

Part of the NHS Research Secure Data Environment Network



West Midlands Secure Data Environment NewsBytes

November 23

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

In this edition, we take an in-depth look at the data and data standards workstream, WMSDE hosting a national event in December and the latest from the Patient and Public Advisory Group.

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 <u>email the programme team</u>.

Focus on the WMSDE's data and data standards workstream

Enabling every health professional to contribute towards research – supporting economic growth through data science in the process – is a key aim of the WMSDE's data and data standards workstream.

While developing ways for more academic researchers to generate high-quality results and conclusions, the workstream also wants to empower more clinicians and NHS staff to use health data to make a difference to their patients.

Professor Krish Nirantharakumar, chair of the workstream, said: "We are working to make data accessible and understandable on the WMSDE. To do this, we will put the data into certain data models, for instance, Observational Medical Outcomes Partnership (OMOP) and provide tools, for instance, Dexter, to democratise it so researchers, at universities and within the NHS, can use it for a wide variety of purposes.

"We believe everyone is equal in terms of generating research questions. You don't need to be a university professor and we can provide a platform to enable more people through the WMSDE.

"Hopefully, with time, we will eventually work with some patient groups and help them to answer their questions and improve care."



Krish Nirantharakumar

As part of this, the data and data standards, and the technical design authority workstreams are working closely to provide the best possible technological solutions, not only giving researchers high-quality data but also presenting it in ways to make their work easier.

A software platform, called Dexter, is already showing huge potential and this will be used to create analysis-ready data on the WMSDE, pending information governance and ethical approvals.

Dexter, developed at the University of Birmingham, processes data and prepares it for analysis, saving tens of hours of staff time by providing robust data on demand.

It is currently being used to support Shrewsbury and Telford Hospitals NHS Trust, with the data and data standards workstream team, clinicians and university staff working in collaboration to great success.

Krish said: "We are extremely excited about Dexter. This work was already under way before the WMSDE, but this has enabled us to do better.



"This shows how a learning health system can work by giving clinicians what they need to use data to develop their services for patients."

The data and data standards workstream team currently has eight members, but recruitment is ongoing to appoint to two new positions in the new year.

WMSDE to host national SDE meeting

WMSDE has been selected to host the national SDE meeting which is to be held 11-13 December at the Edgbaston Park Hotel and Conference Centre in Birmingham.

The meeting will bring together the leaders and subject matter experts from across the different regions to debate and agree the direction of travel for the SDE programme.

This prestigious event will give us the opportunity to highlight some of the great work that is happening within our region and the potential of what we can achieve.

We will update you on the outcomes of the meeting in our January newsletter.

Federated Data Platform contract awarded

NHS England has announced it has awarded the contract to provide the <u>Federated Data Platform</u> (FDP) to a group led by Palantir Technologies UK, with support from Accenture, PwC, NECS and Carnall Farrar.

NHSE says the intention is to roll out the software from spring next year, with the aim of joining up information from across NHS systems to help improve care through better management of available data.

The FDP and the West Midlands Secure Data Environment are both major NHS-led initiatives. Although they are both being delivered at the same time, they have very different purposes and operating methods. The table below outlines some of those differences. Further information on the NHSE Federated Data Platform and opportunity to raise any questions you may have about the FDP can be found here:

Home - NHS Federated Data Platform (england.nhs.uk)

West Midlands Secure Data Environment	Federated Data Platform
The WMSDE will provide an environment in which researchers can safely and securely access and then analyse health data from across the West Midlands to deliver innovation, developing new medicines and treatments and benefiting everyone living in the region.	The federated data platform is software that will sit across existing systems and connect them. It is designed to enable better management of the data currently held in trusts, regions and ICSs.
While the WMSDE will always look to progress in order to increase the benefits to patients and the public, its focus is:	The FDP will bring together information from hospital health records, waiting lists, and theatre and staff rosters to better manage patient care.
 to initially bring data onto the platform against specific data use cases that address local problems, using local patient data, to return local benefits. 	It will use existing data for analysing activity, auditing quality, planning service delivery, and service analysis to improve patient outcomes.
 to provide the infrastructure for specific research projects with their own ethical approvals. 	
The WMSDE will link primary and secondary care data to provide researchers with a more complete picture of people's health and people's health journeys. This will greatly increase what can be learned and the resulting patient benefits.	The FDP will not include GP data.
The WMSDE will only allow approved researchers to access data. It will tightly control what they can see and what they can do with the data.	The FDP will only allow access to patient data for people who need to see it as part of their role in the NHS.
It will only allow data to be used for ethical, safe and transparent purposes with clearly described patient and public benefit. Patient and public contributors are central to the WMSDE. Importantly, patients and the	

public will be involved in the review of data access requests and the decision-making and data access approval processes through our Patient and Public Advisory Group and through our Data Trust Committee.	
Once approved, access and use of the data will be carefully managed by the NHS throughout, following the Five Safes framework – safe people, safe projects, safe settings, safe data, safe outputs.	
Patients and the public will be able to opt out from the WMSDE through the <u>national data</u> <u>opt-out service</u> .	The national data opt-out service does not apply to the FDP.

Job opportunity: Director of Healthcare Data Research

University Hospitals Birmingham NHS Foundation Trust (UHB) is recruiting for a new Director of Healthcare Data Research.

The post sits in the Research, Development and Innovation (RD&I) department at UHB, overseeing a portfolio of impactful research in health research informatics, translating findings into clinically actionable solutions to understand, diagnose, prevent and treat disease. The successful candidate will work collaboratively with the WMSDE.

For more information and to apply, visit the UHB website.

PPI, communications and engagement workstream update

Patient and Public Advisory Group

The Patient and Public Advisory Group (PPAG) members have been very active this month, reviewing the content of the WMSDE application for ethical approval. Their contributions mean we will be in a place to submit the WMSDE application for ethical approval by the end of this month.

In addition to this the group has also been involved in an active discussion around the proposed content for the forthcoming deliberative engagement events. Two initial workshops were held, one with the workstream leads and one with PPAG. A third workshop brought together the two groups to review the outcomes of these and agree the content for the deliberative events.

The next PPAG meeting will be face-to-face on Monday 4 December from 11.30am to 4pm in Birmingham. It will discuss the joint feedback from the deliberative event planning and next

steps. We also plan to share further details on any new engagement opportunities that may exist.

Get involved

Patient and Public Advisory Group (PPAG) members have been meeting since October, during which time they've been involved with, and contributed to, decision making at all levels of the West Midlands Secure Data Environment. This has ensured the patient and public voice has been heard, informing and supporting the programme's development.

We are still welcoming patients and members of the public to join the group to have a say in how the WMSDE will work. We are looking for lots of different people to become members and help make decisions about data access, use and communications.

If you, or anyone you know is interested in joining the PPAG, please let us know by completing our online form. You'll find this at: https://nhs.welcomesyourfeedback.net/nq7mf2.

If you have any questions about the PPAG, or need the application form in a more accessible format, please contact: mlcsu.involvement@nhs.net.

Communications and Engagement

As we are about to launch the WMSDE website, we would like to ask for any news from your organisation that you would like included on our pages.

We would like the website to become a joint regional platform you can use to help promote and showcase the exciting and innovative work that is being done in the region.

If you would like to contribute, we would love to hear about any publications or projects relating to research, in the data space or with data sets, that you and your team are involved in, within the West Midlands.

Please let us know by emailing <u>WMSDE@uhb.nhs.uk</u> if you would like to know more and use the website.

This will be a great opportunity for us all to showcase the great work that is being undertaken in our region and also reiterate how we are all working together.

Deliberative Engagement

We have started contacting community groups with the offer to meet with them to discuss data for research and the SDE. We are looking to hold 60 such meetings across the region to ensure that groups that may not access the main deliberative events have an opportunity to be involved. If you know of any groups that you think would benefit from this type of involvement, please contact Christine Elliott at christine.elliott13@nhs.net.

HDR UK news

HDR UK Conference 2024: the grand challenges in health data

HDR UK's annual conference is a free two-day event bringing people together to accelerate the use of health data for public benefit. The conference is being hosted in person in Leeds, but you can also attend all the sessions online. More information is on the <a href="https://example.com/hdr uk/hbr uk/



HDR UK's response on Federated Data Platform (FDP) announcement

Professor Andrew Morris, Director of HDR UK, has responded to NHS England's FDP announcement. He said: "The NHS intends the Federated Data Platform to enable better use of our medical data in the care we receive – to join up data that may be held in different parts of the NHS to create these journeys of care, and to help see where the service has capacity for offering treatments we may need. But there is a risk. We are worried that concerns about the platform may lead people to use opt-outs that will have no impact on the Federated Data Platform but will harm important medical research." Read more on the HDR UK website.

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 <u>WMSDE@uhb.nhs.uk</u>.

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