

## West Midlands Secure Data Environment NewsBytes

January 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 the public and patient event happening this month, development projects awarded grant funding and an update on the privacy enhancing technologies (PET) underpinning research on the SDE. We also have the latest in our series of PPAG vlogs.

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](#).

### Patient and public engagement event – 27 January

Patients and members of the public are invited to a West Midlands SDE engagement event on 27 January.

We are seeking people's views on how health and care data is used for research in the West Midlands. Guests can join these discussions and play a role in shaping our SDE.

#### Event details:

- Date: Monday 27 January
- Time: 10am to 4pm
- Location: [The Studio in Birmingham](#)
- Places are limited - [book online](#).

People can still attend this event if they've supported previous West Midlands SDE engagement activities.

Please share the details of this event with anyone you feel may be interested in attending.

### Development projects awarded funding

The West Midlands SDE is investing in regional data for research with the award of grant funding to 12 development projects.

Each of the projects, selected from 30 applications, has demonstrated clear potential for public and patient benefit.

The teams behind them are now completing full West Midlands SDE data access requests before going through the usual approval process.

The projects chosen to receive funding are below:

- Developing an automated evaluation pipeline to identify the effectiveness of digital interventions in acute care: A pilot study assessing inequalities in the effectiveness of DERM.
- Investigating causal associations between polypharmacy and patient falls: a primary and secondary care study using routinely collected health data.
- Exploring the health needs of domestic abuse survivors: A pilot for integrating West Midlands police data into the NHS Secure Data Environment.
- Automated triaging system using natural language processing for identification of patients with acute aortic syndromes from radiology reports: external validation.
- COAST (Collecting and develOping Adult Social care daTa for research).
- Developing a national musculoskeletal (MSK) audit and research database for community and primary care MSK services.
- Indoor domestic environmental exposures and asthma outcomes in the West Midlands (The IDEA WM study).
- Impact of personalised care and continuity of carer on disparities in maternity outcomes: an observational analysis of the CORE20PLUS population in the West Midlands.
- Improving care for adults with peripheral nerve injury in the West Midlands.
- Impact of Quality and Outcomes Framework and NICE quality standards for cardiovascular disease for ethnic groups, and patients with chronic disease living in the Black Country.
- Heart rate control and long-term outcomes in NHS patients with comorbid atrial fibrillation and heart failure: A longitudinal cohort study in the West Midlands NHS Secure Data Environment.
- WeMind - The West Midland Initiative for Neurodegeneration.

Watch out for future updates on these projects in the coming months.

## New way to run clinical trials in general practice recruits 1,000 patients

DaRe2THINK, an innovative approach to delivering remote clinical trials in primary care, has reached a major milestone of recruiting more than 1,000 patients.

The pioneering approach, which will be developed further in the West Midlands Secure Data Environment (SDE), will be targeted to address the health issues in the West Midlands region.

The trial platform is now active in more than 400 NHS sites, supporting general practitioners (GPs) and their teams to recruit patients for clinical research that can advance public health.

Designed to open up the benefits of research for NHS staff and patients, DaRe2THINK is able to securely screen routine health records for more than 13 million NHS patients.

The focus of DaRe2THINK is to demonstrate if strokes, blood clots and vascular dementia can be prevented in patients with a common heart rhythm disorder called atrial fibrillation.

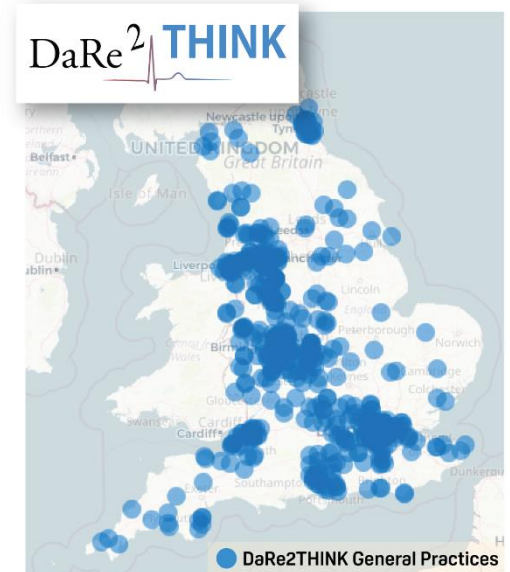
A collaboration between the University of Birmingham, NHS providers and the Clinical Practice Research Datalink, DaRe2THINK has successfully implemented a new way to run large-scale trials and to support research in primary care. The trial is funded by the National Institute for Health and Care Research (NIHR) and supported by the NIHR Research Delivery Network across England.

Professor Dipak Kotecha, co-chief investigator for the study, leads the West Midlands Secure Data Environment's digital clinical trials workstream. He said: "The aim of building these trials into the SDE is to address health inequalities that are a particular problem in our local communities. We will enable our GPs and hospital teams to re-use health data collected as part of normal NHS care, with the objective of preventing poor health outcomes and improving the care their patients receive.

"Bringing these innovations together with the West Midlands SDE will allow us to undertake trials with patients in the comfort of their own home. These trials will help us create real change and improvement in the quality of NHS care and the patient experience. Once the trials demonstrate benefit, we can then implement that change directly into clinical practice for existing and future patients."

Recent innovations of this efficient, data-enabled approach have led to a 'number needed to invite' of 5.3. This means only five patients need to be invited by their primary care team for one patient to be randomised, far surpassing other recent developments in clinical trials.

Supported by a patient and public engagement team, DaRe2THINK has been designed to transform the way trials can be conducted within the NHS. This will open up participation to a



wider range of patients and contribute to the UK's life science strategy to improve health, wellbeing and economic growth.

Dame Julie Moore DBE, Chair of Health Data Research UK, said: "DaRe2THINK is a new way of undertaking research to improve public health by working with GPs. Through screening of comprehensive health records of patients in the NHS, DaRe2THINK is able to identify patients to recruit to trials to improve their health, and the wider health of the nation."

## How PETs support the SDE

The West Midlands SDE is continuing its work developing a series of Privacy Enhancing Technologies (PETs) to support ongoing research.

PETs are software tools that take identifiable patient data and strongly de-identify it. This process is the foundation for data research on the West Midlands SDE because only de-identified data can be accessed by researchers on SDEs.

UHB technical experts have been refining the PETs such as those used on the West Midlands SDE for around five years, including working with specialist suppliers.

As a result, the West Midlands SDE can de-identify both tabular and image data safely and quickly for research purposes. This means spreadsheets of patient data and images (such as MRI, CT and X-ray scans) can be processed for use within the SDE.

### Striking a balance

There are several things to consider when developing PETs in this way.

Firstly, the process must be safe – identifiable data must be reliably and consistently removed before data can be stored on the platform.

Secondly, the speed and resource required to complete de-identification must be efficient and cost effective to work at scale as required by the SDE.

At the same time, the data on the platform needs to retain enough value to give researchers something to work with.

### Next steps

The nature of working with PETs means that the team will always be reviewing and improving them.

One of the biggest challenges currently being investigated is finding reliable ways to de-identify 'free text' information. This is important because data held within letters, notes and other correspondence has rarely been used for research, and will significantly increase the research possibilities for the West Midlands SDE.

Free text is already being de-identified for the SDE, but it is very resource intensive, so the team is exploring new ways to do this.

Stephen Perks, Technical Lead for the West Midlands SDE, said: “It’s immensely exciting to be part of developing PETs. If we can de-identify data safely and quickly it means we can do more of it on a greater scale. The research possibilities we are slowly unlocking make our work increasingly valuable to patients and the data research community, as well as personally rewarding for the team.”

## Patient and Public Advisory Group (PPAG) vlog

Professor Simon Ball, SDE Senior Responsible Officer, attended the latest PPAG meeting to discuss our progress so far and his hopes for the future.

Following the meeting, PPAG member Ruth Hereford and Simon sat down for the latest in our series of PPAG vlogs.

Simon said: “What’s next is increasing the breadth and the depth of the data that we manage so that we can represent the entirety of the patient’s journey.”

Ruth said: “I think the fact the SDE has taken so much care in ensuring that there is broader patient and public input in this is critical.”

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.

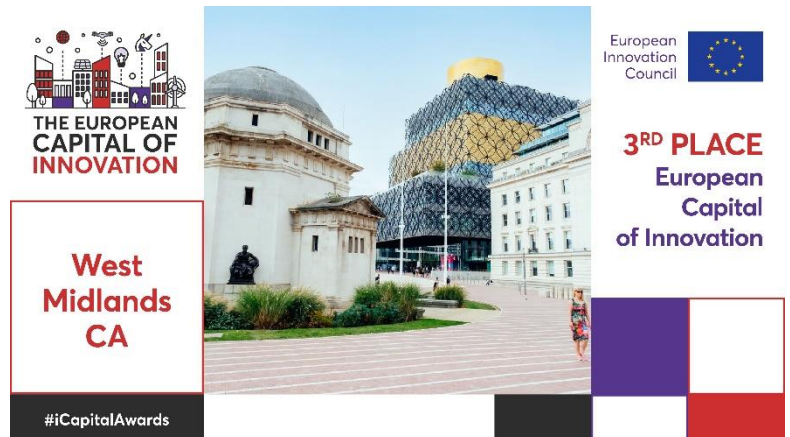
- To find out more about getting involved, please email: [mlcsu.involvement@nhs.net](mailto:mlcsu.involvement@nhs.net)
- More information is also on our [website](#).



## West Midlands among top areas in Europe for innovation

The West Midlands has won a major accolade, being named third place winner in this year's European Capital of Innovation Awards.

The award, split across the three cities of Birmingham, Coventry and Wolverhampton, and four surrounding towns, is recognition of the leading-edge initiatives taking place in the region.



Among the flagship projects that resulted in the success is the West Midlands Health Tech Accelerator. The University of Birmingham-led £16 million project brings together 21 partners across academia, industry and the NHS to help companies overcome the challenges of bringing new health and medical technologies to market. It is part of the [West Midlands Combined Authority's West Midlands Innovation Accelerator \(WMIA\)](#), funded by the Department of Science, Innovation and Technology.

You can read more about the awards and details of the West Midlands entry on the [European Innovation Council website](#).

## NHS Research SDE Network: get involved in user research

The national NHS Research Secure Data Environment (SDE) Network is inviting people to get involved in user research.

As part of the programme's ongoing commitment to deliver services that meet user needs, there are three projects looking for volunteers:

### 1. Finding and understanding data and services

- a. Aim: understand how researchers find data to support their work
- b. Audience: researchers from all sectors
- c. Method: interview and task-based testing (held virtually for approximately 60 minutes)
- d. Benefit: insights will inform future development of the NHS Research SDE Network 'front door'.

### 2. Submitting data access requests

- a. Aim: understand difficulties experienced when preparing information to support a data access request
- b. Audience: researchers and support staff who contribute to data access requests
- c. Method: interview and contextual inquiry (held virtually for approximately 90 minutes)

- d. Benefit: insights will inform the guidance the NHS Research SDE Network offers to support data access requests.

### 3. Developing machine learning models and algorithms

- a. Aim: understand what capabilities, services and tooling are required to support researchers to develop machine learning models and algorithms
- b. Audience: researchers from all sectors with an interest in developing machine learning models and algorithms using health data
- c. Method: interview (held virtually for approximately 60 minutes)
- d. Benefit: insights will inform a minimum set of capabilities to ensure machine learning model and algorithm development is supported within the NHS Research SDE Network.

If you're interested in any of these opportunities, please complete this [short survey](#) so the NHS Research SDE Network can find out more about you and your experience.

Please feel free to share this invitation with colleagues. If you have any questions please contact [data.healthresearch@nhs.net](mailto:data.healthresearch@nhs.net).

You can now find the recordings from the NHS Research SDE Network's Health Data User Group Winter Webinar on the [FutureNHS platform](#). FAQs from the event will also be shared soon.

## NHS England Data Public Panel – recruiting now

NHS England is recruiting patient and public voice partners to support how data is used across health and social care.

They will join a Patient and Public Engagement and Communications group managed by NHS England's People and Communities division.

Members will:

- ensure that the committee/group considers and prioritises the service user, patient, carer, and family perspective
- present a different perspective, including different attitudes and approaches to how people feel about data in health and care. NHS England is looking for people who can reflect broader attitudes, and not just represent their own experience.
- provide 'critical friend' challenge into the group
- champion and advocate for increasing patient and public awareness in data programmes, policies, and strategies.

Applications close on Friday 17 January.

More information is on [NHS England's website](#).

## Podcast: turning the Sudlow Review's vision into reality

Launching publication of her review, Professor Cathie Sudlow stressed the importance of “maximising the benefits to society from the rich abundance of health data in the UK”.

And as [NHS England](#) National Director of Transformation, Vin Diwakar, highlighted, the review calls for us to “go further and faster in building and reforming the national health data research service”.

But what does this look like in practice? In this podcast, [Rebecca Cosgriff](#), former Programme Director for NHS England's Data for Research and Development Programme, joins Health Innovation East's [Piers Ricketts](#) to talk about how work already under way is unlocking the benefits of health data research for patients and the public.



Rebecca shares insights into:

- how we're accelerating access through the NHS Research Secure Data Environment Network
- practical solutions for the research community's data needs
- building infrastructure that already supports 500+ research studies
- ensuring responsible and secure data use while driving innovation to maximise benefits for patients and the public.

This conversation couldn't be more relevant as we work to position the UK as a global leader in life sciences through better data access and infrastructure.

Join the conversation at [Health Innovation Network Health Innovation Podcast / Simplifying the health data ecosystem to turbocharge research, boost innovation and drive advances in care](#).

## HDR UK news

### Health Economics Fellowship opportunity

HDR UK and Queen's University Belfast are offering a Health Economics Fellowship for an early-career researcher, from April 2025 to March 2028. For more information and to apply visit the [HDR UK website](#).



### Brain health research lead appointed

Professor Cornelia van Duijn has been appointed as Research Director for Brain Health. HDR UK and UK Dementia Research Institute, working in partnership with Dementias Platform UK, welcomed Professor Van Duijn into the new role. Professor Van Duijn is Professor of Epidemiology at Oxford Population Health and Fellow of St Cross College, Oxford. Read more 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](mailto: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