West Midlands Secure Data Environment NewsBytes   March 25

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

In this edition we cover work to improve SDEs for developing AI health innovation, our public, patient and stakeholder event in January and updates from the national Data for Research and Development programme.

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.

Improving SDEs for AI product research

We are co-hosting a project exploring how SDEs can support the development of AI health technologies.

The Office for Life Sciences and the National Institute for Health and Care Research (NIHR) Incubator for AI and Digital Healthcare are funding a series of workshops. These will examine how SDEs could put the UK at the forefront of AI health innovation.

Our team are sharing their knowledge and leading some of the discussions during these workshops.

AI technologies have the potential to assist with cancer diagnoses, predict treatment outcomes and optimise clinical workflows. It is hoped they will give health and care professionals more time to spend with patients.

The first workshop, attended by academic, industry and NHS data experts, took place at Queen Elizabeth Hospital in Birmingham in January.

Conversations focused on the datasets available through SDEs, comparing them with what manufacturers would need at different stages to successfully develop products that improve our health and care services.

The workshops have been designed to identify when and how SDEs can make a difference, ensuring SDEs are giving developers what they need at the right times.

A series of draft recommendations will now be compiled, reviewed and finalised. Other aspects of this work, such as explaining and reassuring patients and the public about how data is protected on SDEs, will also be part of future workshops.

Professor Alastair Denniston, Executive Director of the Centre of Excellence for Regulatory Science & Innovation in AI & Digital Health (CERSI-AI) and Co-Director of the NIHR-funded Incubator for AI & Digital Healthcare, is leading this work.

He said: "Optimising secure data environments (SDEs) is crucial for advancing AI health technologies. By adapting SDEs to better support the needs of AI innovators, we can ensure that high-quality NHS data is used effectively to develop and validate cutting-edge AI health technologies, improving patient care while always maintaining public trust."

Data use register and metadata catalogue

Visitors to our website can now see a summary of research projects with approval to use health data through the SDE, following the launch of our data use register.

What is a 'data use register'?

The data use register shows what researchers are doing with the data so patients and members of the public can feel confident it is being used in the right way and for the right reasons.

Approved projects have been reviewed by our data trust committee (DTC) to ensure all research carried out through the West Midlands SDE is in the public interest. Exceptions to this are data projects that are supported under a different legal framework.

Available datasets

The data use register also helps researchers understand the type of health information the SDE holds, as does the SDE's metadata catalogue. This lists datasets currently held in the West Midlands SDE and will be updated regularly as new data becomes available.

Researchers with any questions about the metadata catalogue or its contents can email our team.

Public, patient and stakeholder engagement event – January 2025

Our 'big discussion' engagement event in January brought together members of the public from across the region to help us further understand people's views about health data being used for research.

Those who took part were from a wide range of communities and included representatives from the voluntary sector, disabled people and members of different cultural and health-related groups.

They were asked to share their views on different aspects of the West Midlands SDE, including:

- the importance of transparency in how the SDE uses patient data and what might make people care about data for research and planning

- the use of different types of data through the SDE

- how access to data for research programmes should be prioritised.

All findings from the event will be included in an engagement report to be published soon.

Patient and Public Advisory Group (PPAG) vlog

In our latest vlog, PPAG member Joe Ndilla talks about engagement and how his experience in health and social care contributes to the work of the SDE.

Joe sits down with engagement and consultation consultant, Andrea Clark, to reflect on what it's like to be part of PPAG. He notes that, although most people are comfortable with their data being used once they know more about the SDE, further work is needed to raise awareness.

He said: "The NHS has evolved and it's about time people understood their data has value. If the bigger campaign is about saving our NHS… then secure data environments are things we need to participate in and people need to know what this means."

You can watch the vlog in full on our website.

Find out more about PPAG

We have created a diverse PPAG that represents the voice of all members of the community. 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: WMSDE@uhb.nhs.uk.
- ➢ More information is also available on our website.

NHS DigiTrials Now Taking Applications

NHS DigiTrials is launching a new round of expressions of interest for clinical trials, building on its recent success in recruiting 1.3m volunteers for clinical trials and health research to date.

The service helps researchers identify and contact suitable NHS patients, enabling faster, fairer recruitment at scale.

Applications for new trials recruiting in financial year 2025/26 will close on 11 April 2025. Expression of interest for trials running in financial years 26/27 and 27/28 will remain open.
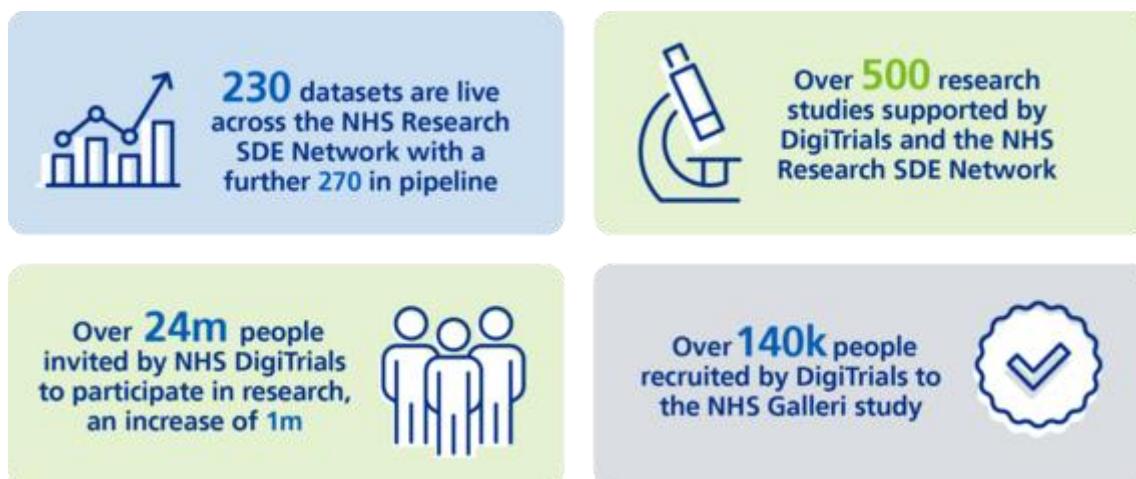
Don't miss this opportunity to accelerate your research and improve patient outcomes through NHS DigiTrials' proven recruitment service.

Learn more at: https://digital.nhs.uk/services/nhs-digitrials/recruitment-service/expression-of-interest

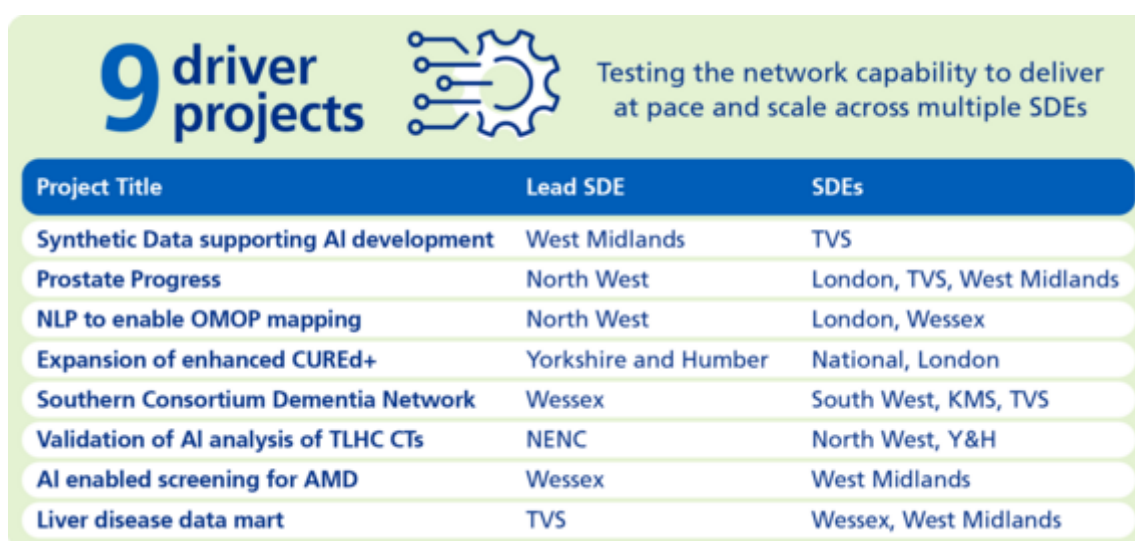## Data for R&D programme – national updates

Data use registers

All SDEs across the NHS Research SDE Network have met the Data for R&D programme's deadline to have a work-in-progress data use register published on their website. Some figures covering the entire network are listed in the infographic below:

230 datasets are live across the NHS Research SDE Network with a further 270 in pipeline

Over **500** research studies supported by DigiTrials and the NHS Research SDE Network

Over **24m** people invited by NHS DigiTrials to participate in research, an increase of 1m

Over **140k** people recruited by DigiTrials to the NHS Galleri study

Driver projects

The first driver project forum took place on Tuesday 28 January with six driver projects coming together to discuss successes and challenges experienced so far. There has been great success in standardising mapping of data, along with progress on creating the meta data for disease-specific data assets. The central challenges remain focused on information governance, commercial standards across SDEs and the implementation of existing software and algorithms within an SDE. The future scalability of these projects (listed in the infographic below) for the network are focused on making unstructured data available for research, standardising approaches to technical federation and the application of AI models.

9 driver projects — Testing the network capability to deliver at pace and scale across multiple SDEs

Project Title	Lead SDE	SDEs
Synthetic Data supporting AI development	West Midlands	TVS
Prostate Progress	North West	London, TVS, West Midlands
NLP to enable OMOP mapping	North West	London, Wessex
Expansion of enhanced CUREd+	Yorkshire and Humber	National, London
Southern Consortium Dementia Network	Wessex	South West, KMS, TVS
Validation of AI analysis of TLHC CTs	NENC	North West, Y&H
AI enabled screening for AMD	Wessex	West Midlands
Liver disease data mart	TVS	Wessex, West Midlands

Blog: NHS Research secure data environments - how collaboration is helping drive improved public health and patient care
Jake Marshall, Head of Life Sciences and Public Sector Partnerships for Data for R&D, blogs about how collaboration between researchers, partners and patients is unlocking the power of NHS data. Read more on the NHS England website.

HDR UK news

Team and impact of the year shortlists announced
HDR UK has announced the shortlists for its Susannah Boddie Award for Impact of the Year and Team of the Year awards. Nominees include the DARE UK Driver Projects to improve SDEs and a new Data Access Agreement (DAA) template for SDEs. Winners of the awards, which celebrate excellence in health data research and team science, will be announced this month. Read more on the website.

Medical students 'must be ready for tech-driven healthcare'
Medical students need AI and data science skills to be ready for an increasingly technology-driven healthcare system, a report has shown. Read more about the HDR UK and Medical Schools Council's (MSC) report on the HDR UK 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

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