

West Midlands Secure Data Environment NewsBytes

August 2023

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 what's happening in the information governance and ethics workstream, mark a major technical milestone for the programme, and highlight the steps being taken to create a commercial framework for the WMSDE.



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 information governance and ethics workstream

The Information governance and ethics workstream is pivotal to the success of the West Midlands Secure Data Environment (WMSDE).

Not only is it responsible for overseeing the legal and moral obligations involved in providing researchers with access to sensitive health data, it also has to be a reassuring voice for the WMSDE's stakeholders.

Professor Liz Sapey and Dr Masood Nazir are the workstream's co-chairs.

Liz said: "Everyone we have spoken with can see the real benefits that would come to patients by using connected, regional health data for research and innovation. Also, the legal frameworks in which the WMSDE needs to operate and the approvals we need are clear, and I don't think anybody would question what we have to do. But it's the detail of how you go about that and what the operational processes will be.



Professor Liz
Sapey



Dr Masood
Nazir

"We need to enable as many regional stakeholders as possible, including healthcare organisations and patients, to contribute to our approach, so they feel confident about being part of this important programme.

“It’s very much about co-designing our approach across the region, working with different people who bring huge amounts of experience and expertise that we can all benefit from.”

Masood said: “This is a journey for healthcare organisations in the West Midlands. While some are already heavily involved in research and innovation using health data, for others it’s early days. I think using the WMSDE safely to answer important questions that make a difference to care will help build trust. In the meantime, Liz and I plan to spend time engaging through stakeholder networks to increase understanding and awareness of the programme, learn from colleagues’ experiences and highlight how they can get involved.”

The workstream also has a responsibility to protect the needs and rights of citizens. Clinicians understand the legal and ethical justification for looking at a patient’s data when needed for direct care. However, when it comes to secondary use, the purpose, benefits and risks of accessing a person’s data all have to be assessed. This is to ensure the use of the data is legal and that, when explained to patients and the public, most people feel comfortable and happy with the reason why it’s happening.

People can choose for their health data not to be used for research by using the [national data opt-out](#) service. The WMSDE will also develop its own regional opt out for anyone who doesn’t want their data used for specific local research projects.

Masood said: “I’m keen that we develop resources that are easy for healthcare staff to understand, making them feel more confident about explaining to patients what we are doing. This will lead to more patients making an informed choice when they have concerns.”

Liz added: “It’s really important we flag people’s choices to them so they’re aware of what their options are. An important safeguard for the WMSDE is that we follow the ‘Five Safes’, which is a framework to make data access as safe as possible. It includes ensuring data is accessed only by safe people, for safe projects and in safe settings. We also check the data very carefully to ensure no one can be identified and that data researchers access only that part of the health record needed to answer a specific question, ensuring safe data. The final step is safe outputs, meaning people can only remove the results of their research, not the data itself, and only after those results have been checked.

“The way we are able to manage risk through the WMSDE is different to how we might have done things five years ago. We need to ensure people understand the new processes so they are confident in what we do.”

IG and ethics: creating a regulatory framework for the region

The initial IG and ethics workstream meeting brought together representatives from across the region to gain an overview of the programme and understand the next steps.

For the workstream, that means creating the regulatory framework for accessing data for research. This will include applying for Health Research Authority approval for the WMSDE, and for Confidentiality Advisory Group (CAG) section 251 support to set aside the common law duty of confidentiality because of the potential benefits to patients, to enable data to be processed.



The ethics protocol for the programme will cover the whole West Midlands region. It is now in draft form and will be shared with colleagues for comment.

Liz said: “It will be vitally important that people on the workstream have the opportunity to look at where we are – to read the draft protocol, contribute to it, and highlight areas they feel comfortable or uncomfortable with. So, together, we produce something that reflects the ambitions of the WMSDE programme and the needs of the population we serve.

“Then it needs to be submitted to the HRA and CAG for approval. As part of this, we’ll need to agree how we operationalise the protocol across the region with different organisations.”

Liz and Masood are keen that as many colleagues as possible from across the West Midlands join with them on this journey. The co-chairs hope their collective experience across primary and secondary care, commissioning, direct care and research and innovation, will help them engage widely with people working across the region’s health and care sector, as well as with patients and members of the public.

Liz, a Consultant in Respiratory and Acute Medicine and the Director of Pioneer – the HDR UK-funded Data Hub – said: “I think we bring very complementary but diverse skills in terms of the areas of healthcare in which we work. We’ve also been on very different paths when it comes to trying to bring data together, which gives us a broader understanding of how things work in different types of organisation.”

Masood, a GP Partner and Medical Director and Chief Clinical Information Officer for Birmingham and Solihull Integrated Care Board, added: “IG and ethics can be a very complex area and it’s vital everyone has the chance to be involved and contribute. Liz and I continue to work with many different stakeholders, but there are many more in this space for us to work with for the WMSDE. Engaging with all these people, listening to their concerns and learning from their experiences is going to be very important.”

Patient and public involvement, communications and engagement workstream

Patient and public involvement

We have now received 17 applications for membership of the Patient and Public Advisory Group (PPAG) and are planning the first meeting, due to take place on Monday, 2 October in Birmingham city centre (venue and timings to be confirmed). This first meeting will be a face-to-face event to give members the opportunity to meet each other and the programme team. For those who cannot make it to Birmingham, we are looking at a virtual alternative.



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 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 above or by visiting <https://nhs.welcomesyourfeedback.net/nq7mf2>.
- To request a paper version of the application, please email mlcsu.involvement@nhs.net.

Initial workstream meeting

The first meeting of the patient and public involvement, communications and engagement workstream will take place as a Teams call on Thursday, 7 September, from 3.30pm to 4.30pm. We have invited PPIE, communications and engagement leads from across the West Midlands. However, if you have not received an invitation and would like to attend, please email us at WMSDE@uhb.nhs.uk, using 'PPIE and communications and engagement workstream request' as your subject line.



The purpose of the workstream is to review and comment on PPIE, communications and engagement activity across the programme and ensure there is a golden thread of communications and PPIE throughout each of the different workstreams.

Technical design authority workstream



Steve Perks
Technical Design Lead

The West Midlands Secure Data Environment has achieved an important milestone, following the completion of the technical integration between the WMSDE data platform and our first integrator organisation – University Hospitals Birmingham (UHB).

This means the UHB IT network and the WMSDE network are now linked, which will allow data for research to securely flow from UHB to the WMSDE data warehouse.

The technical solution will become the blueprint for use with other integrating organisations.

Technical Design Lead, Steve Perks said: "Confirming we can successfully enable the secure flow of data into the WMSDE is a landmark moment for the programme. We now know we have a secure, practical technical solution we can use with other partners."

Commercial workstream

We have taken our first major steps towards the creation of a robust framework for how the commercial workstream will operate, with a number of important pieces of work now under way.

- We are building a commercial model aligned with NHS England's Value Sharing Framework for NHS data partnerships. The principles of the framework are:

- **Principle 1** – Cost of access should not prevent good use of data
 - **Principle 2** – The NHS will always charge a fee for accessing health data
 - **Principle 3** – The cost of access should depend on how data is being used
 - **Principle 4** – The NHS should share in the value created by its data
- We are also working with NHS England to co-develop a suite of products, including:
- a data access application form
 - a data access agreement
 - commercial contract(s)

These documents will be part of a ‘single front door’ for the NHS Research SDE Network, enabling researchers to apply for access to data in the same way, regardless of which SDE this is through.

- Following the workstream’s initial meeting, we have started drafting the data access agreement and commercial contracts with the support of MidTECH – the West Midlands NHS Innovation Hub hosted by University Hospitals Birmingham.



Guy Smallman
Commercial
Workstream Chair

Workstream meetings

Many thanks to everyone from across the region who has engaged with the WMSDE workstreams. Most of the introductory meetings have now taken place, with patient and public involvement, communications and engagement being held on 7 September.

Anyone who has not been involved so far but would like to be, can get in touch by emailing [the programme team](#). You can find a list of our workstreams at the bottom of this newsletter.

SDE network ‘community of practice’ launched

The WMSDE will be represented at the launch of a national ‘community of practice’ in September when senior leaders from across England meet in Oxford.



The event, for the NHS Research SDE Network, will bring together Senior Responsible Officers and Programme Directors to share progress on their SDE programmes.

We will report back on the main themes and discussions in a later edition of NewsBytes.

Blog explores SDE Network common data model decision

The adoption of a common data model across the NHS Research SDE Network is the subject of a new blog by Dr Chris Russell – NHS England’s Head of Delivery, Data for Research and Development.

In the blog, Dr Russell examines the reasons behind the move and the benefits it will bring. Read what he has to say on the [Health Data Research UK website](#).

HDR UK news

Health-related datasets survey

HDR UK has launched a survey to discover what’s most important to those looking for health-related datasets for research.



Anyone currently using or interested in using health-related data assets for their work, including academics, industry researchers, clinicians, healthcare professionals, data scientists, technicians and research support staff is invited to complete the survey. It can be found at https://hubs.li/Q01_MdQ70.

Health inequalities and diversity webinar

Registration is now open for places at the HDR UK Midlands Insight Sharing Webinar on the subject of ‘Health Inequalities and Diversity in Health Data Science’. The virtual event takes place on Wednesday, 18 October from 1pm to 4pm.

More information and booking details are available on the [HDR UK Midlands 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