

West Midlands Secure Data Environment NewsBytes

April 24

Welcome to the latest edition of NewsBytes – the internal stakeholder newsletter of the West Midlands Secure Data Environment (West Midlands SDE).



In this edition, read about how data is managed through the West Midlands SDE, the national public engagement plans and the next Health Data User Group webinar.

If there's anything you'd like us to feature in future editions, or you have something related you think would be of interest to our readers, please [email the programme team](#).

How data is managed through the West Midlands SDE

Researchers using the West Midlands SDE have powerful data at their fingertips.

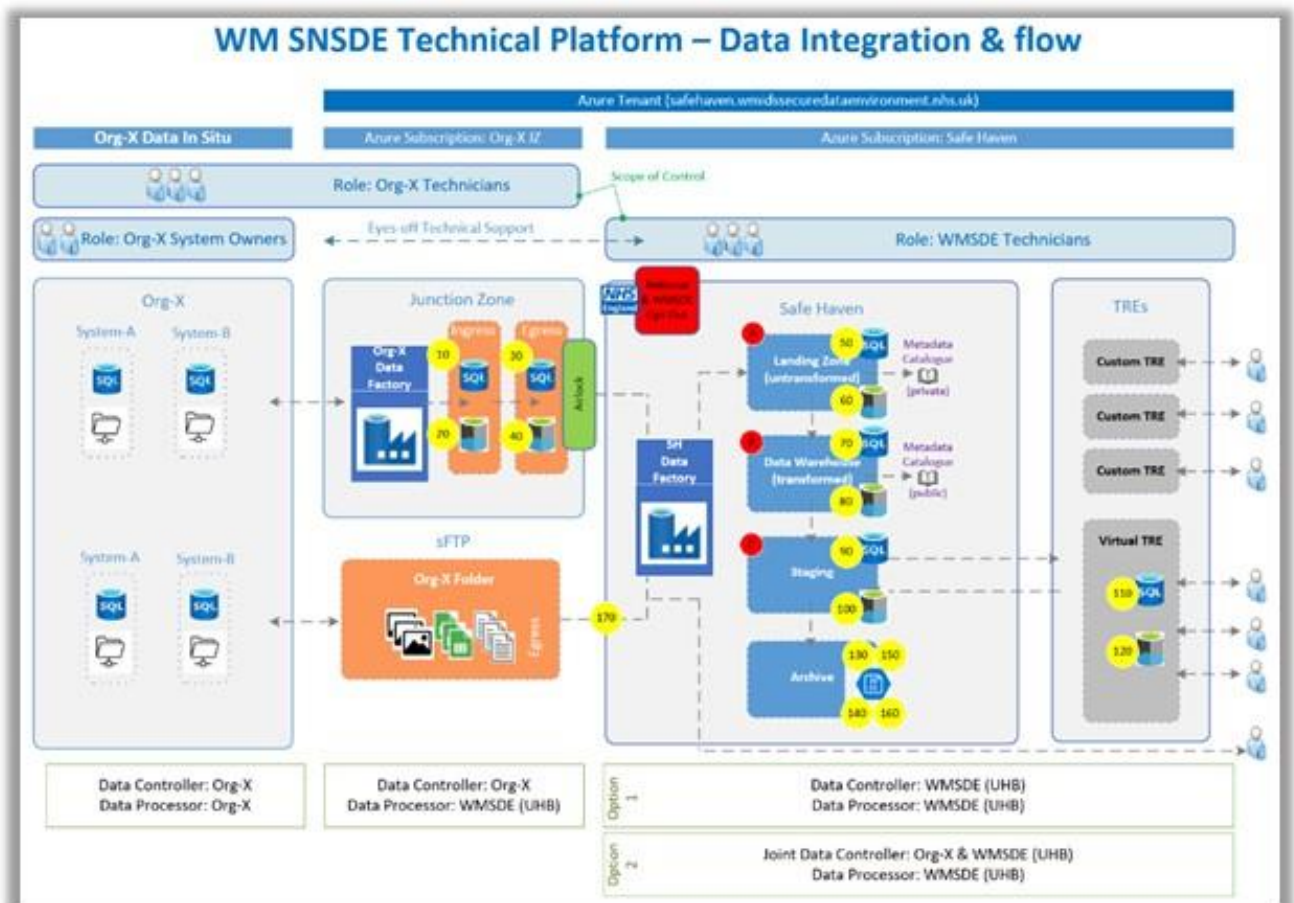
Here, West Midlands SDE Technical Lead Stephen Perks talks us through the processes involved in securely cleansing, managing and providing access to the data.

How the data flows

As data moves through the West Midlands SDE, it is standardised and de-identified to ensure researchers have high-quality, safe data to work with.

This diagram shows how this works:





Firstly, providers work with the West Midlands SDE team to enter data onto a cloud component called the '**Junction Zone**'. Providers control the Junction Zone via a secure encrypted gateway.

When ready, data flows from the Junction Zone into the '**Safe Haven**'. This is where the West Midlands SDE team starts to work with the data.

There are several areas within the Safe Haven:

- **Landing Zone** – is where data arrives after being submitted for research by data providers. This is the point the West Midlands SDE becomes the sole or joint data controller, and the data processor. Patients who have opted out of their data being used for research are identified and their data is removed.
- **Data Warehouse** – is where data is accrued and stored long term, building strong potential for research. The West Midlands SDE team standardises and links the data – the process of matching a patient's records across multiple events and organisations – to provide a more complete picture for potential researchers to work with.
- **Staging** – is where data extracted from the Data Warehouse is temporarily stored and checked before researchers can access it. The data is rigorously de-identified to prepare it for research. Data is only extracted for access requests that have been

approved by the Programme Team and the Data Trust Committee. Only the data needed for each approved request is extracted.

- **Archive** – is a long-term storage area for all data sets researchers have been given access to. This allows the data sets to be reproduced in future, if necessary, because once researchers finish their work, it is removed from the access platform.

This process is followed in full every time new data enters the West Midlands SDE.

If researchers are approved to access data that is already in the West Midlands SDE, the same extraction and quality checking processes still happen for each request.

Research access

A variety of tools and resources are made available to support researchers working with the data in the West Midlands SDE.

Depending on the kind of research being undertaken, there are standard and bespoke options for more complex and intensive studies.

Accredited researchers are provided with access to data on the West Midlands SDE. They are prevented from taking data off the platform by an “airlock” system.

Researchers can take the results of their analysis off the West Midlands SDE platform. This type of output is checked first by the West Midlands SDE team.

Progress update

Stephen’s Technical Design team is currently working across 12 projects at various stages of this process, with many more planned to follow.

Researchers from the University of Birmingham will soon start working on the West Midlands SDE. They will be looking at maternity data for a study using the data extraction for epidemiological research (DExtER) tool.

If you want to find out more about the Technical Design team’s work, please [email the programme team](#).

PPI, communications and engagement workstream update

Patient and Public Advisory Group

We have now held five Patient and Public Advisory Group meetings. The April meeting covered:

- a presentation from Guy Smallman, Commercial Workstream Chair
- update on recruitment to the Data Trust Committee
- plans for a focus on governance at August’s PPAG meeting
- ongoing support and involvement for members to reach out to new groups to support the West Midlands SDE.

We want to continue to create a diverse PPAG that represents the voice of all members of the community, so please do get in touch if you would like to join.

If you would like to know more about how data is used for research, have a question, or want to engage and get more involved, we would be delighted to talk with you.



- To find out more about getting involved, please email: mlcsu.involvement@nhs.net.
- Or complete our online application by scanning the QR code or by visiting <https://nhs.welcomesyourfeedback.net/nq7mf2>.
- To request a paper version of the application, please email mlcsu.involvement@nhs.net.

Focus Group for future NewsBytes format and content

You may not realise but we are now a year on from the first edition of NewsBytes. This means it is time for a review so we are looking to hold a virtual focus group for recipients to let us know what you think of it and how we could improve the content.

The focus group will be a one-off workshop lasting one hour and will take place late May/early June. If you are interested in taking part, please [email the programme team](#) by 5pm on Monday 20 May.

Large-scale public engagement on data

NHS England and the Department of Health and Social Care will be rolling out a large-scale public engagement campaign on data in May.

There has been a strong response so far, with more than 1,000 people applying to be part of the deliberative events. The 'Thinks Insight & Strategy' team is currently shortlisting those applicants.

To ensure true national representation of the population, 12 locations have been selected across England to host the events. The 12 locations are split into three cohorts (four locations in each cohort).

Each cohort will discuss specific topics relating to the use of data, with events taking place from May 2024 through to February 2025. The events will be face-to-face and happen over three days.

The details are as follows:

Cohort	Locations	Topics for deliberation	Timelines
One	Sheffield North London Canterbury Plymouth	Principles of data use and access	May – July 2024

Two	Leicester Liverpool South London Portsmouth	The opt-out landscape	August – October 2024
Three	Newcastle upon Tyne Birmingham Norwich Oxford	Future-facing issues	November 2024 – February 2025

Representatives from the West Midlands will be invited to attend Cohort three, between November 2024 and February 2025, to deliberate future-facing issues.

In addition to the face-to-face events, the campaign will also include:

- inclusive engagement with community/faith/patient groups
- a deliberative survey.

NHS England and the Department of Health and Social Care are working closely with regional SDEs to ensure the national campaign aligns to what is being done locally. Steven Blackburn (PPIE workstream lead) and Charlotte Wonders (Communications and Engagement workstream lead) are representing the West Midlands SDE in these discussions.

We will update you with developments and outcomes as they progress.

Health Data User Group webinar – Wednesday 19 June, 11am-12noon

Following the success of the Health Data User Group winter webinar in February, a further webinar will be hosted on Wednesday 19 June from 11am to 12noon, providing the latest updates on NHSE’s Data for Research and Development Programme.

An interactive agenda will provide an opportunity to go ‘behind the scenes’ to understand how the user journey will work in practice. Attendees will be able to take part in deep dive sessions that match their interest.

If you would like to join the webinar session, please sign up [using this Microsoft form](#). All interested parties will be sent the event link and agenda when they become available.

HDR UK news

HDR UK and GA4GH form strategic partnership

HDR UK and the Global Alliance for Genomics and Health (GA4GH) have announced a new partnership to collaborate in the wider health data space. It is hoped the new partnership will learn from global partners and promote the adoption of health data-related standards around the world. Read in full on the [HDR UK website](#).



HDR UK welcomes new board member

Professor Junaid Bajwa has joined the Non-Executive Board of Trustees. Junaid is the Chief Medical Scientist at Microsoft Research and is a practising GP in London. Read more on the [HDR UK website](#).

HDR UK Midlands Annual Conference – 13 June 2024

HDR UK Midlands is hosting its annual conference in Nottingham on Thursday 13 June, from 10am to 4pm.

The face-to-face event is aimed at clinicians, researchers, data scientists, analysts, technologists and anyone else with an interest in health data science.

Senior representatives from the West Midlands SDE will be attending and we have also been invited to exhibit at the event.

To register to attend and look at the agenda, visit the HDR UK [Midlands website](#).

Get in touch



If you'd like to find out more about the West Midlands SDE, have research that could use the platform or would like to get more involved, please email us at WMSDE@uhb.nhs.uk.

If you're interested in supporting a particular workstream, please clearly mention it when you get in touch so our team can put you in contact with the right person to help.

Our workstreams

- Data trust committee
- Patient and public involvement, communications and engagement
- Information governance and ethics
- Technical design authority
- Data and data standards
- Commercial
- Digital clinical trials