Yorkshire & Humber
SECURE DATA ENVIRONMENT

Part of the
NHS Research Secure Data Environment Network

Providing managed access to healthcare data for Research and Development

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National Data Access Policy

- First published in September 2022, then updated in October 2023.
- A response to longstanding complaints from researchers that access to health data was overly complex and unpredictable, coupled with data security concerns.
- A move away from data sharing to data access by default – keeps the data within NHS control.

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Six main use cases



AI/algorithm development (testing, training, and validation)



Clinical trial activities (feasibility, recruitment, efficacy through short- and long-term trial follow up)



Real world studies (safety, effectiveness, cost effectiveness)



Translational research (academic discovery and implementation of discovery into practice)



Epidemiological studies (large cohorts for population health research)



Health systems research (evaluation of systems or processes, including operational and applied research)

The NHS Research SDE Network

- NHS Secure Data Environments (SDEs) provide managed access to healthcare data for approved researchers and projects.

- The Network contains the National SDE (operated by NHSE) and ten Regional SDEs, providing full coverage across England.

- All SDEs operate according to the Five Safes Framework, originally developed by the ONS:
  - Safe Projects
  - Safe People
  - Safe Data
  - Safe Settings
  - Safe Outputs

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The NHS Research SDE Network

Nationally delivered

- Network Concierge
- User Registration Service
- Data Access Request Form
- Data Access Committee Terms of Reference
- Pricing Calculator
- SDE Accreditation
- National SDE

Regionally delivered

- Regional IG – Section 251 and ethics
- Data onboarding and curation
- Managed Data Access Process, from initial enquiry to project closure
- Data Access Committees
- Approved data access via Trusted Research Environments
- Patient, Public and Professional Involvement and Engagement

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Yorkshire & Humber SDE: combining expertise from across the region

Delivery partners:

- Bradford Teaching Hospitals NHS Foundation Trust
- Humber Teaching NHS Foundation Trust
- Health Innovation Yorkshire & Humber
- University of Hull
- University of Sheffield

Strategic partners:

- Humber and North Yorkshire Integrated Care Board (ICB)
- South Yorkshire Integrated Care Board
- NHS West Yorkshire Integrated Care Board

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Hub and spoke operating model

Central team

- Regional IG
- Regional Data Access Committee
- Data Use Register
- Involvement & Engagement
- Communications & Marketing
- Business Development
- PMO & Finance

Sub-regional Delivery Teams

- IG for legacy data assets
- Data onboarding and curation
- Managed Data Access Process, from initial enquiry to project closure
- Sub-regional Data Access Committees
- Approved data access via Trusted Research Environments

Dedicated Involvement & Engagement team

- Extensive programme including patient information materials, surveys, workshops and deliberative activities.
- Public Advisory Group and Young Person's Advisory Group (aged 18 to 24) guide our thinking on all topics of strategic importance.
- Communications materials are co-produced with the Groups.
- Patients, publics and professionals are involved in reviewing all data access requests.



Achievements

- 25 data products – https://healthdatagateway.org/en/collection/94
- 90+ projects – https://yorkshirehumbersde.nhs.uk/data-use-register/
- Delivering value - https://yorkshirehumbersde.nhs.uk/resources/case-studies/
- Sharing insights - https://yorkshirehumbersde.nhs.uk/resources/reports/
- Collaborating across the SDE Network - https://dareuk.org.uk/how-we-work/ongoing-activities/dare-uk-early-adopters/panorama/

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Working with the No 10 Data Science team to explore patient referral processes

Overview:

The joint project will analyse secure and anonymised patient data to find out how the NHS patient referral system is supporting the management of demand on hospital services.

The research will build an evidence-based picture of how the referral process for specialist care works in practice, and will help lead to improvements to the patient experience.



The data will initially be coming from the Connected Bradford data base which includes anonymised data from people within the Bradford and some surrounding areas.

Connected Bradford is the only research database in England that provides linkage between GP data and data within hospital electronic health record systems.

It includes information from 1.4m individual patients, created by linking data from primary and secondary care, along with data provided by others relating to education, housing and air quality.

John Birkinshaw, West Yorkshire Operational Lead for YHSDE and Research Data Infrastructure Manager for Connected Bradford, said: "We are thrilled to be able to support this request and look forward to working with other customers in the future as we continue to build on our unique, secure data sets to help with progress."

Find out more

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Data helps find 'missing millions' with undiagnosed and serious lung condition

Overview:

A pioneering respiratory project in Hull is supporting the timely diagnosis of Chronic Obstructive Pulmonary Disease (COPD), helping hundreds of people access life-changing care.

Since its launch in 2023, the FRONTIER project has reviewed over 1000 people who have consented to the use of their data and diagnosed COPD in more than 500 of these patients.



A collaboration between Hull University Teaching Hospitals NHS Trust and Chiesi Ltd, a biopharmaceutical company, FRONTIER used patient data from the Hull Lung Health study, hosted by the University of Hull with the Yorkshire and Humber Secure Data Environment (SDE).

Using this data, the study identified people at high risk of undiagnosed COPD during Lung Cancer Screening appointments and offered rapid access to diagnosis, treatment and support in a single visit.

Before FRONTIER, patients showing signs of emphysema during lung screening often received no further assessment.

The project has uncovered significant unmet need:

- 25% of newly diagnosed patients had previously been treated repeatedly for "chest infections"
- 50% patients diagnosed were current smokers
- More than 60% of eligible patients accepted a referral to pulmonary rehabilitation.

Find out more

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Yorkshire & Humber SDE at the heart of pioneering Smart-Health project

Overview:

A pioneering project to collect smartphone and wearable device data from up to 10,000 participants across the UK will store data in the Yorkshire & Humber Secure Data Environment.

The device data will be linked to routinely collected health records to create a comprehensive database, the first time that linked data has been used at scale in this way in the UK.



In the UK, over 90% of people use a smartphone, and approximately 40% have a wearable device which tracks information about their daily habits, activity levels, and cardiovascular health.

The Smart-Health Project combines activity and movement data with lifestyle, socio-economic factors, and official NHS health records, giving researchers a holistic, 360-degree view of a person's health.

Researchers aim to address regional health inequalities and accelerate the diagnosis and treatment of diseases.

The ultimate aim of the project is to create a research-ready database that facilitates vital studies that could improve health outcomes.

Smart-Health is led by the University of Sheffield and Sheffield Hallam University, and is supported by the EPSRC/ UKRI South Yorkshire Digital Health Hub.

Find out more

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Connected Yorkshire & Humber research database

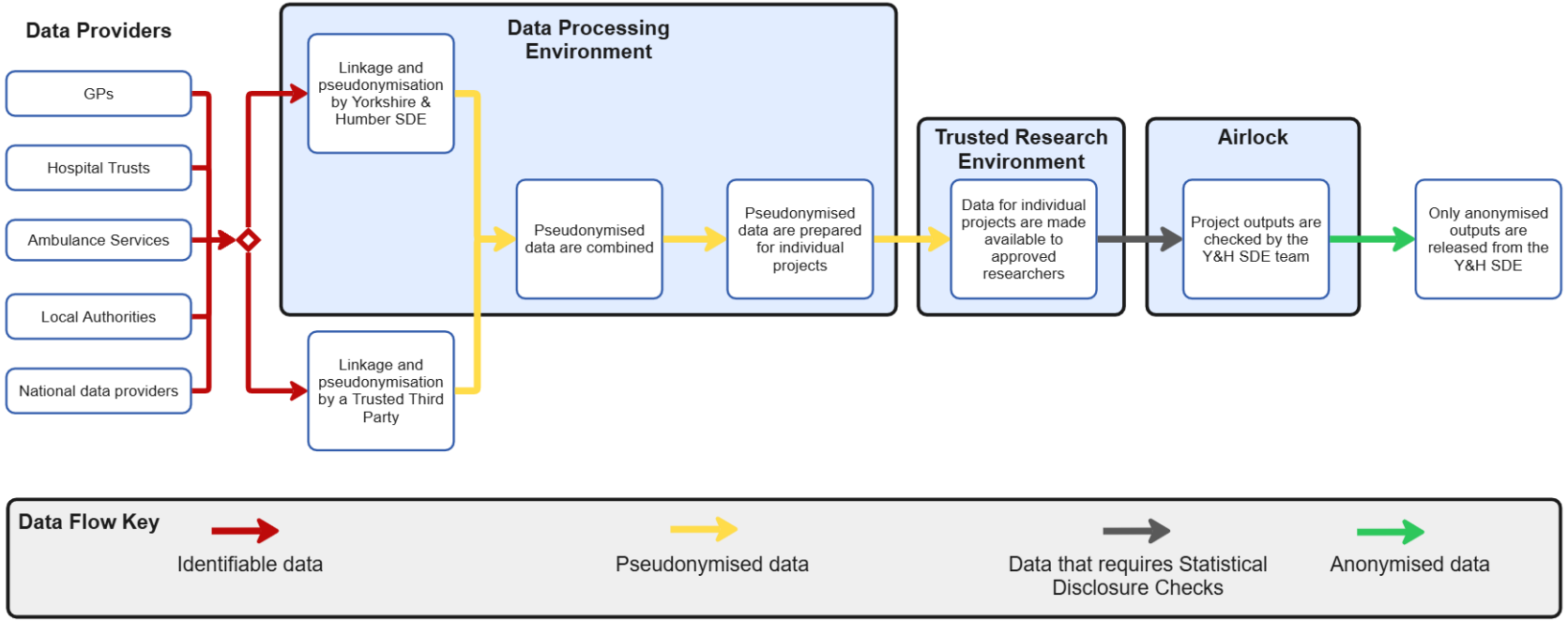
- Support from HRA Confidentiality Advisory Group and Cambridge East Research Ethics Committee provides a legal and ethical basis for:

- Processing of data from all regional GPs, Trusts, ICBs and Local Authorities, plus data from NHSE.
- Making data available for approved projects at three geographical scales – sub-regional, regional and multi-SDE.
- Federated architecture, combining both NHS and university infrastructure with NHS data controllership throughout.
- Pseudonymisation and linkage by either the Y&H SDE team or trusted third parties, such as DSCRO.
- Researchers can apply to bring their own data, including those from consented studies and non-health.

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Lessons learnt

- Risk appetite varies – data providers are often more risk averse than patients and public.
- Annual funding cycles adversely impact staff recruitment/retention.
- Having a national team as both commissioner and delivery partner can be tricky to navigate.
- Being part of a wider ecosystem – what happens elsewhere can impact us (for better or worse).
- ‘Value’ means different things to different people.
- Pricing is contentious due to the wide range of potential customers – from commercial to charity.

A look to the future

- How do we best combine SDE investments with those from other, non-research programmes, such as Shared Care Records and Single Patient Record?
- Requests relating to analysis of health and non-health data are becoming increasingly common and often require linkage – poses a challenge regarding common identifiers.
- A growing need for a national approach to workforce development – is there a case for the Health Data Research Service to fund this?

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WEBSITE

1 **Browse the data products on our website**

2 **Make an enquiry to access the datasets**

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