



NewsBytes 2024/25

April 2025

West Midlands Secure Data Environment is open for business



The West Midlands Secure Data Environment (SDE) is fully operational.

Welcome to this special edition of NewsBytes in which we reflect on our journey so far and look ahead to exciting future possibilities.

Read how the West Midlands SDE has progressed to being one of the first regional SDEs to become fully operational. See how we took our public on this special journey and continue to involve them in everything we do.

Learn what we have achieved to be able to offer access to health data for research, for over 90 projects currently in development.

West Midlands Secure Data Environment Programme Team

Looking back – 2023 timeline

- June 23 First edition of regular NewsBytes newsletter to inform data users / contributors.
- August 23 IG and Ethics workstream held.
- September 23 SDE national network event in Oxford.
- October 23 The West Midlands SDE Patient and Public Advisory Group (PPAG) meets for first time.
- October 23 Health Data
 Research Innovation Gateway publishes data pipelines first step towards a 'single front door'.
- December 23 West Midlands
 SDE hosts national meeting.

February 24 - CAG and REC approvals

The Confidentiality Advisory Group (CAG) and Research Ethics Committee (REC) have approved the West Midlands SDE to proceed (with minor adjustments) to develop the SDE for the use of data for research.

Approval was granted following a great deal of work from our team, with support from PPAG. The commitment to public involvement was noted by the CAG.

This means the West Midlands SDE can now move to the next stages of development and the piloting of the flow of data through the West Midlands SDE.

August 2024: Data-driven prostate cancer approach



In August 2024 the West Midlands, North West and London SDEs began working with charity Prostate Cancer Research.

The major research project aims at improving diagnosis, treatment and care for prostate cancer patients.

Find out more on our website.

November 2024: Brochure release



In November 2024 we released a brochure for data users and data contributors.

The document summarises the West Midlands SDE, how it works, the services we offer and how users can access them.

It is on our <u>website</u> as part of a suite of materials on our resources page.

January 2025: Driver projects awarded funding

After receiving expressions of interest from a variety of project teams, grant funding was awarded to 12 driver projects in January 2025.

These projects, selected from 30 applications, each demonstrated clear potential for public and patient benefit. These include:

- Developing an automated evaluation pipeline to identify the effectiveness of digital interventions in acute care: A pilot study assessing inequalities of DERM.
- Investigating causal associations between polypharmacy and patient falls: a primary and secondary care study using routinely collected health data.
- Exploring the health needs of domestic abuse survivors: A pilot for integrating West Midlands police data into the NHS Secure Data Environment.
- Automated triaging system using natural language processing for identification of patients with acute aortic syndromes from radiology reports: external validation.
- COAST (Collecting and developing Adult Social care data for research).
- Developing a national musculoskeletal (MSK) audit and research database for community and primary care MSK services.

All the projects will be subject to the thorough data access requests process before launching on the platform.

In March 2025, the West Midlands SDE had more than 90 research projects at various stages on the platform.

How data flows through the SDE

Data enters onto a cloud component called the 'Junction Zone'.

When ready, data then flows into the 'Safe Haven' containing:

- Landing Zone this is the point the West Midlands SDE becomes the sole or joint data controller, and the data processor. Opt out data is removed.
- Data Warehouse where data is accrued and stored long term.
- Staging where extracted data is temporarily stored and checked before researchers access it. The data is rigorously de-identified.
- Archive the long-term storage area for all data sets.

This process is followed every time new data flows through the West Midlands SDE.

Review and approval of Data Access Requests

All potential users of data on the platform need to go through a data access request process.

This ensures the data request and requester meet requirements in line with the Five Safes Framework. It also identifies early on whether the West Midlands SDE can deliver what researchers need.

The amount of time the process takes will depend on each individual request, based on the level of complexity involved.

This process was designed following national guidance and previous work and has been in place since August 2024.

As part of this process, requests require recommended approval from the Data Trust Committee.

Following this process to release data for research ensures the West Midlands SDE support secure access to data for innovative projects, while at the same time being transparent about what we are doing and why we're doing it

If you have any questions about data access requests or have a research idea you would like to discuss, please email <a href="https://www.wmsnew.com/wmsne

Development of Privacy Enhancing Technologies (PETs) to support ongoing research

UHB technical experts have been refining the PETs used on the West Midlands SDE for around five years.

PETs are software tools that take patient data and strongly de-identify it.

As a result, we can de-identify both tabular and image data safely and quickly. This means spreadsheets of patient data and images (such as MRI, CT and X-ray scans) can be processed for research.

Everyone's views count

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

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

Listening to local people

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

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

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

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

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

Read more in the Summary Engagement Report on our website.



Watch our PPAG vlogs

Throughout 2024/25 we have produced a series of vlogs to showcase PPAG's work.

The vlogs give viewers an insight into the diversity and experiences of the PPAG members and the variety of areas they were asked to contribute to. The vlogs gave the PPAG members opportunity to ask questions on behalf of the public they represent.

Watch the vlogs on our website.

Engagement activity



2,017 Stakeholder database contacts



Dedicated Patient and Public **Advisory Group 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