

## West Midlands Secure Data Environment NewsBytes

July 2023

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

In this edition, we put the spotlight on clinical trials and how the WMSDE will use digital tools to build them into routine NHS management, improving care for everyone in the region.

We also have updates on the programme’s technical progress, and the communications and engagement work taking place locally and nationally.

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](#).

### Focus on the WMSDE’s digital clinical trials workstream

**The West Midlands Secure Data Environment’s digital clinical trials workstream is led by Professor Dipak Kotecha – Professor of Cardiology at the University of Birmingham and Consultant Cardiologist at University Hospitals Birmingham NHS Trust. Here, he explains the workstream’s role.**



The West Midlands Secure Data Environment (WMSDE) will give us the opportunity to open up clinical trials to everyone in our local communities. That’s hugely important because it will allow us to properly address some of the health inequalities that exist in our region.

Traditional clinical trials in the NHS are focused on patients that are attending hospitals. The patients that benefit are often a selected group. Disabled people, women and those of different ethnic backgrounds are all less likely to take part. This means the results of these trials do not reflect the population of the West Midlands.

In recent years, we have started to run trials through general practices in the NHS, but there is a way to go before trials become a standard part of how we can improve the NHS care we all receive.

The good news is that better technology has revolutionised how health data is securely stored in the NHS. This allows information collected as part of day-to-day NHS care to help make research more successful. We can now run trials remotely, which means patients can be part of important NHS research without having to visit a hospital, or even their GP.

This is now a reality in the West Midlands and beyond (see the article below on the DaRe2THINK programme).

Supported by representatives of patients and the public, our aim is to bring the benefits of clinical trials to the wider West Midlands population, overcoming social and cultural barriers and allowing more patients to benefit from treatments that can prevent a wide range of diseases – from heart conditions to mental health disorders.

Working through the WMSDE and connecting health data held by GPs and hospitals will give us access to a greater breadth and depth of health information. Consent can then be sought from patients who are eligible to join a particular clinical trial that is relevant for them and their NHS care.

Bringing these innovations together with the WMSDE 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.

## Heart and dementia trial to set the stage for WMSDE

DaRe2THINK is a clinical trial testing early treatment in the NHS to prevent dementia in patients with a heart condition called atrial fibrillation. This is a common cause of an irregular heartbeat that results in strokes, cognitive impairment and dementia.

DaRe2THINK uses a range of innovations to securely screen appropriate patients for their GP, allowing for entry into the trial remotely and with much less burden for NHS staff and patients.

It is led from the West Midlands and is currently recruiting NHS patients across England. More than 500 have taken part so far from 315 GP surgeries.



The approach pioneered in DaRe2THINK for easier access to clinical trials will be developed further in the WMSDE and targeted to address the issues in our region.

Dipak said: “The aim of building these trials into the WMSDE 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.”

The [DaRe2THINK](#) trial is being led by the University of Birmingham, University Hospitals Birmingham NHS Trust and the Clinical Practice Research Datalink (part of the UK’s Medicines and Healthcare products Regulatory Agency). It is funded by the National Institute for Health and Care Research (NIHR).

## WMSDE funding confirmed

NHS England has approved the funding allocation for secure data environments, covering 2023/24 and 2024/25.

Programme Director, Hilary Fanning, said: "This is terrific news. We can now move forward confidently in the knowledge we have the funding to continue to develop the West Midlands Secure Data Environment until March 2025."

## PPIE and communications workstream

We are pleased to announce that in July we received 12 applications from people interested in being a member of our Patient and Public Advisory Group (PPAG). This is a great response to the initial call to action.

We are still looking for more applicants and would love to hear from people of all ages and backgrounds. If you are interested in knowing more about how data is used for research, have a question, or want to engage and get more involved, we would love to talk to you.

- To find out more about getting involved, please email: [mlcsu.involvement@nhs.net](mailto:mlcsu.involvement@nhs.net).
- Or complete our online application by scanning the QR code to the right or by visiting <https://nhs.welcomesyourfeedback.net/nq7mf2>.
- To request a paper version of the application, please email [mlcsu.involvement@nhs.net](mailto:mlcsu.involvement@nhs.net).



## WMSDE website



In July, we held a workshop at which members of the public were invited to give feedback on the concept for the West Midlands Secure Data Environment website. The debate was lively and we received very useful feedback, which we are now using to amend the look and content. The planned launch date for the website is early August 2023.

## Powered by NHS data campaign

NHS England has launched a series of video case studies to increase public understanding of how health data is used to benefit everyone. Two videos are currently running on social media under the banner '[powered by NHS data](#)'.



The first highlights how NHS data supported the [HPV vaccine](#) programme, reducing cervical cancer rates. The second looks at how NHS data has led to clean air zones being introduced in the north of England to reduce cases of [child asthma](#). A third, focusing on diabetes, will follow soon.

A survey revealed only a third of people who were asked knew how the NHS uses patient data, other than for direct care. The case studies are designed to show the bigger picture of how it also helps improve care and save lives.

## Chance to join workstreams: data/IG and ethics

Two opportunities to get involved in the WMSDE are on offer at the start of August, as the programme's workstreams start to hold their first meetings.

- The data workstream's initial meeting will take place on Tuesday, 8 August, from 2pm to 3pm.
- The information governance (IG) and ethics workstream follows a day later – on Wednesday, 9 August from 9am to 11am.

The meetings will include an overview of the WMSDE and an introduction to the individual workstream, its aims and objectives.



Dr Masood Nazir



Professor  
Liz Sapey



Professor Krish  
Nirantharakumar

At the data meeting, Professor Krish Nirantharakumar and WMSDE colleagues will discuss key areas such as common data models and data pipelines for the region.

Professor Liz Sapey and Dr Masood Nazir will lead the information governance and ethics agenda, as they and members of the team focus on the need for a clear and robust framework for governance and compliance.

By actively taking part in either workstream, you will be able to help shape the policies and guidelines that will govern the WMSDE. If you'd like to attend, please [email Amy Gosling](#), stating the meeting in which you're interested.

## Technical design authority workstream

Over the past month, we have made a significant amount of progress on the technical development of the West Midlands Secure Data Environment.



- We have partnered with NHS England and healthcare software supplier MetadataWorks to put in place standards-based metadata catalogue tools, as used by NHS organisations, HDR UK, NIHR and Genomics England. This will allow the WMSDE to collect, maintain and share metadata through a high-quality WMSDE-branded user interface, and electronically through an application programming interface (API). This is a further step towards national SDE connectivity.
- We have now introduced enhanced tools to our Trusted Research Environment (TRE) area, which will provide data researchers with the ability to import pre-prepared 'containerised' research tools. This will greatly improve our operational efficiency and our ability to get researchers up and running much faster with the bespoke resources they need.
- The technical teams from West Midlands, London and East of England are working together to share knowledge on their platform designs.
- In partnership with Microsoft Platinum Partner, Ensono, we are working with the University Hospitals Birmingham (UHB) IT technical services team to put in place a strong and efficient integration solution, allowing research data to flow efficiently at scale and pace from UHB into the WMSDE data warehouse.
- Along with our programme team, we are also working with Ensono and the PathLAKE (pathology data) team on a new highly secure, efficient, and scalable data platform, and to integrate this with the WMSDE data warehouse.

## Join HDR UK Midlands network

The Health Data Research UK (HDR UK) Midlands network is inviting new members to join its regional community.

Membership is open to anyone who works in, or has an interest in, health data science – whether a professional or member of the public. The network has recently launched a new [community platform](#) to help connect those involved.

The network brings together the healthcare and data science communities from across the Midlands to improve the quality of health data and develop new tools and technologies to equip frontline healthcare staff to deliver excellent care.

**HDRUK**  
Health Data Research UK

In April, the University of Birmingham, in collaboration with University Hospitals Birmingham and University of Nottingham, received a further five years' research funding to host the network.

HDR UK Midlands has three high-level objectives:

- to maintain and expand the network, reaching out to all parts of the region
- to upskill and improve the knowledge and capabilities of the workforce by enabling them to learn from each other
- to maximise opportunities for the region through the community platform.

For more information, and to join the regional community, visit the platform at <https://www.hdrmidlands.org.uk/>.

## Get in touch

If you'd like to find out more about the WMSDE, 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 are:

- Data trust committee
- PPIE (patient and public involvement and engagement) and communications
- Information governance and ethics
- Technical design authority
- Data and data standards
- Commercial
- Digital clinical trials