West Midlands SECURE DATA ENVIRONMENT

Part of the **NHS Research Secure Data Environment Network**

NHS

West Midlands Secure Data Environment

Supporting inclusive research to reduce health inequalities

Contents

Foreword

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The West Midlands population of 6.2 million people generates vast amounts of health and social care data. This spans many different settings and types of data, from structured data such as laboratory results, to semi-structured data such as correspondence and unstructured data such as imaging.

The West Midlands Secure Data Environment's (SDE's) mission is to bring this data together, providing a unique representation of individual patients and their journey through the healthcare system: the reasons they seek healthcare, the way they access it, the care they receive, and the outcomes from that care. This is to enable discovery, catalyse innovation, and improve decisions about the care of individuals and populations. This innovative work is delivered within a strong governance framework.

Collaborating with 848 regional health and care organisations, and supported by academic institutions and other regional partners, our aim is to provide breadth and depth to the characterisation of our patient population.

By linking records across the system, we will provide information that makes sense to patients and professionals alike, reflecting the complexity and the continuity of care received and delivered.

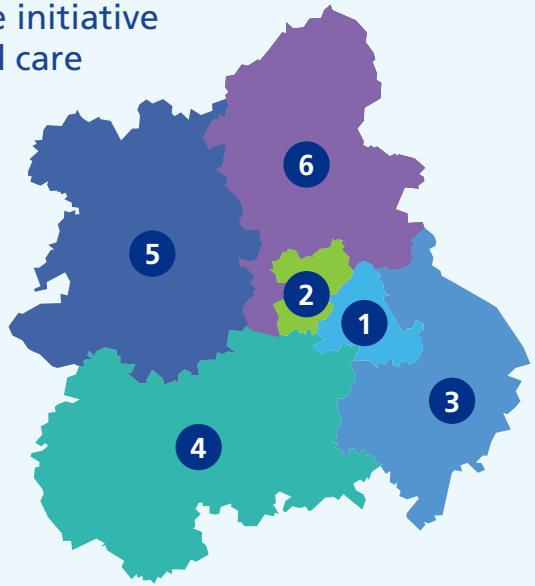
The West Midlands SDE and its collaborators offer extensive expertise in technology evaluation, clinical trials, translational studies, and real-world assessment of treatments and healthcare delivery systems. In our first fully operational year, we are focusing on developing services in three key areas: platform, data, and consultancy. We look to continuously improve the way in which data is accessed, managed, and surfaced to effectively and efficiently support researchers and innovators. The quality of these services and the diversity of the West Midlands population provide the opportunity to support research and innovation that is of national and international reach.

We look forward to continuing our work alongside researchers and innovators, and ensuring our success and improvements in the health and care of our population.

October 2024

About us

The West Midlands SDE is a West Midlands-wide initiative across six integrated care systems (ICSs):



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.

The aim of the West Midlands SDE is to offer near real-time, privacy-protecting, access to rich, linked data spanning different types, including imaging, pathology and genomics, for research and development purposes.

It is NHS-led and run, and brings together NHS integrated care boards with industry partners and local universities to build on existing collaborations and successful research partnerships.

What we offer

Three levels of service are available through the West Midlands SDE. These are aligned with the national SDE Network commercial approach, which ensures a consistent service offer and user experience across all 12 SDEs.

Platform as a Service (PaaS)

Provision of a secure research environment, including delivery of data into the secure environment, research tools, archiving storage where required and tech support. The platform provides a secure cloud environment for analytics.

Data as a Service (DaaS)

This includes any service to support the extraction, curation, linkage and storage of data in the required format, e.g. OMOP. Datasets can include structured and unstructured data, along with all associated clinical data as requested.

Consultancy as a Service (CaaS)

Research support and advisory services (data analysis and clinical support). This can be completing governance documentation, reviewing PPIE aspects of an application or providing technical support.

West Midlands SDE data pipelines

In line with the national Data for Research & Development Programme, the West Midlands SDE is making information about data it holds available through the **Health Data Research Innovation Gateway** and the **West Midlands SDE-hosted catalogue**. This is to ensure we continue to work within the FAIR (Findable, Accessible, Interoperable, Reusable) principles maintaining the quality, usability, and impact of data.

At present, the West Midlands SDE-hosted catalogue is showing datasets that have been prepared for specific research purposes or with specific ethical approvals. Additionally, the team is progressively adding pipelines of data into the SDE, including electronic health records (EHRs).

In the next few months, the West Midlands SDE will automate the ability of the metadata catalogue to show the datasets on the Health Data Research Innovation Gateway. Over time, datasets will represent increasing coverage of the patient journey across our population.

In the interim, if you do not see a data collection that meets your requirements, please direct enquiries to:

WMSDE@uhb.nhs.uk

Datasets

A publicly available metadata catalogue shows the datasets housed on the West Midlands SDE. This is continually updated.

The West Midlands SDE metadata catalogue can be shared on request.

Examples of available datasets include maternity data, pharmacy data, and specialist curated pathology data.

The datasets curated through the West Midlands SDE can vary significantly in size and complexity and the team will work through each individual request.

Requestors can request either readily available stored datasets or datasets the team can help to curate from across the region.

Use case:
Translational research in the West Midlands

Project title: AI-Driven Predictive Analytics for Hypertrophic Cardiomyopathy (HCM)

Objective:

To develop an AI-based system to improve the prediction of disease progression of Hypertrophic Cardiomyopathy (HCM), improving patient care, facilitating personalised treatment, and optimising disease management strategies.

Overview:

This project leverages advanced artificial intelligence to predict disease progression of HCM, with the potential to improve patient care and identify patients for new approaches to treatment. The project demonstrates the potential for AI to derive useful insights based upon deep phenotyping, contributing to clinical care and research.

Key highlights:

Data-driven approach: The project included data from 536 adult HCM patients (collected between 2008 and 2018) with a wide array of variables such as demographic, clinical, laboratory, echocardiographic, and MRI data, providing a rich foundation for robust predictive modelling.

Structured development process:

The project follows a systematic, multi-phase approach:

- Project initiation and scope definition
- Data acquisition, curation, and transformation
- Quality assurance and validation of datasets
- Continuous data analysis and model refinement
- Dissemination of findings and AI tool deployment.

Industry impacts:

- **Improved predictive capabilities:** The ability to more accurately predict disease progression can lead to better management of HCM and more targeted therapeutic approaches.
- **Commercial and collaborative potential:** The success of this project could pave the way for the development of new AI-driven healthcare technologies and partnerships between industry and academia.
- **Cost efficiency:** More efficient disease management may reduce the need for hospitalisations and interventions, offering significant cost savings for healthcare systems, including the NHS.
- **Research innovation:** The curated dataset and resulting AI model will provide a valuable resource for future medical AI research, driving innovation in disease prediction and management.

Our technical platform
Safe by design

Researchers using the West Midlands SDE will have access to data to complete a wide range of projects and analysis types. As data moves into the SDE, it is standardised and de-identified to ensure researchers have high-quality, safe data with which to work.

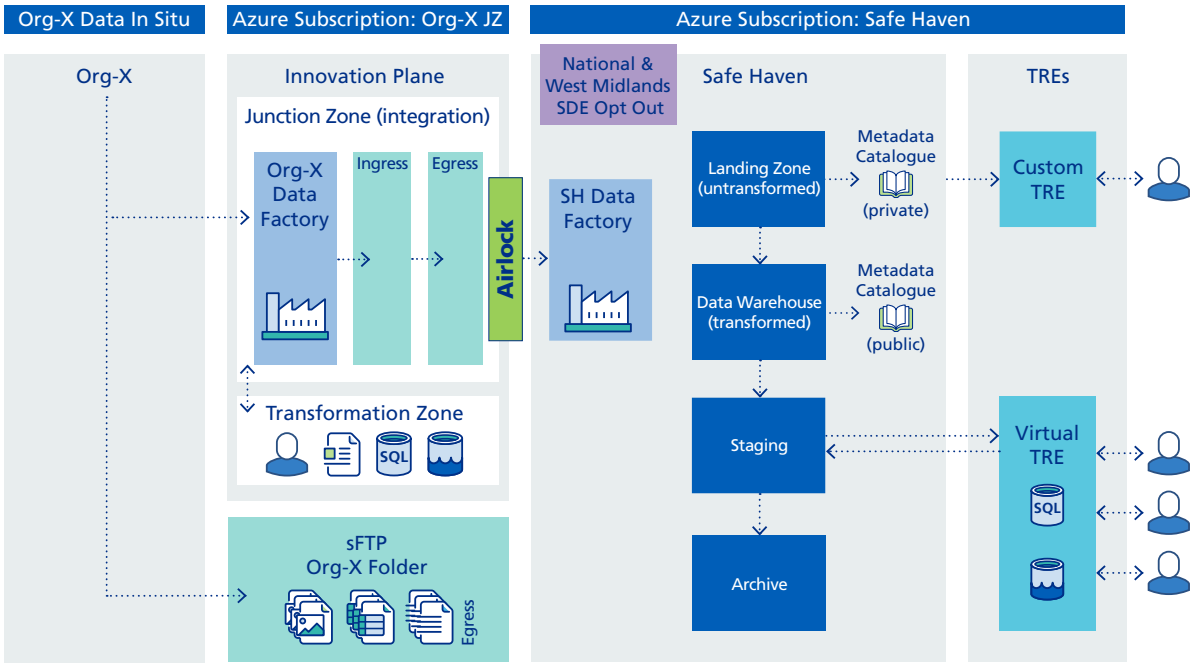
Healthcare data providers collaborate with the West Midlands SDE team to upload data to the cloud-based West Midlands SDE platform. Upon arrival, the West Midlands SDE assumes the roles of both data controller and processor. Data from individuals who have opted out of research use is removed. The remaining data is then de-identified before being stored for researchers to request. This process is repeated each time new data enters the SDE.

A variety of tools and resources are available to support accredited researchers working with this data. The SDE team helps researchers access their results, while an 'airlock' system ensures no patient data can be exported from the platform.

The team can create either bespoke or shared tenancy Trusted Research Environments (TREs), where de-identified data is made available for analysis. The team is highly flexible in staging these TREs, accommodating custom requests or using open-source tools when necessary.

The technical team is available to discuss the feasibility of specific requests. A service catalogue, detailing available services and tools, can be provided on request.

West Midlands SDE Technical Platform – Data Integration and Flow



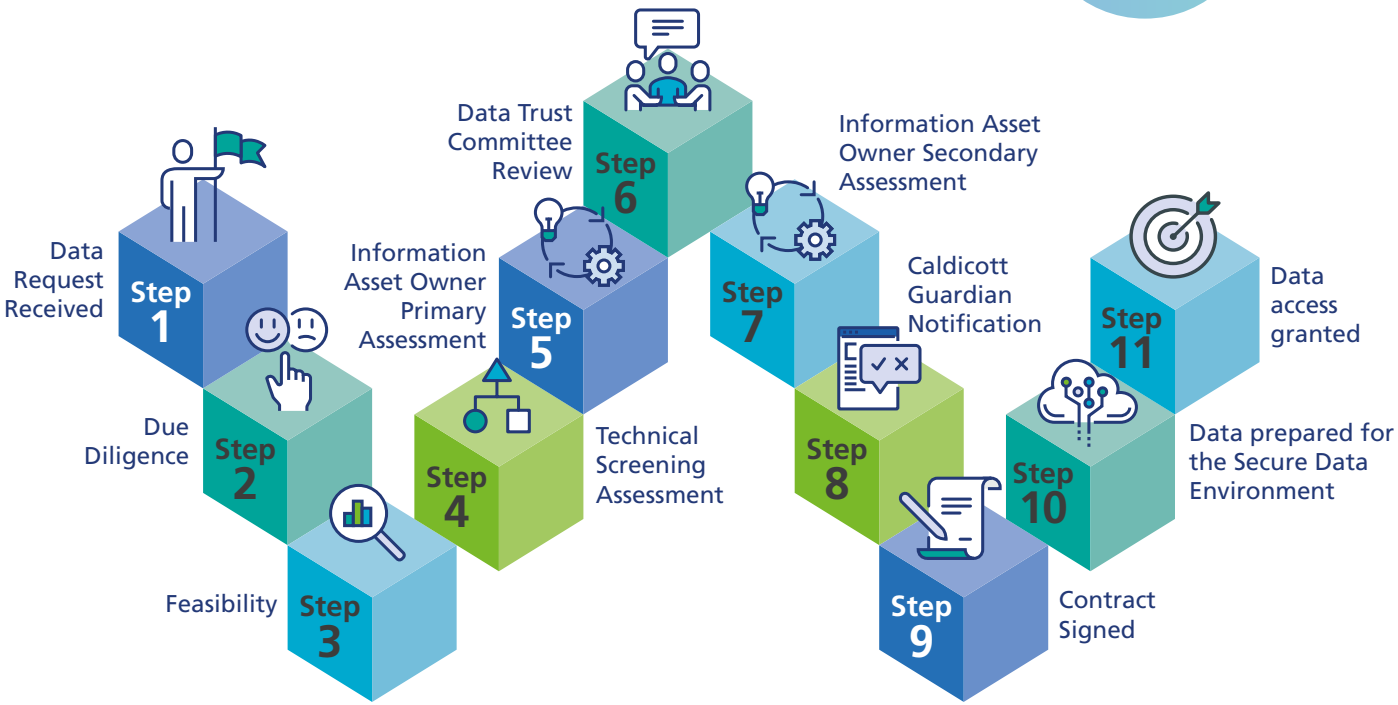
Data request process

All data requests must be submitted using a data request form. Once the form is completed, the West Midlands SDE programme team will review the request, and the technical team will assess its feasibility. At this stage, governance checks are conducted to ensure compliance with established standards and approvals.

Requests that pass these initial steps are then reviewed by the Data Trust Committee, which is responsible for making the final decision on each request. The committee ensures transparency throughout the evaluation process. A request requires a meaningful prospect of benefit to patients and the public.

Contract negotiations run concurrently with the review process. Once all steps are successfully completed, the team will collaborate with the requestors to provide the appropriate data within the required Trusted Research Environment (TRE).

Each requestor will be talked through each step and given appropriate information for planning against targets and milestones.



Cost construction

Costs are determined on a project-by-project basis, according to several variables.

Charges to include:

- **People** - environment 'spin-up', support, data wrangling and curation, any data provider charges
- **Technology** – third-party platform base cost contribution, project specific compute, storage and tool charges and sundry software licences.

These include but are not limited to:

- Availability and complexity of data (associated volumetric effort)
- Consultancy service required (e.g. West Midlands SDE commissioned analysis)
- Storage and compute platform costs (e.g. data volume, data modality, flexible compute requirements, duration)
- Intended use case(s).

Costs are variable depending on the project, but the West Midlands SDE aims to support a wide range of data requests from academic, industry, clinical, and other stakeholders.

The team has experience in establishing long-term data collaboration relationships and is committed to continuing this growth by reaching mutually agreed-upon costs, fostering innovation and maximising the impact of data analysis.

Customer view of charges

Service	What is included
Setup	The standard fee when submitting a new application, which covers application, review, legal and business costs.
DaaS - Data as a Service	The charge of the data analysts' time to extract, prepare, curate and transform the data so that it is available for use within a secure environment.
Data Cost	The data cost, which includes a cost/record of the data being supplied, any linkage costs and cost per number of data drops.
PaaS - Platform as a Service	Costs for providing a secure environment to store and analyse data as per request.
Structured Data	The secure research environment (SRE) charge, which includes setup, hosting, access costs, data storage and shared monthly services e.g. firewall.
Unstructured Data	Data storage, consumption and processing cost, customer to stipulate area e.g. hot, cool, archive.
CaaS - Consultancy as a Service	A cost is provided for the use of specialised expertise and the time associated with the effort of the request.

Visit our website

You can find out more about the West Midlands Secure Data Environment by visiting our website at:

www.westmidlandssde.nhs.uk

Enquiries to:

WMSDE@uhb.nhs.uk