environment and improving outcomes for patients. Informed by the equality impact assessment, it was important to recruit as diverse a group of people as possible. Information on how to become a member was shared through the SDE's bespoke database and its newsletter. Integrated care boards across the region were also asked to cascade the opportunity to existing patient groups. Recruitment resulted in the formation of the PPAG.

PPAG Members:

14 people recruited

Members described as:

12 Male

2 Female

Areas covered:

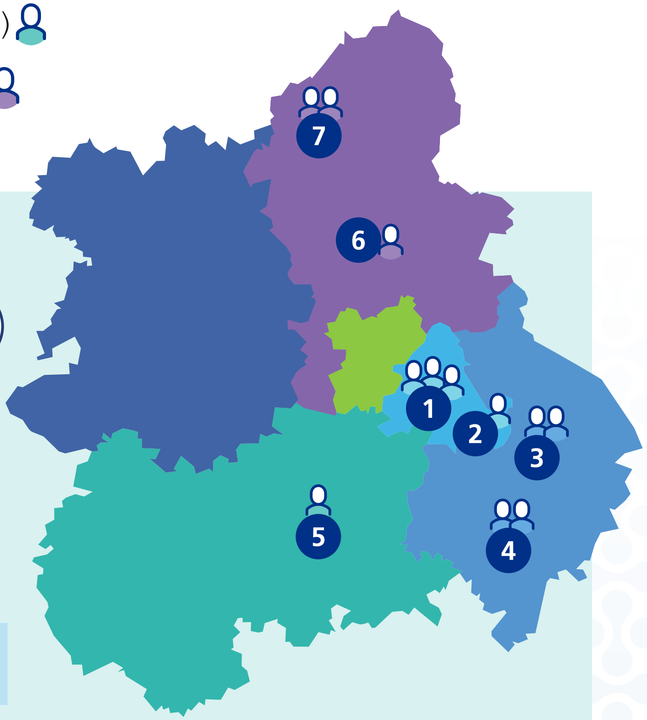
1 Birmingham (3)
2 Solihull (1)
3 Coventry (2)
4 Warwickshire (2)
5 Worcestershire (1)
6 Staffordshire (1)
7 Stoke-on-Trent (2)

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

Activity and Influence of PPAG

The group began with a welcome meeting attended by the SDE's Programme Director. Since then, programme board and workstream leads have taken part in PPAG meetings to ensure members have been kept informed on the various stages of the West Midlands SDE's development. PPAG members have been involved in activities including:

- reviewing the communications and engagement plan
- contributing to the engagement approach with community groups
- providing feedback on the concept for the West Midlands Secure Data Environment website and later updates (westmidlandssde.nhs.uk)
- reviewing the content of the West Midlands SDE application for ethical approval
- reviewing communications materials, for example patient leaflets, banners and social media adverts
- contributing to discussions on introducing a Data Trust Committee
- contributing to discussions on local and national data opt-out processes
- reviewing and helping amend the application form for researchers who wish to access the West Midlands SDE
- producing video blogs
- identifying engagement opportunities within their communities.

4.3.3. Setting up the Data Trust Committee

Following discussions with PPAG members, an email explaining the function and purpose of the DTC and how to express an interest in becoming a member was sent to 1,500 stakeholders and community organisations. This resulted in a membership of 15 public members for the West Midlands SDE Data Trust Committee.

Following a welcome meeting, the newly appointed DTC members underwent training on the secure data environment and how it works. This included briefings on how data is introduced into the SDE and how researchers can view and use it. Members also learned about the rigorous 11-step application process researchers must go through if they want permission to use data through the SDE.

DTC Members:

15 people recruited

Members described as:

8 Male

7 Female

Areas covered:

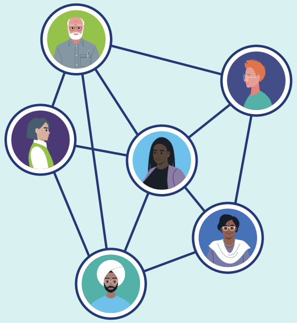
1 Wolverhampton (1)
2 Walsall (1)
3 Birmingham (2)
4 Rugby (1)
5 Leamington Spa (2)
6 Warwickshire (1)
7 Worcestershire (2)
8 Shropshire (1)
9 Telford (1)
10 Staffordshire (1)
11 Burton-on-Trent (1)

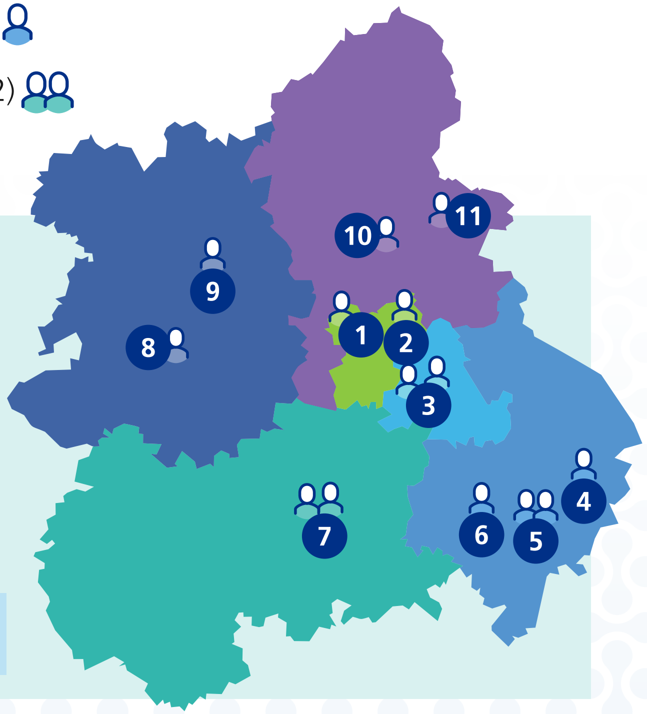
Out of area:

12 Melton Mowbray (1)

Ethnicity:

8	White: English/Welsh/ Scottish/Northern Irish/British
4	Asian/Asian British: Indian
2	Asian/Asian British: Pakistani
1	Mixed/Multiple ethnic group





= DTC Member

Members then took part in practical training in how to assess a data request application and make decisions based on the Five Safes, which is the guiding framework used by the SDE to ensure data can only be used by the right people, in the right way, for the right reasons. The Data Trust Committee is now fully up and running, with regular sessions taking place to assess applications.

Data Trust Committee

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.

4.3.4. Engagement Activity

Once 64 meetings with community groups had taken place, the Equality Impact Assessment (EIA) was revisited. We did this to make sure we captured the views of all those highlighted in the EIA report.

During August and October 2024, we met with people visiting high-footfall public events and busy venues:

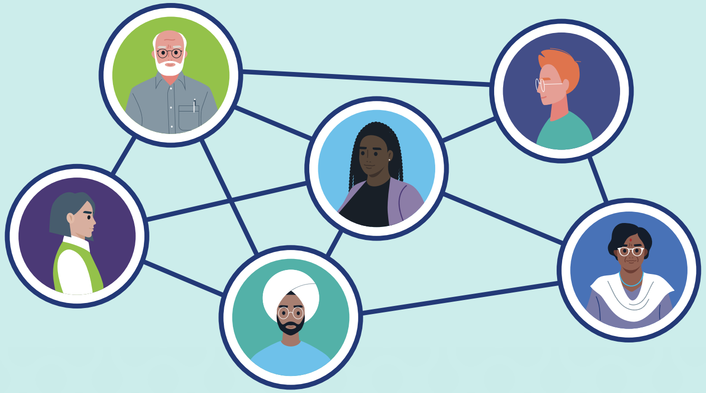
- **Family Fun Day at Draycote Water, Warwickshire**
- **Walsall Community Event**
- **Staffordshire Fire and Rescue Public Event**
- **Shropshire Wellbeing Festival**
- **Atherstone Leisure Centre, Warwickshire**
- **Wyre Forest Leisure Centre, Worcestershire**

The aim was to inform patients and the public about the West Midlands SDE programme and explain how health data can save lives. It also provided an opportunity to hear any concerns the public might have about their data being used for research through the West Midlands SDE.

As part of the community activity we also ran a survey. This attracted completed questionnaires from 186 people across the region.

Engagement activity

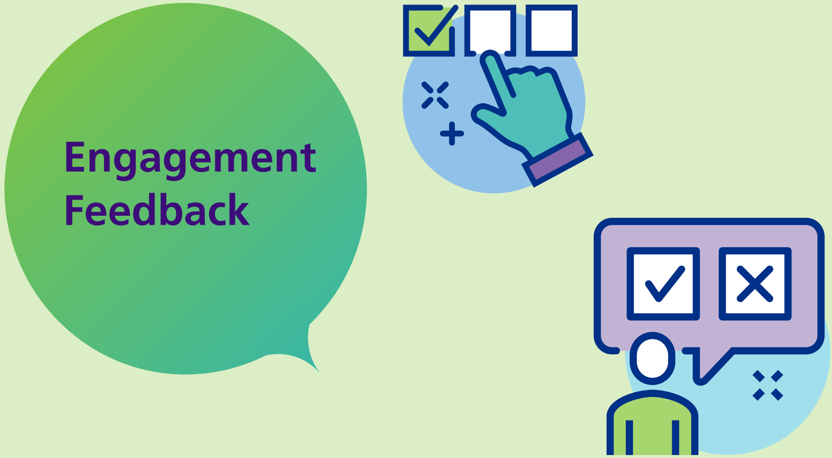
Stakeholders



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

4.3.5. Face-to-face engagement

We were actively supported by voluntary sector groups, charities and local authorities in our efforts to reach people from community groups across the West Midlands. This enabled us to include people from all protected characteristics groups through comprehensive face-to-face engagement activity, giving them the opportunity to have their say. The groups we visited are detailed on the next few pages.

Engagement Events - Protected Characteristics *(Table 1 of 3)*

		Protected Characteristics								
Group visited	Area	Age	Disability	Gender Reassignment	Race	Religion or Belief	Sex (Gender)	Sexual Orientation	Pregnancy and Maternity	Marriage and Civil Partnership
Ahmadiyya Muslim Association (Women's Group)	Coventry	✓	✓		✓		✓			✓
Abraham Darby Leisure Centre	Telford	✓	✓		✓	✓	✓	✓	✓	✓
African Caribbean Community Association	Walsall	✓	✓		✓	✓	✓			✓
Age UK	Wolverhampton	✓	✓		✓		✓			✓
Age UK Herefordshire and Worcestershire – Craft Group	Hereford	✓					✓			✓
Age UK Herefordshire and Worcestershire – Walking Group	Hereford	✓					✓			✓
Armed Forces and Veterans Breakfast Club	Telford and Wrekin	✓	✓				✓			✓
Benn Partnership Meet and Eat Community Café	South Warwickshire	✓	✓			✓	✓			✓
Birmingham Youth Forum	Central Birmingham	✓					✓			
Cerebral Palsy Mid Staffordshire	Staffordshire	✓	✓				✓			
Chesta Asian Women's Group	Wolverhampton	✓			✓	✓	✓			✓
Chinese Community Health Champions	Central Birmingham	✓			✓	✓	✓			✓
City Centre Mosque	Stoke-on-Trent	✓	✓		✓	✓	✓			✓
Cohort 4 (survivors of domestic abuse, prison leavers and mental health sufferers)	Warwickshire	✓	✓				✓			
Craft and Chat Solihull Library	Solihull	✓					✓		✓	✓
Diabetes UK Support Group	Coventry	✓			✓		✓			✓
Dudley Beehive LGBT group	Dudley	✓		✓	✓		✓	✓		✓
Dudley Stroke Association	Dudley	✓	✓		✓		✓			✓
Duncan Edwards Leisure Centre	Dudley	✓	✓		✓	✓	✓	✓	✓	✓
Fenton Manor Sports Complex	Stoke-on-Trent	✓	✓		✓	✓	✓	✓	✓	✓
Fibro-Family (Fibromyalgia support group)	Telford	✓	✓				✓			
Go-Womans Alliance - New Arrivals to the United Kingdom (ladies group)	East Birmingham	✓			✓		✓			✓
Guru Ka Niwas Gurdwara - Ramgarhia Board	Wolverhampton	✓	✓		✓	✓	✓	✓	✓	✓

Engagement Events - Protected Characteristics *(Table 2 of 3)*

		Protected Characteristics								
Group visited	Area	Age	Disability	Gender Reassign-ment	Race	Religion or Belief	Sex (Gender)	Sexual Orient-ation	Pregnancy and Maternity	Marriage and Civil Partnership
Gypsy Traveller Community - Griff Caravan Site	North Warwickshire	✓	✓			✓	✓	✓	✓	✓
Gypsy Roma Traveller group	Coventry and Warwickshire	✓	✓			✓	✓	✓	✓	✓
Headway	Coventry and Warwickshire	✓	✓				✓			
Khushi Asian Women’s Group	Solihull	✓	✓		✓	✓	✓			✓
Ladies Craft and Chat	Solihull	✓	✓			✓	✓			✓
Ladies Walk Centre at Sedgley Library	Dudley	✓					✓			✓
Leek Library Craft Group	Staffordshire and Stoke-on-Trent	✓		✓			✓			✓
MD Support Centre - West Midlands	Coventry and Warwickshire	✓	✓				✓			✓
North Midlands LGBT older people’s group	Stoke-on-Trent	✓	✓		✓		✓	✓		
Oak Park Active Living Centre	Shropshire	✓	✓		✓	✓	✓		✓	✓
Oswestry Leisure Centre	North Warwickshire	✓	✓		✓	✓	✓		✓	✓
Parents of under 5s group	West Bromwich	✓			✓	✓	✓		✓	✓
Parkinson Cafe	Birmingham and Solihull	✓	✓				✓			✓
Parkinson’s UK Birmingham and Sutton Coldfield	Birmingham and Solihull	✓	✓				✓			✓
Positive Mental Health group at Birmingham mental health centre	Birmingham	✓					✓	✓		
Sedgley Library (Mindfulness group)	Black Country	✓	✓			✓	✓			✓
Shree Ram Mandir Hindu Temple	Sparkbrook Birmingham	✓	✓		✓	✓	✓	✓	✓	✓
Shrewsbury Carers Group	Shrewsbury	✓	✓				✓			✓
Shrewsbury Library Craft and Chatter	Shrewsbury	✓					✓			✓
Solihull Hebrew Congregation	Solihull	✓				✓	✓			✓
St Mary's Church Group	South Warwickshire	✓	✓		✓	✓	✓	✓	✓	✓

Engagement Events - Protected Characteristics *(Table 3 of 3)*

Group visited	Area	Protected Characteristics								
		Age	Disability	Gender Reassignment	Race	Religion or Belief	Sex (Gender)	Sexual Orientation	Pregnancy and Maternity	Marriage and Civil Partnership
St Matthew's Baby and Toddler Group	Wolverhampton	✓			✓	✓	✓		✓	✓
Stay and Play group	Handsworth Birmingham	✓			✓	✓	✓	✓	✓	✓
Stepway (Banter and Brew) – supporting veterans in Civilian life.	Hereford and Worcestershire	✓	✓				✓			✓
Stepwell Wellbeing Centre Veterans group	Oldbury, Sandwell	✓	✓				✓			✓
Stirchley Asian Ladies Circle	Stirchley Birmingham	✓			✓		✓			✓
Stoke Changes (mental health conditions)	Stoke-on-Trent	✓	✓				✓	✓		✓
Stoke Library (playgroup)	Stoke-on-Trent	✓			✓		✓		✓	✓
SYDNI Centre Drop-in cafe	South Warwickshire	✓	✓				✓			
Taking Part (Learning disability and neurodiversity)	Shropshire	✓	✓				✓			
Telford MS Society, Salvation Army	Oakengates, Telford	✓					✓			✓
The Active Wellbeing Society	Tyseley Birmingham	✓	✓				✓			
The Carers Trust Solihull	Solihull	✓					✓			
Uplift – African Communities	Handsworth Birmingham	✓	✓		✓		✓			✓
Uttoxeter Leisure Centre	Uttoxeter	✓					✓			
Vals Pals (previously known as CAMEO (come and meet each other)	Oldbury, Sandwell	✓	✓				✓			✓
Walsall Society for the Blind	Walsall	✓					✓			✓
West Bromwich African Caribbean Resource Centre	West Bromwich	✓			✓		✓		✓	✓
Writing, reading and pre-school Library group	Newcastle-under-Lyme	✓					✓		✓	✓
Writing, reading and pre-school Library group	Newcastle-under-Lyme	✓					✓			
Young Persons Forum, Telford	Shropshire and Telford	✓					✓			

5. Engagement with young people

We met with two groups of young people – one based in Warwickshire and the other in Telford and Wrekin.

Group 1: Warwickshire Youth Council

11–18 years

Online workshop

Attended: July 2024

This section summarises feedback received from a Young Women's Group of 24 people regarding the use and management of health data in the West Midlands Secure Data Environment. The young women were recent arrivals from various countries in South Asia and Africa so had little or no knowledge of the NHS. Their feedback provides valuable insights into the perspectives and concerns of the group and highlights areas for further engagement and assurance.

The feedback was gathered during an engagement session where attendees had the opportunity to voice their opinions through an interpreter or in English.

1. When asked how they felt about researchers accessing their health data, many respondents expressed positive views, recognising the potential for data to benefit health outcomes and research. They did have concerns around anonymity and data protection and wanted reassurance that personal information would be safeguarded. Overall, they all wanted their health information used in order to help others.

> **"This is a good idea. It can be used to help our community."**

> **"As long as our name and personal information is not shared."**

2. Respondents were asked what would help people feel reassured and more confident about their information being accessed through the SDE. They emphasised the need for data security measures and clear communication.

They also felt the need to ensure that communities were not vilified or singled out with a negative undertone from the accessed data. Respondents felt that, in particular, any information relating to children must be safeguarded.

> **"They need to make sure our personal information is kept confidential."**

3. When they were asked if they were more reassured that the NHS was leading on the project, there were mixed reactions as they did not know enough about the running of the organisation. However, the overall sentiment was that, as the NHS deals with healthcare anyway, it made sense they should be running the SDE. The one criticism was that they did not believe the NHS was currently doing its job in terms of providing healthcare so they should not be involved in this.

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> **"I'm not sure what the NHS is but if they deal with health then it's okay."**

4. On the perceived benefits and disadvantages of data being used through the SDE, some commented about ensuring data from all communities would be available for research instead of how, historically, only those who signed up to studies and who might not always be representative of all communities were involved. They also believed the information would be good for the future health of local communities. The underlying sentiment, and the disadvantage as seen by the group, was about the system being hacked, saying that information must be kept anonymous. One comment was that, in theory, this project would be good but they did not believe the information would be used for the good of communities and the NHS should be spending money on seeing patients first.
5. When asked whether patients and public representatives should have a role in the approval process the response was overwhelmingly yes, they should have a role to play in this so they can have some reassurance that use of the information is approved appropriately.
6. The respondents were asked specifically about academic researchers, commercial analytical companies, charities and pharmaceutical companies being able to access data. While the responses were mainly positive and they had no issues with any of these organisations accessing data, there were conditions around ensuring that no data would be shared with unauthorised people. Two people had concerns, with one not trusting the people who would be working with the information and one that was unsure whether to trust these organisations.

> **"It would be OK for them to use my data for research as a lot of work is being done so it shouldn't be wasted."**

> **"It's good to share information especially for the Asian community where (like you said) we don't normally take part in research ourselves but this will be confidential so it's a good idea. Good for our future health for our communities as long as it stays confidential."**

7. In response to the question regarding how they felt about these organisations being charged for the information, the overall sentiment was that of mistrust that the organisations would not pass on the cost to the end user. For example, pharmaceutical manufacturers recouping the money by charging the NHS additional costs for medicines that are developed or universities charging students extra to attend their courses. If there was reassurance that this would not happen then they generally did not mind. However, one person did not want charges to go ahead at all because of this.

> **"I don't have a problem with charging companies as long as they don't start getting money out of us patients."**

8. When asked if there should be the option to opt out, everyone strongly agreed that there should be an opportunity to opt out if people did not want their data used in this way.

Group 2: Telford and Wrekin Young person's forum

11-18 years
Online workshop
Attended: January 2025

This feedback was gathered during an engagement session in January 2025 where attendees shared their opinions on the SDE.

The respondents were asked if they understood health data and why it was being collected.

1. They all understood the concept of allowing their health information to be accessed and why it was important, particularly for studies and especially around young people with mental health issues. The young people acknowledged that there may be some challenges with people living with mental health conditions because this part of their life might be sensitive to them and they might want to opt out of sharing that aspect of information about themselves.
2. The group was passionate about the need for more transparency because they said, even at the moment, no-one knew what was being recorded about them, or who was accessing their health information.

> **"Need some transparency and might have challenges about mental health issues because it's sensitive."**

3. The group was unsure where health data currently comes from. They thought it would be walk-in centres, schools and education but admitted that they did not have much of an idea about this.

> **"Maybe we should know but we don't."**

4. When asked whether permission should be sought before health information was made available for this kind of use, the group was in full agreement that they should have to give permission first. They discussed occasions when their information had been shared, for example, for making referrals or appointments, but permission had not always been given by them.

> **"Yes, they should definitely get permission from people to share records."**

5. The group was asked who they believed would want to use their data for research and service planning and they said pharmaceutical companies would see the data as 'gold dust'. They said that was the risk. They asked how far we would go with data sharing and said we would need to be careful about sharing this information.
6. Another comment was around the context of the data to be used. They felt it would be flawed if it did not include things like environmental factors so that a holistic approach could be taken rather than just looking at, and working with, statistics and data.

> **"How will the information be shared? Sometimes they need context otherwise it won't be helpful."**

7. The group was unaware of the West Midlands Secure Data Environment but, when it was explained to them, they were generally happy for it to go ahead as long as people had the choice to opt out of including any information they felt was sensitive to them. They felt this might be a better option than having to say a blanket 'yes' or 'no' to everything.
8. When discussing whether patients and public representatives should be included on the application assessment panel, they were in favour of having representation from people whose data would be available to use, giving them some say over who would have access. They believed they should be given training and education, but it was only right to include those who were allowing their data to be used in this way.

"If you're asking for patients for their data then you should allow them to be included."

9. When the youth forum was discussed, it was met with enthusiasm and interest as well as a sense of feeling included. They said it would mean young people would be given the opportunity to understand how their data was being stored, accessed and used, which could help put their mind at ease. They believed it would work well as an option for work experience from schools.

"This is a good idea because it allows us to see into what is being shared and that it's secure."

10. They discussed at length how awareness should be raised. They had many ideas about how the subject should be included in their school curriculum as fun interactive sessions for year 9 upwards to make it more relatable.

"If schools cover this it would be really effective."

11. When discussing if there were any organisations they would not want to access their information, they said they would not want their data to leave this country. They said there could be certain companies with negative histories they might not want to share their data with, such as some pharmaceutical companies using data for their own benefit. The question arose as to how there could be certainty that a company could be trusted even if it says it would be doing research for the benefit of others. There would have to be due diligence for each specific request, they said.

"I wouldn't want data to go to other countries."

12. The group did not think that universities should be charged or, at least, there should be charges depending on the type of organisation. For example, pharmaceutical companies should be paying more than students. They agreed that by charging companies it would demonstrate almost a purity in their commitment to use the data in a responsible way.

In summary, the consensus of the group was that the West Midlands SDE was good and worthwhile. They believed there was more work to be done on providing assurances on data security and communicating the purpose of the SDE to the wider population.

"Need some transparency and might have challenges about mental health issues because it's sensitive."

"By charging organisations it will show their commitment to research."

6. Findings from face-to-face engagement with diverse community groups

Between January and December 2024, 64 community engagement events took place with communities across the West Midlands, of which 58 were face-to-face and six virtual.

At these events, attendees were presented with information about the West Midlands SDE, allowing in-depth conversations to take place. Conversations with 339 people were encouraged by asking open-ended questions. Please see Appendix A.

The analysis in this section of the report shows conversations that took place at the community events.

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

A high number – 89% – felt this would be a positive move. A total of 58% expressed the importance of their data being available to access through the SDE to improve future health services for individuals and communities, support staff training, raise awareness of illnesses and treat early diagnosis.

> **"I support my data being shared with researchers. I think it's a great idea. I would want to know how this information would be used though. The information needs to go both ways, with my health also being prioritised."**

“This is a good idea. It can be used to help our communities. I don’t mind who wants to know about my health – in our countries they wouldn’t ask these questions, they just do it.”

“I think research is brilliant, but it’s the safeguarding and expense and technology behind it and keeping up to date with it.”

A further 18% of respondents agreed with researchers being able to access health information on the following conditions.

- They would be happy if they were sure it was 100% safe and secure and that data remained in the UK.
- In principle it would be acceptable to use health information for research. However, some patients asked to be kept informed about what medical information was available and who would be given access to use it.
- Involvement would depend on who had access to the data and which projects it was supporting.
- If it improved the current computer systems used to avoid patients having to repeat their health information.

“Would support if it was for ethical research and not profit driven.”

“Would be happy for anonymised data to be used for research purposes providing it was secure and not accessible by third parties.”

“As long as used in the right hands - hacking - insurance implications - how much in-depth information would be taken into account.”

Across all respondents, 12% had other reservations and would not want their health data used due to concerns about:

- the use of health information e.g. who would have access – a sense of general mistrust was relayed in respondent answers
- who would give permission for the information to be used
- how the information would be used
- what information would be collected
- what information would be used to make money e.g. would data be sold to the highest bidder.

“I don’t like the idea of anyone having access to my health information.”

“It sounds like a good idea in principle but even if they said no personal info will be shared I wouldn’t agree to it.”

> **“I’m not too happy about it... I think they can get so much information and I worry about data security and how it is all safe.”**

Respondents also expressed other areas for consideration.

- **Access/security of data**
    - How the NHS would gain patient trust to work in this way, given the recent security breaches in data at other organisations.
    - Concerns over any external organisations/teams accessing this data as patients were reluctant for data to be used outside the NHS.
    - For all information regarding the West Midlands SDE to be explained to patients clearly, in different languages, in order to avoid confusion and anxiety.
- **Funding**
    - Where the funding would come from and how long it would last.
    - Whether working in this way would increase funding for other services.
    - Implications on resourcing this work and the impact it would have on staff from other departments.

> **“It is very important - lots of headway is being made into conditions like mine but there is a challenge on how to share data. I’m on a working group to advance clinical trials - we’re working with six other centres. One of the issues we had was around how to share data around GDPR and how to develop a framework, especially for rare conditions. For broader health conditions it is easier but for rarer ones it is more difficult.”**

> **“It’s ok as long as you don’t make it confusing so people don’t know what’s going on, e.g. knowing who will go in to see the data. People need to be able to understand so information needs to be in easy read and not in jargon.”**

> **“Depends who has access to the information. Depends on the reasoning and what sort of research it is. Because, financially, if it’s ethical to do the research and if it helps people in the long term then it’s OK.”**

In summary most respondents agreed with their health data being available but some did have concerns on how the security and access to data would be managed and communicated.

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

Respondents expressed many factors that would reassure them, including:

Data security: 32% of respondents said:

- all data must be kept confidential and anonymised to provide reassurance that access to any data was safe and secure
- examples should be provided of what the data would look like when it was made available to use.

Better health outcomes for the future – 27% of respondents needed to be reassured that it would lead to:

- quicker diagnosis of conditions
- medical staff being able to access the data required to help manage conditions
- development of new medicines to treat rare conditions.

IT systems – 21% of respondents wanted reassurance around IT systems to feel confident. They wanted to know:

- the systems used to store the data would be safe and secure
- more about how the data was stored and the processes followed to keep the data safe
- who was responsible for managing the IT systems
- how use of data in this way could help improve current IT systems.

> **"I think we all need reassurance that the database is secure and confidential. It will take time to prove this and we need to know that there hasn't been a breach in the next few years that will get other people to sign up when they see that there haven't been any problems."**

> **"I would want to see an example of how the information would look when it's given to the organisation requesting it just to reassure me that it will remain anonymous and people will not be identifiable."**

> **"Information about SDE in a number of accessible formats (e.g. clear information about why, how and where data will be used, how information is received, information about data safety and safeguarding, case studies about how data sharing has improved health outcomes, timeframes, outcomes)."**

To feel confident about their data being accessible to researchers, 13% of respondents asked for:

- information about the West Midlands SDE in a number of accessible formats and languages
- more communications for elderly patients and those digitally excluded
- more clarity about why, how and where data would be used, how information was received, and information about data safety and safeguarding
- case studies about how using data for research had improved health outcomes and the associated timeframes.

A total of 7% of respondents felt nothing would reassure them about their data being used in this way. This was due to recent reports of loss of data and misuse of data, which has led to loss of trust.

> "Nothing would reassure me because there is no system 100%."

> "It's my personal data so it's my choice. There is nothing anyone can do to change my mind."

In summary, 93% of respondents suggested areas that would help reassure people about their data being used in this way. Many of the themes emerging from this question related to wanting better communication and transparency with patients and service users. One positive way suggested was by demonstrating how the West Midlands SDE had supported the NHS to improve health outcomes for patients through research and collaboration, with health information for studies based specifically on UK residents.

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

In all, 46% of comments received were positive. A further 6% conditionally agreed, 17% were negative, and 17% were neutral. Another 8% had concerns or queries.

> "It does, but what would be even better is that if data sharing and the SDE would help on a general communication level and making sure that everything is up to date and everyone knows your health story – it would be a shame if this didn't help to link everything up. The communication is awful between different parts of the NHS."

> "It doesn't necessarily reassure me just because it's the NHS because things aren't as concrete as they used to be, so you have less confidence now in the NHS. That's why patients and patient representatives are useful."

> "It doesn't make a difference who runs it. I can't say yes or no. Medical research goes on all the time, this is just a different way of doing it."

- 40% of comments were a positive 'yes' – that it was reassuring the SDE was being managed by the NHS, and that the NHS was better than commissioning a private provider; 2% were unable to think of an alternative organisation they would trust more to run the programme.
- There was trust in the NHS as people said it was a professional body with ethics and was more accountable, with a duty of care to patients (4%).
- Conditional agreement was generally around ensuring the information would be used to make changes directly within the NHS and support the NHS to improve health outcomes.
- The negative responses centred around people's previous experiences and a lack of trust developing in the NHS over the past few years (17%).

- 17% of comments were from people who did not have an opinion about the NHS running the West Midlands SDE, including a group of young people newly arrived in the UK stating they were not aware of what the NHS was so did not have a strong opinion (5%).
- There were some general concerns or queries, mainly related to the security of health information being used and whether the NHS would be able to manage it appropriately (8%).

In summary, just more than half of respondents were reassured that the NHS was running the West Midlands SDE, with 2% unable to think of an alternative organisation they would trust more to do so.

What do you see as the benefits and disadvantages of health information being used for research?

This was a question that allowed for reflection and consideration on the pros and cons and people did carefully consider both aspects with multiple responses for each.

- The result was 51% positive comments and 31% negative, with 8% saying they could see no disadvantages and 10% making general comments.
- There was consensus of opinion that research was important and that it would be of benefit for health information to be used in this way, with a belief it would improve health outcomes for everyone. A further thought was that it could potentially lead to increased development of futuristic and innovative treatment options and medicines (37%).
- 4% of comments were from people from an Asian background, with a feeling that the West Midlands SDE was important for Asian communities as they were not normally reflected in statistics or studies.
- 22% of comments on disadvantages were concerns about the potential for the SDE to be hacked and the security aspects of information being stored. The Post Office scandal and other recent incidents of system failure were given as examples, with concerns also being raised about the potential for selling data inappropriately.

It is important to note there was some concern about people living with mental health conditions who:

- might not have the capacity to opt out and would, therefore, be in the system without necessarily realising they had the choice to
- did not wish to share details of their condition because they felt it could perhaps affect areas of their life such as employment.

“The benefits are that you can see trends and whether a percentage of the population is on a specific drug etc. It will help with a risk analysis on certain factors in the population, whichever study is being done.”

“If data collected was not safe and secure (e.g. it could be misused, hacking, if information got into the wrong hands, data stored in one place makes it easier for cyber attacks).”

In summary, overall the responses to this question were positive but people wanted more transparency and assurances that the information would be used appropriately and access to the system would follow good governance processes.

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

A total of 71% of respondents said there should be representation from patients and public representatives. The general opinion was that this could lead to increased trust in the system. The people who did take part would then become experts by experience and ensure that it was accessed appropriately.

> **"If it does go ahead the patients should be on the panel and GPs should have patient groups who should have input into the panels across the board."**

> **"It should be people from a data experience background or we need to leave it to experts of GDPR and other compliance."**

> **"I think the committee is fine but it's the safeguarding of the data that is a bigger thing. They'll need external advice on this. For example, AI is moving so fast that you'll need AI experts on the panel."**

- 9% of respondents did not believe patients and public representatives should be included on the assessment panel, with 2% saying they did not agree with the West Midlands SDE.
- 5% of respondents were unsure and wanted further information before they could answer this question.
- 26% of respondents generally agreed that there should be representation from relevant professionals and public representatives but with some considerations including:
  - Wanting to know how the patient and public representatives selection process would work, e.g. how they would be selected, whether they would be paid and whether they would be experts by experience. Use of GP patient participation groups (PPGs) could also be considered (6%).
  - If patient and public representatives were part of the approval process then they should include people from diverse and marginalised groups (5%).
  - West Midlands SDE should be monitored, controlled, regulated and working to the Caldicott Principles. Information needed to be confidential, with clear reporting processes and data should be stored in the UK (4%).

In summary the majority of respondents agreed there should be patient and public representation on the panel to assess data access requests but also thought it important that they had some initial training. Concern was also highlighted about ensuring everyone involved worked to the Caldicott Principles as well as GDPR compliance, with clear reporting processes.

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?

In all, 78% of respondents said they were supportive of these partnerships in some shape or form.

- 48% of respondents were generally supportive of collaborating with these partners but with considerations or concerns such as:
    - concern about collaborating with pharmaceutical companies (10%)
    - concern about collaborating with commercial analytical companies (8%)
    - apprehension about options for collaboration; the need to be reputable companies (6%)
    - 6% of respondents expressed that they did not support any collaborations, with 2% wanting to keep the information within the NHS.
- 20% of respondents were concerned about data and security including:
    - ensuring the data was anonymous (8%)
    - ensuring data was handled securely and responsibly – compliant with Caldicott Principles and legislation (6%)
    - collaborations should be governed and monitored with representation from patients and the public (2%).

Additional concerns raised by respondents included:

- collaborators making profit from the data (6%)
- transparency about what information was being used and who it would be shared with (5%).

> **"As long as it helps to get the information to improve services, but pharmaceutical companies must be able to provide assurance of security of data because I don't trust them, they're in it for the money."**

> **"What about overseas organisations? We don't want anyone being able to see any of our personal details – I think it's an important point because I don't want anyone selling anything to us."**

> **"I'm comfortable with all of them, but there could be manipulation. The NHS would have to provide us with reassurance that the information would be used correctly."**

In summary, although 78% of respondents were supportive and understood the nature of collaborations, 48% agreed with conditions. Some were sceptical about the potential for profit-making organisations such as pharmaceutical companies accessing the data for their own gain.

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

A total of 61% of respondents believed charges should be applied.

- Of the 61% believing charges should be applied, 16% of respondents believed there should be a sliding scale approach. This, they said, should depend on data use and number of records accessed, as well as the type of organisation, with charities or voluntary organisations paying less than profit-making organisations such as pharmaceutical companies. A further 8% believed only some of the partners should be charged, depending on the organisation.
- 22% of respondents were unsure, did not agree with charging, or would be happy with a small charge or donation. Some said if the data was being used for non-profit-making research, it should be made available free or for a small administrative charge and not sold for profit.
- 5% of respondents raised concerns about data security and confidentiality, which they felt needed to be addressed.
- 38% had other considerations, including:
    - if charges were applied, then the funds should be used appropriately, i.e. not for profit; either in the NHS (24%), or to develop research (3%)
    - 5% of respondents believed there should be transparency around:
        - who had accessed the information
        - why the information was needed and how it was used
        - how the funds would benefit patients or how they had been distributed
        - charges to partner organisations
        - profits made.
    - 3% of respondents felt that organisations would be more responsible with the data if they had to pay for it.
- 12% had other concerns such as distrust in the NHS growing if organisations were charged. Points raised included:
    - concerns that charging for access would ultimately cost patients through organisations charging the NHS more in the long run
    - that the NHS should not fund the SDE – charges for data access should cover the operating costs.

"Should be charged as NHS cannot fund this alone, need money to be spent on care."

"As long as the money is used for the right purpose as well as the data. I would like to see a report or something at the end of each year to share how many have requested access and how many were approved, also what studies the info was used for."

"I'm not happy for companies to be charged. These companies will pass the charge on to members of the public in one way or another. For example pharmaceutical companies will make the drugs more expensive to access."

> **“Transparency around the health information is required (e.g. charges to partner organisations, profits made, why is the information needed, who has accessed the information, how the funds benefit patients, how the information was used, how the charges have been distributed within the NHS).”**

In summary many respondents believed that charges should be applied, particularly to profit-making organisations, with suggestions of sliding scale charges depending on the organisation requesting the information. Some respondents also felt it depended on where the money was going to be used and they would prefer for it to go back into the NHS and not used for profit.

It was suggested that charging might lead to more distrust in the NHS.

Should people who do not wish their health data to be used be given the option to opt out?

There were many reasons why people wanted their health data to be made available, but there was strong support for giving people the choice of opting out.

When respondents were asked if people who did not wish their health data to be used in this way should be given the choice of opting out, 92% of people agreed or strongly agreed, with 3% disagreeing. One person disagreed because they believed it should be an ‘opt in’ rather than ‘opt out’ situation. A further 5% did not have a strong opinion, neither agreeing nor disagreeing.

7. Findings from questionnaire at high-footfall events and online engagement

From July to November 2024, a questionnaire was promoted through six high-footfall, face-to-face events and locations, websites, stakeholder communications and a social media campaign. The questionnaire received 186 responses.

The questionnaire (see Appendix B) was used to capture feedback at the six high-footfall events and venues as time available to speak to people in such situations is limited. To view the demographic data of respondents, see Appendix C.

The questions aimed to understand how the public felt on the issues of:

- bringing together people's health and care information from across the region into a secure data environment to improve treatment and health
- bringing together people's health and care information from across the region, so people who plan health and care services might use the SDE to learn if those services were still right for local people
- the types of people who would access the data to improve health and care
- the types of settings where data would be used
- charging organisations for accessing health data within the West Midlands SDE
- having the choice to opt out from health and care data being available to access through the West Midlands SDE.

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

We asked people if they had any further comments about the West Midlands SDE.

Some respondents mentioned other areas that should also be considered. These included:

- Ensuring data in the SDE was kept confidential while improving health services for the future.
- That all NHS teams should have free access to the West Midlands SDE as this could help improve all services. Charges should only be applied to those external to the NHS.
- Whether the use of data could be extended to opticians and dentists as they might find the data helpful.
- Providing greater awareness to the over-70s about the benefits of using data for research through the SDE, how data would be kept safe and how this had helped services so far. This, it was said, would gain trust and an understanding as this age group were very concerned.
- That under no circumstances should data be shared with private companies, regardless of any health benefits specified.
- That patient data within the West Midlands SDE should also be shared with local authorities to support safeguarding of patients.
- That current data-sharing methods should be improved so patients did not need to repeat information several times to different health specialists.
- That further information about the opt-out process needed to be given so people could fully understand and make an informed decision.
- Not wanting, or feeling confident about, the use of under-16s data.

In summary, the majority of respondents – 96% – agreed with bringing together people's health and care information from across the whole region into the West Midlands Secure Data Environment, while ensuring it was safe and only allowed to be accessed by trusted organisations. Fewer than 10% of people disagreed with all statements and would not want their data used in this way under any circumstances.

8. Findings from patient, public and stakeholder engagement event – 27 January 2025

The invitation to this event was extended to a range of groups and individuals from different communities as well as those who support communities across the West Midlands. The event was attended by people from a cross-section of the community, including those from the voluntary sector, disabled people and representatives of community groups.

The attendees sat at tables of three to five people. Throughout the day, they were asked to share their views by discussing different aspects of the West Midlands SDE based on a series of questions. This section summarises the results of these discussions.

8.1. Workshop 1

This was introduced by explaining the importance of transparency to the programme as well as the need for people to care about data for research.

Questions to stimulate discussion included:

Q1. What will make people feel the SDE has been totally transparent?

Most people believed in the sincerity of the SDE being set up for the public good and were surprised that health and care information was not already being used for 'useful purposes'. They felt people did care about their data and said more communication with the public was needed so they could make informed decisions and understand the implications of their data being used. It might also, they said, encourage more people to allow their data to be used. They said a target number of people should be included in the engagement plan, for instance, a percentage of the West Midlands population, and there should be face-to-face engagement work across different community groups.

There was a discussion about the language being used, part of which focused on the term 'research'. There was a feeling this might not be the most helpful word because, it was said, people tended to think they needed to take action, such as having clinical tests or answering questions. One suggestion was to use the term 'service improvement' and then be transparent about whether this was to improve clinical outcomes or service planning.

There were ideas such as using the NHS app to send out messages, with a clear focus on people. The example of the organ donation opt-out was given when it was heavily advertised in the media.

Some people felt being digitised was ‘dehumanising’, saying that people needed to be kept informed and that it was the role of a health service to communicate this clearly. They felt people would want to know what the benefits were of their health information being used – for themselves, their families and neighbours.

There was a discussion about people needing to know what the data sharing agreements were, how data would be accessed and what it would look like. It was felt some people would opt out because they did not know these things.

There were a number of discussions about mistrust, and concerns were raised about how the data might label diverse communities. An example was given about how children could be targeted because of a narrative that might emerge from data, vilifying some communities due to certain conditions. It was said messaging needed to be clear about organisations using the data being open minded and doing so in the best interests of the public.

There were suggestions of face-to-face engagement work across different community groups, explaining the rigorous process anyone wanting to access data through the West Midlands SDE would have to go through, with examples of the questions they would be asked.

One group had experience of working with Gypsy, Roma and Traveller communities. They said that, similar to other ethnic groups, there were nuances within the communities that were not picked up when coding on GP systems. They were concerned that using this type of data only would generalise issues across communities.

A delegate speaking as a deaf person felt that deaf people were a relatively small cohort of people, so might be concerned about their personal data being made available to use in case it was identifiable. They believed a lot more work needed to be done to engage with the deaf community in simple accessible language so they had a better understanding of how their data was being used.

Summary

The general consensus was that the West Midlands SDE was worthwhile but there needed to be more clarity on the process and data sharing agreements. Messaging should include clear answers to questions around what the data was being used for, what the end result would be and how it would improve the life of patients.

Concerns were raised about data causing certain communities to become vilified, so delegates said it was important to demonstrate how information had been used to benefit communities. They said if the messaging was appropriate and positive outcomes were demonstrated, it was more likely people who were initially sceptical would allow their data to be used.

Q2. When will we know we have done enough to achieve transparency?

In response to this question most people believed the SDE would continue to evolve and the need for transparency would be constant.

To achieve transparency, attendees felt clarity on the intentions of researchers should be available to the public. Currently they felt this was not the case and were concerned that if something went wrong there would be repercussions. Once people had an emotional response to something, they said, it would be hard to change minds. Their conclusion was that the SDE's process for accessing data needed to be set up in the right way from the start.

They said it would be good to find out why people had chosen to opt out. Reducing the opt-out rate and bringing on board some of the more critical people through engagement or communications that addressed the issues would demonstrate that the messaging was right.

One group felt people would be able to make the connection between better services and the SDE when they saw the SDE being given credit for genuine improvements. They also said there needed to be a way of sharing data between SDEs across regional borders to support people who travelled to other areas.

Another group said enough would have been done when patients and the public were actively engaging with GPs and more widely across the region about use of their data and the opt-out process.

It was suggested the West Midlands SDE could provide information to the region's integrated care boards, tailoring it based on demographics to identify gaps in the data so ways could be found to make sure it more accurately represented the population.

They felt it would help if details of what NHS trusts were doing with data were continually published, along with evaluation and the improvements made as a result.

Putting measures in place

Polls or surveys across different communities were suggested as a way to ensure people felt engaged, informed, confident and happy about the SDE. One person said even if the public did not care, the SDE team needed to be confident local people were engaged.

It was felt there was a need to measure people's awareness and opinion of the West Midlands SDE and others around England, particularly in the case of key stakeholders. People said some indicators could include whether people were actively reviewing the data privacy notice and videos, and whether further engagement was needed when the number of people engaging with the SDE reduced.

One group said many people were unaware of the number of research projects that take place. They suggested the SDE could share success stories through social media platforms or a website to keep people updated.

Summary

Most participants believed the process should continually evolve and not have a definitive end point. They said it should be constantly monitored for improvements to encourage those opting out to opt back in. Participants were adamant throughout that the key was to ensure outcomes of studies were shared, including any resulting reduction in inequality.

There was a further thought that the SDE should work with key stakeholders to support engagement with different communities, such as Sign Health for the deaf community and others. This, it was said, would provide opportunities to demonstrate the impact of data use through the SDE.

Q3. What will make people care about data for research and service planning?

There were strong discussions about the need, as a priority, to develop clear lines of communication between the SDE and local communities about how data will be used, its benefits and limitations.

The general themes across the groups included demonstrating the impact of the research using data from the SDE. One example was improvements in healthcare outcomes for individuals and their families, along with better access to professionals, which it was noted would support people's mental as well as physical wellbeing. These were seen as major motivators for people's acceptance of their data being used. There was hope this use of data would help relieve the pressure on GPs. Macmillan Cancer Support was held up as an organisation that used hard-hitting examples and had many support tools for patients.

There was a discussion about the concerns of deaf patients, some of whom have multiple disabilities that could make it difficult for them to understand information from the SDE. People said communication needed to be accessible in ways that took this into account and that it was important to consider support for those with more complex needs, such as those who might be deaf, blind and have learning disabilities.

There was a feeling that having all communications signpost to the website would exclude those deaf patients who were digitally excluded.

People also said not enough information was available, particularly for those in diverse communities.

One group said people already thought data was used in this way and that it would be helpful if outcomes were shared.

Most groups believed patients would find it useful to see how many applications had been received asking to use data through the SDE, including the name of each organisation, why they wanted access, for how long and how it would help.

One group felt the SDE should not only highlight the benefits of data use for major health issues such as cancer. Doing the same for other healthcare concerns would allow people to care more by seeing potential improvements for their own problems.

Educating NHS staff was seen as important to ensure they talked with patients about the SDE in a clear and consistent way. Staff they thought most suitable for this training included GP receptionists due to the amount of patient contact they had.

Having two ways for people to opt out of allowing their data to be used for research and planning was seen as strange. People questioned whether patients would understand the difference between the national data opt-out and the local data opt-out. They wanted to know why two sets of information were collected. They also raised the question of whether children's data was available to use through the SDE and, if so, who gave permission for this.

Summary

Positive outcomes such as reducing waiting times and broader improvements in healthcare were considered potential incentives for people to be happy about their data being used through the SDE.

Participants believed the results of data use through the SDE needed to be shared, using accessible messaging to demonstrate inclusivity for all communities.

8.2. Workshop 2

Using different types of data in the SDE

Q. What are your views regarding the use of unstructured data and structured data?

The overwhelming response to whether structured or unstructured data should be used was that both have their place and are equally important. It was felt both also have strengths and weaknesses.

> **“We should be able to look at data holistically and have enough resources to be able to decipher what data is useful from a structured and unstructured perspective.”**

A weakness of using unstructured data was believed to be potential breaches of confidentiality. It was felt there was no structure to prevent this and there were questions around whether smaller communities could be identified.

The use of artificial intelligence (AI) was discussed in relation to data. Most participants felt that, although AI was a useful tool, it needed to be used with care as it could make mistakes and was still in its infancy. They felt AI was only as good as the data provided, so if notes and other information were not accurate, clear and concise, there was the potential for mistakes.

Although there were concerns, they felt the need to have an implementation plan and good governance structure for the use of AI. Some participants felt implementation of AI should be a priority and aligned with improving patient outcomes.

Summary

Although each group felt the use of either type of data could be justified, depending on the project, the discussions did not indicate a detailed understanding of the subject so this might be an area for potential further clarification.

AI came out as the main topic of discussion during this workshop, with concerns about the quality of data potentially leading to mistakes. However, it was acknowledged that AI had a lot to offer in terms of being able to efficiently sift through historical information.

8.3. Workshop 3

Q. How do we best prioritise which projects to support?

Participants said we should listen to what local communities wanted, including those from diverse community groups, to ensure the research projects approved by the data trust committee were relevant to everyone. They also said research practices of integrated care boards (ICBs) should be improved by using community networks. People felt there had to be a place for rare conditions as well as the more popular studies.

Some people felt projects should be supported on a first-come, first-served basis, but they understood this might not be feasible.

Participants emphasised the importance of human involvement but also discussed the benefits of using AI to develop a tool that could analyse requests – linking with existing studies and community priorities.

Questions included whether there were staff available to make such decisions and whether the SDE could advise statutory bodies for prevention.

Suggestions included:

- a central system for ICBs to submit their ideas and priorities so decisions could be made on what might be feasible

- a matrix using AI to decipher which requests should be prioritised, based on work that had already taken place
- supporting research by reimbursing groups for giving their time to provide feedback.

Summary

On this question, the main focuses for participants were around:

- ensuring projects aligned with the most important healthcare needs of the community
- how AI could support the use of data in the West Midlands SDE
- demonstrating a clear public benefit.

Q. What makes one research study higher value than others? And what is the value of projects?

Answers to these two questions have been combined as they were very similar.

Participants reflected from previous conversations that if we wanted the focus to go from hospitals to communities then funding needed to move as well. They said they were concerned that by ‘community’, the NHS meant community hospital trusts rather than the actual communities. One group said different communities might have different values or priorities. However, another felt what was of value to one community could also be to others, for instance, genomic data.

They said they would prefer access to data to be more expensive for commercial companies and free for researchers such as PhD students and local clinicians. They believed there should be an agreed, structured fee depending on the requesting organisation.

Discussing what was important to people and the impact on society and health, they said it would depend on who would benefit. They felt there should be a shift of emphasis from longevity to quality of life and asked how prevention could be improved to add value to the SDE. Better population health could reduce health inequalities and increase the value to the NHS, they said. This would enable the NHS to spend less with fewer people being ill.

Other points discussed included:

- projects that enabled more people to access services
- access to services within people’s own community, for instance, local churches, promoting prevention within the community
- awareness-raising and education from a young age about the availability of different services.

One group felt organisations such as the National Institute for Health and Care Excellence (NICE) should be able to feed into the prioritisation of research, placing projects at a higher value if connected with national NHS priorities.

Participants felt it was important for the NHS to be able to take forward findings from research, such as identified treatments. This would demonstrate to the public that work was taking place and making progress.

It was felt the value of projects might increase if more people were going to benefit, but smaller communities might benefit less. Some felt value could be linked to life expectancy and whether the study was looking to improve that.

Some groups felt organisations being asked to pay for access to data might add to the value of a project. However, it was recognised that ‘value’ did not always mean money.

Participants felt patients needed to be at the centre of research, with it being mandatory for results to go back to the community.

There was a discussion around there being value in research that resulted in something new and innovative. However, it was also recognised that researchers would not necessarily know the outcome until they were close to completing a project.

Summary

The discussions across most of the groups focused on high-value research studies aligning with critical healthcare needs within communities, being able to integrate AI, and demonstrating a clear public benefit.

They felt the broader reach and impact of a study, prevention and improving life expectancy, were factors that could increase its perceived value.

Participants questioned whether a study being new and innovative should determine value, though some noted that the outcome of research was often uncertain until near completion.

Q. What should our guiding principles be?

This question was discussed across all the groups. The following list of guiding principles was developed from their feedback.

- A strong emphasis on prevention rather than reactive treatment, with person-centred care as a priority.
- Ensuring projects improve quality of life and provide tangible benefits to communities.
- Transparency in project goals, outcomes, and impact assessment shared with stakeholders.
- Equitable access to information, and support for all communities.
- Financial fairness, including charging commercial organisations more than researchers such as PhD students or local clinicians and ensuring subsidies support voluntary sector research.
- Establishing consistency in principles across all SDEs nationally.
- Trust in decision makers to ensure research is inclusive of all population groups, including those affected by rare diseases.
- Avoidance of financial or commercial bias in research prioritisation, with mechanisms to ensure genuine intent and accountability.
- Mandatory feedback mechanisms to ensure research benefits communities and fosters a learning process.
- Emphasis on education and awareness to empower communities in understanding and engaging with research.

Conclusion

To summarise, the workshop discussions highlighted participants' key concerns and expectations, particularly around accessibility, transparency, and the demonstrable impact of data usage. There was strong support for a proactive, preventative approach to healthcare research and a focus on community engagement.

Participants were adamant throughout that the key was to ensure outcomes of studies were shared, including any reduction in health inequalities.

Financial considerations, inclusivity, and trust were recurring themes, with calls for structured frameworks to ensure fairness and long-term benefits. While some areas, such as unstructured data usage and project valuation, produced more questions and lacked extensive feedback, they provided opportunities for deeper engagement in future discussions.

Ensuring ongoing dialogue with the public and stakeholders will be crucial in shaping a secure data environment with access to richly diverse data, providing a resource more reflective of the community.

9. Points for consideration

By far, the greatest concern voiced throughout all the engagement was that of data security.

- On the question of how people would feel about allowing their health data to be used by researchers, 18% said they would agree to do so on condition they could be assured it was '100% safe and secure' and that the data would remain in the UK.
- When it came to the benefits and disadvantages, 22% of respondents expressed concerns about data security, system failure and inappropriate selling of the data.
- On collaborating with partners, 20% said they were concerned about data security.
- Regarding feelings about the NHS leading and managing the SDE, 11% had concerns or queries, mostly about data security and the NHS's ability to manage it appropriately.

In respect of the NHS charging for access to data, more than 60% said it was the right thing to do. However, some people were either not happy, or undecided.

- Among community groups, 22% said they were unsure, did not agree with charging or suggested a small charge or donation.
- 12% of respondents had other concerns, including whether charging would increase distrust in the NHS.
- 29% of questionnaire respondents said they were 'not sure' whether researchers should be charged to access data.

Other themes arising from respondents' comments included:

- wanting to be told what information from their data would be used, by whom and for which projects
- providing wider community reassurance through the availability of information about the SDE in different languages and formats
- being told how the SDE would be funded and for how long
- concern for those with mental health conditions, including whether some might not have the capacity to opt out
- wanting reassurance the SDE would lead to quicker diagnosis and development of new medicines and treatments.

9.1. Conclusions

From this report it is clear the majority of people are positive about the development of the West Midlands Secure Data Environment. Most welcome the benefits it can provide for the region's population.

However, there are clear concerns about data security. People require the reassurance that, if their data is to be used through the SDE for research, it will be safe and free from exploitation. There is also a strong belief that people should be able to opt out if they wish to do so.

Close to two-thirds (61%, community groups and 63%, questionnaire respondents) agree with charging for access to health data held by the NHS, although there are differences of opinion on what this should look like. Others are undecided or see it as a potential issue.

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9.2. Recommendations

The recommendations of this report are:

1. Continued communication with patients and the public.
    - For the success of the West Midlands SDE, people need to feel confident about their data being used through the SDE for research and reassured that they have the choice to opt out should they wish to do so.
    - As the SDE develops, ongoing communication within the region will help build further awareness and also knowledge of the benefits delivered. Continuing to communicate with patients and the public is, therefore, recommended to promote further understanding, trust and appreciation of the SDE's value in terms of health and care improvement. Any future communications plan should have input from patient and public representatives as has been the case so far.
2. Continued engagement with patients and the public.
    - The Patient and Public Advisory group (PPAG) has made valuable contributions to the communications and engagement programme, the SDE's workstreams and governance. It is recommended that PPAG continues with this role.
    - Data Trust Committee members have also been invaluable to the work of the SDE, reviewing applications from researchers and ensuring their access and use of data is in the public's interest. It is recommended the DTC also continues.
    - Patient and public input has been critical to understanding the views of local people and will inform the continuing development of the SDE. It is recommended there is ongoing engagement across the communities of the West Midlands to maintain interest and community involvement, promoting and adding value to research undertaken in the region.
    - People from Asian communities told us the West Midlands SDE was important for increasing their representation in research. It is recommended that communication and engagement continue with community groups to ensure data available for research through the SDE is as diverse as possible to help address health inequalities.
    - It is recommended the SDE engages further with young people to increase the currently limited amount of feedback from this age group. It is also recommended young people are included in the research approval process as part of the Data Trust Committee or by developing a youth forum.
    - We also recommend 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.

3. Based on the findings, the following topics are recommended for future engagement.
    - How can we reassure people their data being used for research through the SDE will result in better health outcomes?
    - How will researchers be charged for accessing the West Midlands SDE and how will any profits be used?
    - Who are responsible partners?
    - Do we need to ask West Midlands SDE applicants how proposed research fits into broader research and commercial strategies?

10. Appendices

10.1. Appendix A – Questions to community groups

1. How would you feel about researchers using your health information for research through the West Midlands SDE?
2. What do you feel would reassure you and others and help people feel confident about health data being available to use through the SDE?
3. How reassuring is it that the NHS is leading and managing the West Midlands SDE?
4. What would you see as the benefits or disadvantages of health information being used for research?
5. Do you think patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects?
6. 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?
7. What are your thoughts and feelings around charging organisations to access health information for research purposes?
8. Should people who do not wish their health data to be used be given the option to opt out?

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10.2. Appendix B – Questionnaire

Your views are important to us. People living in the West Midlands are essential to informing the development of the West Midlands SDE. Please take a few minutes to complete the questions below:

How far do you agree or disagree with the following:

1. It is important to bring together people’s health and care information from across the whole region into the West Midlands Secure Data Environment **so that, working with the NHS, researchers can investigate ways to improve treatment and health.**

   ☐ Strongly agree
   ☐ Agree
   ☐ Neither agree nor disagree
   ☐ Disagree
   ☐ Strongly disagree

2. It is important to bring together people’s health and care information from across the whole region into the West Midlands Secure Data environment (SDE) **so that people who plan our health and care services will be able to use the SDE to learn if those services are still right for people living in our local communities.** Having that understanding will show them what might need to change, and how.

   ☐ Strongly agree
   ☐ Agree
   ☐ Neither agree nor disagree
   ☐ Disagree
   ☐ Strongly disagree

3. It is important that the West Midlands Secure Data Environment will only be **used by the right people** – researchers and health and care service planners wanting to improve health and care.

   ☐ Strongly agree
   ☐ Agree
   ☐ Neither agree nor disagree
   ☐ Disagree
   ☐ Strongly disagree

4. It is important that data in the West Midlands Secure Data Environment will only be used **in the right way** – in secure and controlled data settings.

   ☐ Strongly agree
   ☐ Agree
   ☐ Neither agree nor disagree
   ☐ Disagree
   ☐ Strongly disagree

5. Organisations applying to access health data in the West Midlands SDE for research **should be charged a fee** to do so (to cover costs for the SDE and feed any surplus back into the NHS).

   ☐ Strongly agree
   ☐ Agree
   ☐ Neither agree nor disagree
   ☐ Disagree
   ☐ Strongly disagree

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6. It is important that people who do not wish their health data used for research through the West Midlands SDE are **given the option to opt out**.

☐ Strongly agree
☐ Agree
☐ Neither agree nor disagree
☐ Disagree
☐ Strongly disagree

7. I would like the opportunity to discuss in detail at a face-to-face engagement event aspects of the West Midlands SDE. These events could take place across the West Midlands at various times.

☐ Yes (please email us your contact details)
☐ No

8. If you answered yes to question 7, please tick as many topics as you wish from the list below that you would like the opportunity to discuss in detail:

☐ Secure storage of data
☐ How data will be accessed
☐ Charging for access to data
☐ Opting out
☐ Other – please specify

9. Do you have any further comments about the West Midlands SDE?

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10.3. Appendix C – Questionnaire respondent demographics

Demographic breakdown of questionnaire responses

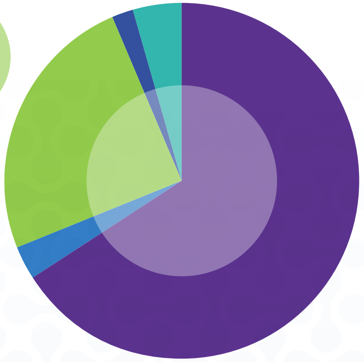
71% of respondents were female, but other genders were represented including males, trans man, non-binary and gender non-confirming

60% were married

17% single

8% lived with a partner

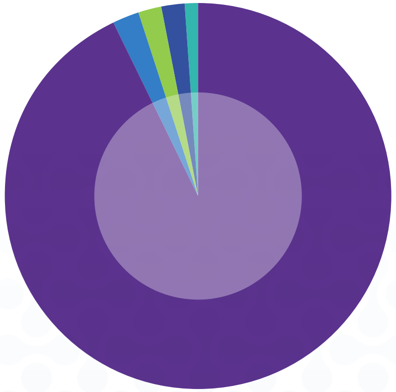
34% were carers for other people (children or adults)



- ● **62%** had no level of disability
- ● **3%** had a mental health need
- ● **23%** had a physical or sensory disability
- ● **2%** had a learning disability
- ● **4%** had a long-term illness/condition

The majority of respondents identified as white British

Just over **6%** described themselves from another background



- ● **93%** White (British/Irish/Gypsy or traveller/Other)
- ● **2%** Asian/Asian British (Indian, Pakistani, Bangladeshi, Chinese, Other)
- ● **2%** Black/Black British, African, Caribbean, Other
- ● **2%** Other ethnic group
- ● **1%** Preferred not to say

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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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