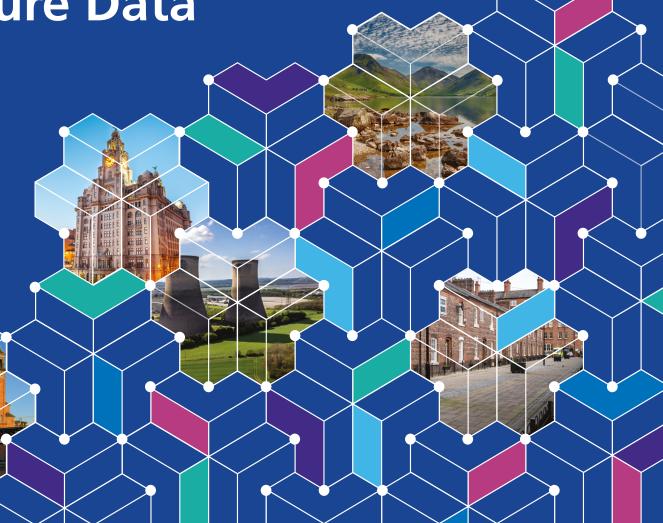




Making a positive impact on the health and care of people in the North West through better use of data





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## **Foreword**

The North West region is a combination of urban, rural and coastal communities with a population of 7.4 million people constantly generating valuable health and social care data.

In 2022, the Government announced it would invest up to £200 million to boost NHS healthcare data research. This was in line with the core recommendations of the Goldacre Review, the Data Saves Lives strategy and the Life Sciences Vision. A network of 12 secure data environments (SDEs) was developed to enhance our abilities to access data for research and health planning. The North West Secure Data Environment (North West SDE) is a vital part of that network.

The aim of the North West SDE is to provide faster and more secure access to different types of NHS data for research. By improving access to NHS data, the North West SDE will enable world class research to prevent, diagnose, and treat our biggest healthcare challenges. The healthcare data available will help researchers understand local population needs and target development of innovative solutions to areas with the greatest potential for improvement. The depth and breadth of data that will be available will help bring about major improvements in healthcare for the region. Linking data across multiple settings will also have a much wider purpose, helping researchers understand patients pathways and interactions with the health systems.

The North West SDE has been developed to offer a well-designed, joined-up service, to benefit all. It is designed to be used by NHS and public bodies, academia, life sciences, industry including MedTech and pharmaceutical companies.

Adrian Jonas
Senior Responsible Officer,
North West Secure Data Environment



Our guiding principle is to ensure everything we do is of benefit to our population. We have carried out civic engagement across the localities within the region to ensure the North West SDE is being developed in line with our population needs and desires. Our local and regional patient groups hold the North West SDE to account. A diverse group of public members sit on our data access committees and review each research project to ensure it is for public benefit.

The security and access of data within the North West SDE is of utmost importance to us. All data within the North West SDE is de-identified to protect and preserve the identity of the data subjects. And finally, but most importantly, we adhere to the Five Safes framework to ensure complete transparency and public trust.







Safe Projects



Safe Settings



Safe Outputs



Safe People

## **About us**

The North West Secure
Data Environment (SDE) is a
collaboration between three
integrated care boards covering
the North West of England.
The North West SDE teams are
a cross-regional collaboration
between NHS organisations and
academic organisations within
the North West ensuring that we
harness the power of data for
research responsibly and drive
meaningful change in healthcare
for the North West and beyond.

Secure data environments are data storage and access platforms. They uphold the highest standards of privacy and security for NHS health and social care data, when used for research and analysis. SDEs give approved users access to relevant health data for research and analysis on the platform.

The North West SDE is one of 11 regional SDEs, along with a national SDE, within the NHS Research SDE Network. These platforms will become the main route for accessing NHS data for research.



# **About our region**

The North West of England is a vibrant and diverse region known for its rich industrial heritage, dynamic cities, stunning landscapes, and strong sense of community. The North West region is the second largest SDE within the network of regional SDEs.

The North West is unique in the challenges it faces. We have some of the most deprived areas of the country with lower life expectancies. We also have some of the widest health inequalities. Some of our great cities have significant concentrations of deprivation and some of our coastal areas also experience high levels of deprivation. Demand for health and care services in the region is increasing at a greater rate than its population growth.

#### **North West SDE population**

The North West SDE covers three integrated care systems with a combined population of 7.4 million people.



NHS Cheshire and Merseyside

Population: **2.6 million** 



Greater Manchester Integrated Care Partnership

Population: **2.8 million** 



Lancashire and South Cumbria Integrated Care Partnership

Population: 2 million





# The service offer

Three elements of service are available through the North West SDE. These services are aligned with the national SDE network service provision, which ensures a consistent offer and user experience across the network.

Each research project can request a specific set of services and data assets to meet their requirements by completing a Data Access Request (DAR) form. Each element of this bespoke service will be included within the overall costs for the North West SDE service. Every project will include Platform as a Service and Data as a Service.



#### Platform as a Service (PaaS):

Provision of a secure research environment, including delivery of data into the secure environment; selected research tools, optional archiving storage where required and technical support.



#### Data as a Service (DaaS):

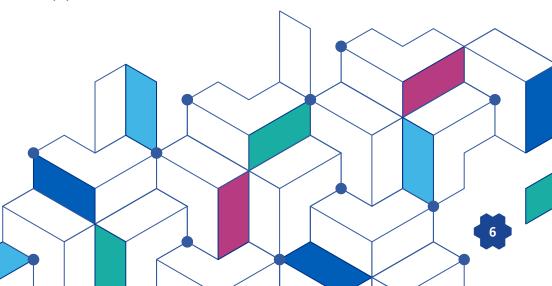
Data assets shown on the <u>Health Data Research</u> <u>Gateway</u> can be selected to address specific research questions.



#### **Consultancy as a Service (CaaS):**

Research support and advisory services from subject matter experts).

The North West SDE service offer will be in continuous development to meet the needs of our users. From April 2025 to September 2025 a series of pilot projects will be undertaken to work with users to develop processes.



North West Secure Data Environment

### **Services available from September 2025**

If you would like to discuss any of these services please contact the team to discuss your requirements.

Platform as a Service	Data as a Service	Consultancy as a Service	
<ul> <li>Cohort discovery</li> <li>Azure Secure workspace standard package</li> <li>Provision of a synthetic data set</li> <li>Data sets mapped to OMOP</li> <li>Project archive</li> <li>Re-activation of archived data for reanalysis/follow up</li> <li>Bring your own tooling</li> <li>Bring your own code</li> </ul>	<ul> <li>Provision of single data set</li> <li>Access to multiple linked data sets</li> <li>Pseudo at source</li> <li>Creation of bespoke linked data assets</li> <li>Bring your own data</li> <li>Work across the SDE Network</li> </ul>	<ul> <li>Data analysis service</li> <li>Refresh/update data</li> <li>IG consultancy service</li> <li>Research design</li> </ul>	

Clinical trials: In addition to the core three levels of service we are also developing our service offer to support clinical trials. This is an important development area for the SDE and our capacity and capability is growing all the time

- Clinical trial feasibility
- Clinical trial outcomes
- Clinical trial recruitment



### Why come to the North West SDE?

The benefits of using our service are:

#### Safe Data:

- The North West SDE offers a more secure environment where data is accessed as opposed to shared.
- The North West SDE has access to a broad range of population healthcare data (subject to IG approvals) spanning three ICSs in the North West of England, covering a diverse demographic
- We can also offer links to research infrastructure within the North West.

#### **Safe Projects**

 The application process is much easier – a single application process for England with a uniform national Data Access Request process. You do not need to apply to every organisation to request access to their data  Applications are reviewed by subject experts and members of the public to ensure public benefit

#### **Safe Settings**

 The North West SDE has been developed and is managed by the NHS. Our data analysts work within the NHS.

#### **Safe Outputs**

 Outputs from analyses only leave the North West SDE when they have been checked to ensure patient confidentiality is maintained.

#### **Safe People**

 There is a central and standard User and Organisation validation process, which is completed once to access SDEs across the network.



### **Our credentials**

The three integrated care boards as data controllers for the North West SDE, hold the Section 251 Confidentiality Advisory Group (CAG) and Research Ethics Committee (REC) approval, which provides the legal basis for using and sharing health and care data under the common law duty of confidentiality.

#### CAG and REC reference numbers:

- Cheshire and Merseyside ICB CAG Reference: 23/CAG/0033, REC Reference: 24/EE/0035
- Greater Manchester ICB CAG Reference: 24/ CAG/0034, REC Reference: 24/EE/0036
- Lancashire and South Cumbria CAG reference: 25/CAG/0020 REC reference: 25/ SW/0011

Each partner organisation is bound by a duty of confidentiality and must abide by the Data Protection Act 2018 and UK GDPR.

For further information please visit the privacy policy on our website <u>Your Privacy - North West SDE</u>

# How to access the North West Secure Data Environment?

# The SDE network will simplify the process to gain access to health data.

The SDE network supports the move away from sharing NHS data by providing a service to access data within a secure setting.

Information on North West Data Assets is available from the North West Secure Data Environment HDRUK Gateway. The gateway shows high level data assets with summary information. To fully review data assets, users must register and undertake a validation at both user and organisation level.

Once the need for access to data has been realised there is a simple process to follow outlined in the steps below:

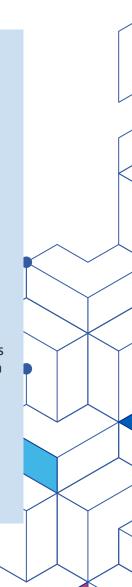


1. User and organisation registration and validation. The SDE network will conduct a validation process for users and their employing organisations. The validation process will include verifying users and organisational credentials, ensuring appropriate governance and user training has been completed.



#### 2. Data discovery:

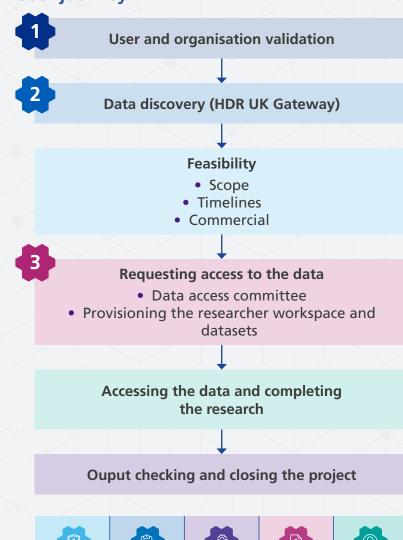
- 2.1. Identify available data assets: The HDR UK Gateway, describes all available datasets. The metadata catalogue includes details such as dataset name, description, data providers, data dictionary, access restrictions, and data quality indicators.
  - a. Learn more about the populations within each dataset: The HDR UK discovery tool will allow researchers to identify population sizes and characteristics within data assets to support the feasibility stage of the project.
  - b. Data Concierge: Once the request has been made, the Data Concierge team will work with you to understand the following components of the proposed North West SDE project:
    - i. Scope
    - ii. Timelines
    - iii. Commercials





- 3. Requesting access to the data: All projects wishing to use the North West SDE will need to go through a Data Access Request process. This will ensure the project meets the requirements of the Five Safes framework, public benefit and ethical requirements. Patients and the public are members of the Data Access Committees. They will review requests and are at the heart of our decision making
  - **3.1.** Data Access Committee (DAC): The request will be reviewed by the DAC(s) to ensure that data access requests align with ethical guidelines, data protection laws, balancing the need for research and innovation with the protection of individuals' privacy and confidentiality.
  - **3.2.** Provisioning of the researcher workspace and datasets: Projects approved at DAC will be given access to the data they requested in a secure workspace on the North West SDE.
  - **3.3.** Accessing the datasets and completing the research: The secure workspace on the North West SDE will contain a set of tools required to analyse the data. There will be the ability for researchers to bring their own, code, technology and data into this workspace, as outlined and approved in the Data Access Request process.
  - **3.4. Output checking:** When the researcher has completed their analysis, the outputs are checked to ensure they comply with the Statistical Disclosure Control policy. Only once these checks are completed will the outputs (for example, tables, graphs) be released from the secure data environment. This process ensures that we uphold the Safe Outputs element of the Five Safes framework.
  - **3.5.** At the end of a project, we offer the facility to archive a dataset to allow re-analysis, checking or production of additional outputs. Linked datasets can be archived for as long as you require through legal or funding requirements. This service will be built into the cost of the project.

#### **User journey**





Safe Data



Safe Projects



Safe Settings



Safe Outputs



Safe People

### **Data assets**

The North West SDE will offer access to data assets from both national and local sources. As we onboard different data providers to the North West SDE more datasets will become available. Datasets will be added through controlled phases allowing for the evaluation and security of those assets.

In addition to our regional offer, the HDR UK
Innovation Gateway, Health Data Research
Gateway, allows access to the metadata catalogues
from all the SDEs within the network.

#### **Tooling**

Researchers would be given access to a Virtual Machine and workspace within the Secure data environment that would contain the following standard tooling.

#### **Windows 11 Enterprise**

With the following software installed:

- SQL Server
   Management Studio
- Visual Studio Code
- R Project
- R Studio
- Python 3.11
- Anaconda 3
- Azure Data Studio
- Azure Storage Explorer
- Mozilla Firefox

- Notepad++
- Azure CLI
- Az Copy
- Microsoft Power BI
- Libre Office
- Git
- Java Runtime Environment
- Jupiter
- R Tools

#### **Data Asset Roadmap**

#### **Local assets**

Primary Care (C&M)*	Acute Local (Lancashire Teaching Hospitals)*	Mental Health (MRIC/Mersey Care)*
Primary Care (GM)**	Ambulance Local (NWAS)**	Pathology (direct from Labs)**
Telehealth	Primary Care	Acute Local
(C&M ICB)**	(LSC)**	(Alder Hey)**
Acute Local (Liverpool	Acute Local	Acute Local
Hospitals Group)**	(Manchester FT)**	(Morecambe Bay)**

#### National assets\*\*\*

SUS	Civil Registrations Births & Deaths	Medicines Dispensed in Primary Care
Community Services Dataset (CSDS)	Mental Health Minimum Dataset (MHMDS)	National Cancer Registration Service (NCRAS)
Improving Access to Psychological Services (IAPT)	Adult Social Care	E-Referrals
Elective Waiting Times	Maternity Services Dataset	Residential linkage Datasets (UPRN)
Ambulance National	Cancer Waiting Times	Alcohol Dependence

<sup>\*</sup> available for use. \*\* data asset preparation work required and subject to Data Sharing Agreement.

<sup>\*\*\*</sup> all national assets available for use subject to Data Sharing Agreement with NHS England.

# Potential uses of the North West SDE

The development of the North West SDE is aligned to six high level use cases:

- Al/Algorithm development, testing training and validation for use in healthcare.
- Clinical trial activities including feasibility, recruitment, and short-and-long term trial follow up.
- Real world studies including safety, effectiveness, cost effectiveness studies.
- Translational research including academic discovery and implementation of discovery into practice.
- Epidemiological studies including the incidence, distribution of illness and factors related to health.
- Health systems research.
   Evaluation of health systems or processes, including operational and applied research.

### Real examples of what the North West SDE could do

Below are some examples of research projects which have been undertaken within the North West.

# Virtual wards – Greater Manchester

The UK aims to have 40 to 50 virtual ward beds per 100,000 people, with Greater Manchester (GM) being well on the way to achieving its target of 1,250 virtual ward beds. The initial focus is on respiratory and frailty care, with plans to later include heart failure, children's, and end-of-life care.

The project aims to assess activity levels, patient demographics, and variations across localities. It will evaluate patient outcomes, cost implications, and system-wide healthcare utilisation, as well as the impact of different virtual ward models. The results and conclusions will inform future policy decisions and service improvements, shaping the future of virtual ward provision in Greater Manchester and potentially influencing national strategies.

### **Groundswell – Cheshire and Merseyside**

Prevention of ill health is increasingly prioritised by the NHS, and has an NHS net zero co-benefit, with implications for mitigating climate change. Prevention of ill health will sustain the NHS as a viable organisation.

This project uses primary care data and environmental data to predict protection against onset of common mental health conditions and other non-communicable diseases to understand who will benefit the most from existing local facilities and where is the greatest burden of ill health. The aim is to prevent the onset of ill health by providing suitable facilities that encourage healthy behaviours, thereby reducing the number of people with limiting long-term conditions.

# DIAPHRAM – Cheshire and Merseyside (with collaboration from Lancashire and South Cumbria)

DIAPHRAM is a study to assess the effectiveness of parent champions intervention in children's centres at reducing risk of hospitalisation of infants (under 3) with bronchiolitis.

This project will benefit considerably from mother-baby linkage which can be challenging in NHS data sets. Lancashire and South Cumbria will be looking at these linkages with potential for federated analyses.

# Cost to access the service

The cost of accessing and using a secure data environment (SDE) varies depending on type of data required, and the services provided.

Pricing within the North West SDE adheres to the NHS England five commercial principles (developed for the Data for R&D programme):

- Principle 1: Costs of access should not be prohibitive.
- **Principle 2:** The NHS will always charge a fee for accessing health data.
- **Principle 3**: The cost of access should depend on how the data is being used.

- **Principle 4**: On top of costs for access, the NHS intends to share in the value created by its data.
- Principle 5: The NHS need to retain flexibility to change the exact value sharing options.

Projects are priced per project using a regulated consistent framework. Working with funding bodies and aligned to NIHR. Generally, costs are associated with:

#### Platform as a Service (PaaS):

Provision of a secure research environment, including delivery of data into the secure environment; selected research tools, optional archiving storage where required and technical support.



#### Charge to include:

- Secure data environment workspace configuration set up including data engineering to supply assets and data provider charges associated with provisioning data.
- Technology third party platform base cost contribution, project-specific compute, storage and tool charges and sundry software licences.

#### Data as a Service (DaaS):

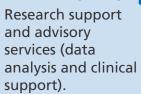
Published and agreed, bespoke data sets.



#### Charge to include:

- A negotiated price for bespoke datasets that may include pricing for royalty or intellectual property if the output from the project is to be commercialised at a later date.
- Each project request will be individually evaluated based on several factors including type of request and complexity.
- Timelines will be dependent on type of request and complexity. This will be agreed during the enquiry/application process.

### Consultancy as a Service (CaaS):



#### Charge to include:

 People with subject matter expertise used to support the researcher based on a national rate card price per day/hour.

Please contact the team to discuss use of the North West SDE services: <a href="mailto:nw.sde@lthtr.nhs.uk">nw.sde@lthtr.nhs.uk</a>

## **Elements included in cost**

Each project using the North West Secure Data Environment will have a bespoke costing plan, based on the services required.

There are options for payment for data access. These include payment of a fee based on the services and revenue share or equity share based on the innovations developed within the North West Secure Data Environment.

### **Price to customer**

Platform as a service

Data as a service/ consultancy as a service Share in the value derived from Data Access

Service management

Storage and compute

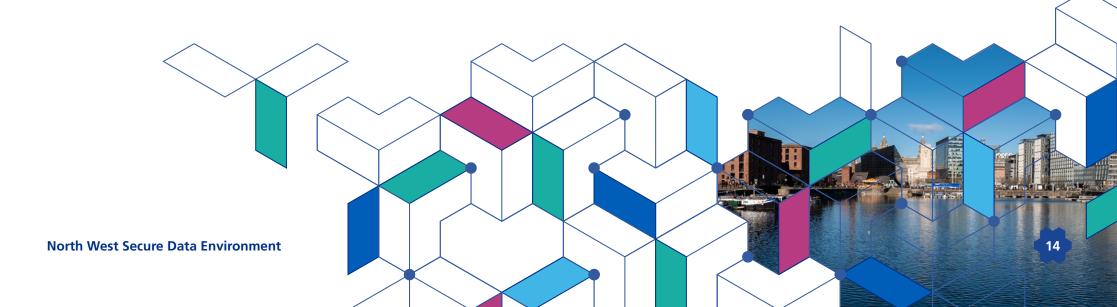
Data provision

Service and support

Specialist services

% revenue share % equity share

f upfront fee



# Our technical platform

The North West SDE federates data from several data stores. These data stores hold multiple data assets from different local health systems. Data is prepared to research-ready standard, structured into a standard format ready for analysis, with metadata available on definitions, content and structure and data quality and integrity performed so that the data asset is ready to use for research.

The data is in source data stores ready for extraction into the North West SDE. Data enters the North West SDE workspace on a project-by-project basis against criteria approved at the Data Access Committee. Each project has its own workspace with the tooling available for researchers to undertake their analysis.

The federating and processing of the data is subject to a strict Information Governance framework and follows all legal requirements around the use of data.

Data within the North West SDE is de-identified and only leaves the platform in aggregate form after output checking and approval is complete.

#### Key:

**ADF:** Azure Data Factory

**C&M ICB:** Cheshire and Merseyside

Integrated Care Board

**GM ICB:** Greater Manchester

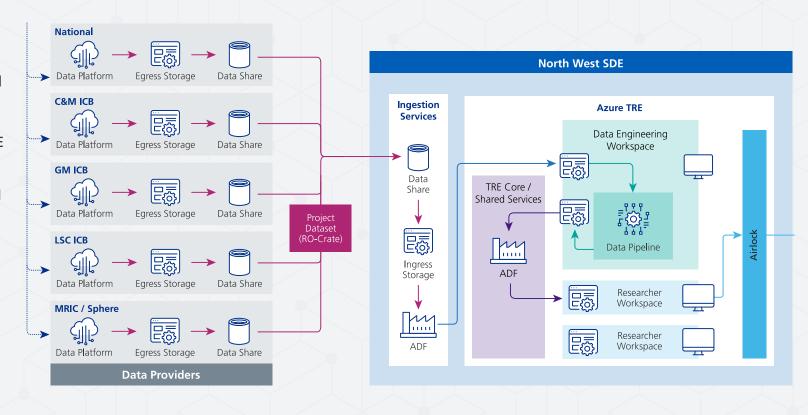
Integrated Care Board

**LSC ICB:** Lancashire and South Cumbria Integrated Care Board

M-RIC: Mental Health Research for

Innovation Centre

TRE: Trusted Research Environment





Part of the
NHS Research Secure Data
Environment Network



# Visit our website

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



northwestsde.nhs.uk

Enquiries to:

nw.sde@lthtr.nhs.uk



Guided by the principles of the Five Safes:

