West Midlands Secure Data Environment NewsBytes

January 24

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 commercial workstream, the CAG/HRA application being submitted and updates as targeted engagement begins.

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 commercial workstream

The WMSDE's commercial workstream is working with responsible partners to develop ways for the platform to be sustainable, while ensuring it aligns with NHS England's Value Sharing Framework.

The Framework sets out how the NHS will collaborate with academic and industry partners to use health and care data for research, development and innovation. NHS England has published four commercial principles, setting out how data can be used for research purposes to deliver major benefits for patient care and the UK economy:

1. Costs of access should not be prohibitive to good use of data.
2. The NHS will always charge a fee for accessing health data.
3. The cost of access should depend on how the data is being used.
4. On top of costs for access, the NHS intends to share in the value created by its data.

The commercial workstream's members meet monthly and include representation from Health Innovation West Midlands, NHS organisations from across the region, Clinical Research Network West Midlands, lay membership, industry engagement, technology transfer and the higher education sector.

Guy Smallman, Industrial Partnerships & Intellectual Property Manager at University Hospitals Coventry and Warwickshire (UHCW) NHS Trust, chairs the commercial workstream. Guy has extensive experience in the private and public sector,

Guy Smallman

including national and international contract negotiations with NHS organisations, academia and industry partners.

As well as working closely with partners in the West Midlands, the commercial workstream is also playing an active role in shaping and defining the Operations and Commercial workstream within the NHS Research SDE Network Community of Practice. This programme is developing a unified approach for SDEs, including single front door access to all data access requests.

Hilary Fanning, WMSDE Programme Director, chairs this national programme, with Guy also representing the WMSDE in the Community of Practice working group.

Guy said: "It is important to have regional and national approaches that are fully aligned, and these discussions have been extremely helpful.

"Groups like our Information Governance & Ethics workstream are essential when reviewing applicants who wish to access data, but we also need to make sure costs are affordable and access is straightforward and rapid.

"Work is ongoing with NHSE to define a pricing strategy for access to data."

Guy, in his role at UHCW, was heavily involved in the contracting for PathLAKE; one of a network of five centres of excellence in digital pathology and medical imaging funded by Innovate UK. Through its own secure data environment, PathLAKE has made digital histopathology image data available to researchers and companies developing AI-driven diagnostic tools to increase efficiency in pathology reporting and improve patient outcomes – through advanced cancer diagnostics and selection of patients for personalised medicine. Discussions are currently taking place to expedite the migration of the PathLAKE data to the WMSDE.

This kind of innovation is what inspires Guy.

He said: "Helping to realise the enormous potential of our health data is very rewarding. Like many families, my own has been affected by cancer, so being part of initiatives such as this means a great deal to me."

If you would be interested in finding out more about the commercial workstream, please contact WMSDE@uhb.nhs.uk.

The Data for Research and Development programme: NHS Research Secure Data Environment (SDE) national conference, 11-13 December 2023, Birmingham

The West Midlands Secure Data Environment programme team hosted the national SDE conference held on 11-13 December 2023. The conference offered an opportunity for Senior Responsible Officers, Programme Directors, Architectural Leads, IT Leads and PPIE and Communications Leads to meet face-to-face to take forward plans for developing the network of SDEs throughout England. During the three-day event it was agreed that certain aspects of

the SDE should be developed across the whole network, harnessing expertise from the regions. Important aspects of the SDE network development that were discussed included:
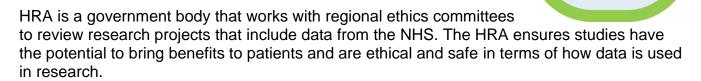
- using The Health Data Gateway as the "front door" to the SDE network
- standardising contracts with users
- looking at a standard Data Access application
- principles for contracting
- developing a seamless approach to data access for requests seeking access to data across multiple regional SDEs
- aligning regional PPIE work to the national engagement campaign.

The work undertaken at the conference will be developed further through the NHS Research SDE Network Community of Practice (CoP). The CoP has working groups focused on each of the key development areas and membership from subject matter experts and representatives of the regional and NHS England SDEs. We will report on the progress of these projects.

CAG / HRA application submitted

The Information Governance and Ethics workstream has submitted the WMSDE's Confidentiality Advisory Group (CAG) and Health Research Authority (HRA) application. This is needed to gain the necessary legal approvals to bring together patients' de-identified health data across the region, enabling it to be used for research and innovation.

CAG is an independent body that reviews requests to link patient health data, protecting and promoting the interests of patients and the public, while enabling the appropriate use of confidential patient information to improve patient care through research. CAG is especially interested in technical approaches to data safety, and how patients and the public have been informed about the WMSDE and involved in its development.

HRA is a government body that works with regional ethics committees to review research projects that include data from the NHS. The HRA ensures studies have the potential to bring benefits to patients and are ethical and safe in terms of how data is used in research.

Liz Sapey, Information Governance and Ethics workstream co-lead, said: "Submitting our CAG/HRA application is a significant step forward for the WMSDE.

"We need to make sure we are doing everything we possibly can to protect sensitive health data while unlocking the potential of health data to improve the lives and health and social care for patients not only in the West Midlands, but across the UK. Gaining CAG and REC approval is the next important step in the WMSDE.

"It has taken a great deal of work over the past 12 months to get to this point. I would like to recognise and thank everyone involved for their efforts in completing this crucial first part of the process. We have had help and support from patients, members of the public and ethics and governance teams across the West Midlands."

PPI, communications and engagement workstream update

Targeted engagement begins

To date, we have reached out to around 550 organisations across the six ICS regions in the West Midlands. This work is continually evolving as we develop links to new contacts and networks to support our engagement work.

A very positive response has been received and engagement events are being booked in across the localities. To date, we have events booked in with groups reaching a broad range of under-served communities including:

- LGBTQ+
- neurodiversity and learning disabilities
- physical disabilities and long-term conditions
- Gypsy, Roma, Traveller communities
- mental health
- older people.

We have provisional sessions (dates to be confirmed) with audiences including:
- young people
- ethnic minority groups
- deprived communities
- carers
- families
- expectant parents.

Patient and Public Advisory Group

We continue to work with our Patient and Public Advisory Group to inform and discuss future engagement sessions with the public and wider stakeholders to support the WMSDE programme. The first two meetings have covered:

- an introduction to West Midlands Secure Data Environment
- supporting the work of PPAG members
- future event planning
- review of communications materials.

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 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.

Health Data User Group – Tuesday 6 February

The next Health Data User Group (HDUG) event will be on 6 February 2024, from 12.30pm to 1.30pm. This is a chance to reflect on recent developments and look forward to next steps.

Please complete your details at the link below to register for the event. This will be an online webinar via MS Teams, with an Outlook invitation and details to follow in due course.
Please register here

PEDRI-UKHDRA workshop, 8 February – drafting Best Practice Standards

The Public Engagement in Data Research Initiative (PEDRI) and UK Health Data Research Alliance (UKHDRA) are hosting the second in a series of events to draft Best Practice Standards.

This work is designed to drive forward best practice for public involvement and engagement with data research.

You can book a place for the event, on Thursday 8 February at 1.30pm, on Eventbrite.

In advance of the meeting, PEDRI is inviting participants to help set the agenda by completing a short survey.

The meeting will be recorded and anyone with concerns about that can email contact@pedri.org.uk.

HDR UK news

HDR UK Midlands Insight Sharing Webinar – 29 February, 1-4pm
The next HDR UK Midlands Insight Sharing Webinar, 'Making a difference: using data to improve care', will take place on Thursday 29 February, from 1-4pm. It will include a national HDR UK update, a session on making data accessible with power BI dashboards and a focus on the MELODY study, which used national data for mass recruitment to a COVID-19 vaccine effectiveness study in rare diseases. You can register for the Zoom webinar with this booking form.

Seven new members join the UK Health Data Research Alliance

New members joining the UK Health Data Research Alliance include: two industry trade associations, a research centre, a medical research charity, two programme investors and a research support service. Read more on the [HDR UK website](.).

First UK-wide population study shows impact of COVID-19 under-vaccination
A study suggests better COVID-19 vaccination coverage across the UK could have averted more than 7,000 hospital stays and deaths in summer 2022. Researchers identified that 44.4% of the total population was under-vaccinated from 1 June to 30 September 2022, meaning they had not received the recommended vaccinations and boosters. The COALESCE study is the largest carried out in the UK, with data from across four countries pooled and harmonised to provide insight that could inform future policies. More information is on the [HDR UK website](.).

Get in touch

West Midlands
SECURE DATA ENVIRONMENT

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