West Midlands Secure Data Environment NewsBytes

October 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 technical design authority workstream, Hilary Fanning, Programme Director, receiving an Honorary MBE and the publication of initial data pipelines on the Health Data Research Innovation Gateway.

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 technical design authority workstream

The WMSDE's technical design authority (TDA) oversees the digital systems used to securely collect and store data, before approved researchers are given controlled access.

The TDA oversaw the WMSDE becoming one of the first regional SDEs to complete its first-phase system build earlier this year – using the Microsoft Azure cloud-hosted service. This month the WMSDE has also made 54 research-ready data resources available as part of the Health Data Research Innovation Gateway's initial launch, which is the highest number by any regional SDE (read more on the Health Data Research Innovation Gateway in a separate article below). There are prior ethical approvals in place for these data resources.

Steve Perks, Technical Design Lead, heads up the TDA, which consists of senior technical leaders and specialists with expert knowledge of cloud-based data management and the enhanced information governance requirements for handling NHS data.

**Steve Perks
Technical Design Lead**

They meet fortnightly to review the workstream's progress, welcoming insights from partners across the West Midlands. So far there have been 21 of these meetings and Steve, who has worked in computing across the public and private sectors for many years, is delighted with how this is working.

He said: "There's been wide and enthusiastic engagement from across the region for which I'm very grateful. We've had input from technical leaders across multiple trusts and they're the exact people we need to be working together on this modern platform."

Getting to this point has already been a journey for the TDA, given the NHS has traditionally relied more on physical data centres than cloud-based solutions.

Steve and some of his team had a head start in this regard, having previously built a smaller-scale cloud-based platform for the Health Data Research UK hubs Insight and Pioneer in 2019. This meant they were already well versed in the increased scalability, flexibility and security that cloud-based solutions can provide for research.

Steve said: "Four years down the line we've been able to leverage a lot of our learning and the tools we built then to get us in a much better position now than we would've been if we'd had a standing start."

The next steps for the TDA include exploring what data is already being collected, or could be collected, that is potentially useful for researchers. One of the things Steve is looking at is information that is already collected but is then largely ignored because it doesn't have much value for direct patient care.

Steve added: "There is data that isn't necessarily needed by clinicians to inform treatment, but that could be useful for researchers. For example, the make and model of a machine that was used to complete a test. That information has little value for clinicians delivering direct care, but it can inform researchers of important details which are essential to correct interpretation of the data generated by that machine."

Another project the TDA is currently working to implement is a metadata catalogue, ensuring data contributors have a clear audit trail of the data assets they commit to the WMSDE. This 'data-about-data' also gives researchers a digestible catalogue of available assets, as well as providing an electronic connection to facilitate future federation of research data between SDEs.

If you would be interested in finding out more about the TDA or be considered for membership of the workstream, please contact WMSDE@uhb.nhs.uk.

Programme Director recognised in Honours List

Hilary Fanning, Programme Director, has been awarded an Honorary MBE for her services to genomic delivery in the NHS.

Hilary, who is the Director of Research and Innovation at University Hospitals Birmingham NHS Foundation Trust (UHB), is one of just 62 individuals named in the Honorary awards to foreign nationals, which is approved by His Majesty the King. The Honour recognises the impact Hilary has had on genomic delivery not just at UHB, but across the West Midlands region and nationally.

In her role at UHB, Hilary manages the research and innovation portfolio, overseeing more than £300m research infrastructure and approximately 350 research development and innovation (RD&I) colleagues.

Professor Dame Sue Hill, Chief Scientific Officer for England and Senior Responsible Officer for Genomics in NHS England, said: "I am delighted Hilary has received this honour, which reflects her unwavering commitment to research and innovation in the broadest sense for patient benefit and improving outcomes. This was, and is, exemplified in her leadership and contribution to the 100,000 Genomes Project and the ongoing transformation supporting the adoption of advanced genomic technologies into healthcare that continues to benefit many people in the West Midlands and beyond."

You can read more about Hilary's work on the UHB website here.

Health Data Research Innovation Gateway – initial data pipelines published

The Health Data Research Innovation Gateway has published initial data pipelines on its website as a first step towards evolving into the 'single front door' to the NHS Research SDE Network.

These initial data pipelines, which include Insight and Pioneer data assets from the WMSDE, have been published as a first snapshot of the kind of datasets that will be made available through the network.

The gateway is being developed by the NHSE Data for R&D Programme and Health Data Research UK (HDR UK).

Over time this gateway will be subject to change based on user feedback, patient and public involvement and engagement, and information governance and legal permissions. It will eventually include significantly more granular information.

You can support this work by providing feedback on the website's information and design to gateway@hdruk.ac.uk.

Medilink Midlands webinar – Thursday 16 November

Hilary Fanning, Programme Director, is presenting at a Medilink Midlands webinar discussing SDEs on Thursday 16 November, from 10-11am.

Hilary will discuss the infrastructure and services SDEs will provide and how they will integrate with HDR UK. The webinar is being delivered in partnership between Medilink Midlands, Health Innovation West Midlands and UHB.

You can find out more and book a free place on the Medilink Midlands website.

PPI, communications and engagement workstream update

National communications campaign

NHSE is to run a national public engagement campaign on the use of health data, planned to start in early 2024 and going through into the following year.

Up to £2m will be spent on large-scale deliberative events designed to hear the thoughts of patients and the public on how their data might be used.

Possible areas for discussion will include secure data environments, the Federated Data Platform and reform of the national data opt-out.

Publicly developed recommendations from the campaign will be published as part of a report following the events.

Patient and Public Advisory Group

There was an enthusiastic start to the WMSDE Patient and Public Advisory Group (PPAG) when it met for the first time in October.

Two launch events were held – one face-to-face in Birmingham, with a second taking place virtually for those unable to make it in person.

Agenda items included an introduction to the WMSDE, a look at what membership of the group involves, and the potential opportunities ahead for members.

Applications for membership of the group are still open. We want to create a diverse PPAG that represents the voice of all members of the community, so welcome applications from everyone. As women are currently under-represented on the group, we would be particularly keen to hear from any who might be interested in joining.

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 love to talk with you.

➢ To find out more about getting involved, please email: 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.

NHS Research SDE Network launch event - pack

As promised in last month's NewsBytes, here's a copy of the post-event pack from the NHS Research SDE Network launch event held in Oxford in September (double click pin below):

A patient's perspective of using data

Margaret Grayson is passionate about data.

She advocates for patients sharing their data so it can be used to improve patient care, diagnosis, treatment and outcomes as part of the 'use MY data' movement.

In a video case study for NHS England – Transformation Directorate, Margaret said: "I believe that as a patient I have a responsibility to the rest of society in permitting my data to be used, but I also have the right to ask clinicians and researchers, or perhaps rather demand, that my data is used, remove the barriers, use for purposes of audit, comparison, research, ask questions and find answers for me and all the other patients like me."

You can find out more and watch the video on the NHS England – Transformation Directorate website, or alternatively watch the video on YouTube.

HDR UK news

UK Health Data Research Alliance: Special Interest Group meeting – 8 November, 1-2pm
The UK Health Data Research Alliance convenes a Special Interest Group meeting quarterly that is devoted to the Observational Medical Outcomes Partnership Common Data Model (OMOP CDM). The next Zoom webinar, on 8 November from 1-2pm, will include a discussion around studies applying this model across organisations. It will be co-chaired by Daniel Prieto-Alhambra, Professor of Pharmaco and Device Epidemiology, University of Oxford, and Geoff Hall, Professor of Digital Health, University of Leeds. More information is on Eventbrite and if you have questions about the event you can email ukalliance@hdruk.ac.uk.

Patient and public groups join UK Health Data Research Alliance (UKHDRA)
Two patient and public groups have joined the UKHDRA for the first time. 'Understanding Patient Data' and 'use MY Data', two organisations that work closely with patients to explain and advocate for data use in healthcare, have become UKHDRA members – helping to bring total Alliance membership to 93. More information is on the HDR UK website.

HDR UK announces new Deputy Chair
Patsy Wilkinson has joined HDR UK in the newly established role of Deputy Chair of its Board of Non-Executive Directors and Trustees. Patsy will provide support for the chair, the board and the wider senior leadership team, drawing on experience from a senior government career in national security and defence. Her leadership experience includes data and analytics, science and innovation, and digital transformation. More information is on the HDR UK website.

Other news

West Midlands Imaging Network (WMIN) digital strategy
The WMIN's priorities and plans to share regional diagnostic image and image-related information between 15 participating NHS trusts were approved at a meeting on 20 September. The BI project is now under way with PACS/RIS convergence funding progressing. More information is on WMIN's website.

'Using NHS data to improve healthcare' – article
Professor Sir Chris Whitty has written an article for The Times on how using data effectively and safely can improve patient care and research. He discusses the need to better integrate data systems across the NHS, and the huge difference research can make to patients. He also welcomes NHS England's plans to start a programme of national conversations around data policies and programmes. You can read the article in full on the Government's 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 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