

## West Midlands Secure Data Environment NewsBytes

March 24

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



In this edition, read about what it's like being part of our Patient and Public Advisory Group (PPAG) and the Digital Health Rewired 2024 conference.

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 Advisory Group – a member's view

Ruth Hereford knows from personal experience how important research can be for patients – this is why she values her role on the West Midlands SDE's Patient and Public Advisory Group.

She said: “If you want to see a change, you must be part of that change. If you think things aren't the way you want them to be, get involved and participate.”

Ruth has [facioscapulohumeral muscular dystrophy](#), a rare condition affecting around four in 100,000 people. It is a slow-progressing genetic condition, developing in childhood or adulthood, that impacts muscles' abilities to function.

Ruth is the Chair of Trustees for the [Muscular Dystrophy Support Centre](#), a Midlands-based charity helping people like her who live with one of the many different types of muscular dystrophy (MD). As part of this work, she has seen first-hand how important research into new treatments and therapies can be.



“Ruth said: “There are around 30 different kinds of MD and the knowledge for each type can be quite specialist.

“When you get the diagnosis, they tell you what you have, whether you need a wheelchair, and they provide reactive support, but there isn't much in the way of proactive support to better manage the condition. This is the main reason why the MD Support Centre was created, to bridge that gap.”

Ruth, who was first diagnosed with MD at 18 years old, has been involved with PPAG since September 2023 and has already seen huge changes as the West Midlands SDE has evolved in that time.

PPAG meets bi-monthly, with a mix of virtual and face-to-face meetings, and Ruth is one of 12 members of the public who attend to support the programme's decision making.

Ruth said: "It has been very interesting to see how the NHS is using health data to improve research and play a part in this huge step forward for our health services.

"I hope the SDE will facilitate better data on what people are experiencing with MD, improving the way information is captured, quantified, and shared to enable services to improve."

She added: "Before hearing about the SDEs and how they work, I would have had concerns about my personal data being used but the measures in place to de-identify and protect our data reassure and give me confidence.

"I have been really impressed by how well the PPAG is run, with lots of support to help us understand complicated materials so we can add value."

*If you are interested in joining Ruth on the PPAG, or know of a good candidate, details for getting in touch are below in the PPI, communications and engagement workstream update.*

## **Digital Health Rewired 2024: NEC Birmingham, 12-13 March**

With more than 200 speakers across 11 stages, Rewired 2024 had something for everyone in the digital and data arena, including a focus on secure data environments.

Our West Midlands SDE team was well represented with Hilary Fanning and Krish Nirantharakumar introducing the West Midlands SDE to a packed audience. They explained how it is providing opportunities for universities and industry. They also talked about democratising health data research for better care.

This was followed the next day with Liz Sapey and Steven Blackburn enlightening attendees on the ethics around SDEs and how to effectively and meaningfully involve the public. The stage was shared with representatives from Oxford and London and gave a cohesive walk-through of the SDE, from architecture build to benefits and involvement.

There was a notable keynote speech from NHSE Interim National Director for Transformation, Vin Diwakar, in which he outlined the size of the challenge and the journey towards prevention, place-based care and decision-based medicines, along with a need to reduce duplication and waste in the system. He also said he appreciated that digital exclusion was still a challenge.

Vin noted that data infrastructure was key, highlighting the ambition that the SDE network will provide one of the richest data platforms in the world.

## PPI, communications and engagement workstream update

We want to continue to create a diverse PPAG that represents the voice of all members of the community, so please do get in touch if you would like to join.

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).
- Or complete our online application by scanning the QR code 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).

## Healthcare Data and Information Conference: Underpinning NHS Innovation – 18 June

The Healthcare Data and Information Conference: Underpinning NHS Innovation is being held on 18 June at the 15 Hatfields Conference Centre in London.

Speakers, networking events and activities at the conference will explore the progress and challenges of the “Data Saves Lives: Reshaping Health and Social Care with Data” initiative.

Free attendance is available for a limited number of NHS staff, with different prices available for private sector and not-for-profit delegates.

For more information and to book, visit the [Convenzis website](#).

## HDR UK news

### **New AI tool predicts patients’ future health**

A new AI tool called Foresight predicts the future health of patients. Foresight uses a deep learning approach to recognise complex patterns in health records to produce insights and predictions. Researchers, supported by HDR UK, are currently investigating it. A study published in The Lancet Digital Health found that Foresight accurately predicted patients’ next diagnosis for around 68%-76% of cases. Read more on the [HDR UK website](#).



### **New initiative to build on pledge to improve public involvement**

A new initiative is building on the pledge to improve public involvement in health and social care research. The initiative will see 22 health and social care organisations, which are part of the Shared Commitment, meet every quarter to share best practice. Read more on the [Health Research Authority 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

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