

## West Midlands Secure Data Environment NewsBytes

February 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 the West Midlands SDE receiving Confidentiality Advisory Group (CAG) approval, the creation of a Data Trust Committee 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](#).

### Confidentiality Advisory Group (CAG) approval

The West Midlands Secure Data Environment has become one of the first SDEs to achieve Confidentiality Advisory Group (CAG) approval to process patient information for research.

Along with the 'favourable opinion' of the Research Ethics Committee, granted just days before CAG approval, this critical milestone paves the way for work to begin on the programme's planned data integration projects with regional data providers.

CAG is an independent body that provides expert advice on the use of patient information. Its purpose is to promote the interests of patients and the public in determining whether confidential information can be used for purposes beyond direct care without consent. Having reviewed the West Midlands SDE application, CAG said it was 'very impressed', particularly with the SDE's work on public involvement.



**Hilary Fanning**

Each SDE is required to present to CAG for review before the Health Research Authority (HRA) decides whether to grant its own approval. Following CAG's decision, the HRA gave its support, stating that 'the legal basis to allow access to the specified confidential patient information without consent is now in effect'.

Hilary Fanning, West Midlands SDE Programme Director, said: “We are delighted to receive approval from CAG and the Health Research Authority. This is the result of many months of hard work from our extremely talented and dedicated project teams.

“It shows our processes are robust and the authorising bodies are confident patient information will be handled correctly. This is an exciting development as it brings us significantly closer to delivering benefits to patients, the public and the NHS across the West Midlands.”

Principal Technical Lead, Steve Perks added: “This is excellent news. It means the technical team can undertake data ingress projects with regional data provider organisations and, where approved by our Data Trust Committee, make these data available for research on our platform.”

## Data Trust Committee update

The West Midlands SDE is looking for people to join its Data Trust Committee (DTC) – the body that acts as the patient and public voice in decisions about which research projects are supported through the SDE.

The DTC will meet regularly to approve or deny all requests for access to the West Midlands SDE. It will include membership from patients and the public, supported by NHS and academic experts.

Researchers will not be able to access data on the West Midlands SDE without DTC approval.

The DTC provides an in-depth review of data access applications to ensure proposed research is likely to result in patient and public benefit and is aligned to the ethical approvals. The DTC and all applications to the West Midlands SDE are covered by the Research Ethics Committee (REC) and Confidentiality Advisory Group (CAG) approvals.

Before applications are sent to the DTC, they will be carefully reviewed by technical, clinical and governance experts in the West Midlands SDE team – checking the feasibility, scientific and information governance merits of each request.

Efforts will be made to ensure the DTC reflects the region’s diverse population.

We will soon be sharing the opportunity for people to join the DTC. A training and induction programme with supporting materials will help DTC members contribute confidently and effectively.

Steven Blackburn, Patient and Public Involvement and Engagement (PPIE) Lead, said: “Creating our Data Trust Committee is extremely important for the West Midlands SDE. We are committed to having the public at the centre of



**Steven Blackburn**

decision making about who has access to data in the SDE and why. This is why we are inviting people to join us in these vital roles now.”

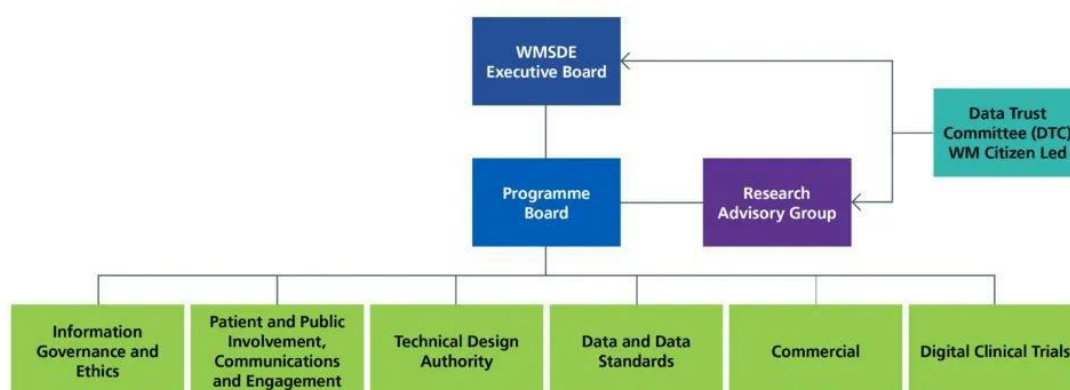
If you would be interested in joining, or you know of a good candidate for the DTC, please email the team at [mlcsu.involvement@nhs.net](mailto:mlcsu.involvement@nhs.net).

## Chair of the Research Advisory Group – expressions of interest

Professor Simon Ball, Senior Responsible Officer (SRO) for the West Midlands SDE, is inviting expressions of interest for the role of Chair of the Research Advisory Group (RAG).

This key leadership position, accountable to the SRO and Executive Board, is critical to the West Midlands SDE as RAG informs research priorities.

The West Midlands SDE’s governance structure is set out below:



Ideal candidates will be dynamic professionals with experience of research and research administration. Programmed Activity (or equivalent time for non-clinical post holders) is available to support the successful candidate in completing this role.

The post holder must be in receipt of relevant managerial or departmental support.

Candidates should submit a current Curriculum Vitae and a one-page EOI stating their interest, experience, and track record to the West Midlands SDE SRO, via Alice Young: [alice.young@uhb.nhs.uk](mailto:alice.young@uhb.nhs.uk) no later than **22 March 2024**.

For any informal discussions please contact [Simon.Ball@uhb.nhs.uk](mailto:Simon.Ball@uhb.nhs.uk).

## PPI, communications and engagement workstream update

### Patient and Public Advisory Group

We continue to work with our Patient and Public Advisory Group (PPAG) to inform future engagement sessions with the public and wider stakeholders to support the West Midlands SDE programme. This has involved engaging with more than 50 new groups resulting in 26 confirmed engagement sessions taking place between January and March 2024.

We have now held three Patient and Public Advisory Group meetings. The February meeting covered:

- ongoing support and involvement for members to reach out to new groups to support the West Midlands SDE programme
- discussion on introducing a Data Trust Committee
- discussion of local data opt-out vs national data opt-out.

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.

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](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).

## Digital Health Rewired 2024 conference – 12-13 March

The West Midlands SDE will have an exhibition stand and speakers at the Digital Health Rewired 2024 conference at the NEC in Birmingham on 12-13 March.



You can attend, meet our team and find out more about our work as well as many other healthcare initiatives. Steven Blackburn, Patient and Public Involvement Lead, and Liz Sapey, Information Governance and Ethics Lead, will also be speaking at the conference.

The Digital Health Rewired 2024 conference is a CPD-accredited event, with high-profile guest speakers and exhibition stands, bringing the NHS, social care, private healthcare, suppliers, start-ups, innovators, policy makers and patients together under one roof. Find out more and register on the [website](#).

## HDR UK news

### **HDR UK Alliance's fifth anniversary**

The HDR UK Alliance, established in February 2019, is an independent network of leading healthcare and research organisations. They work together to champion system-wide improvements in the availability of UK health data for research and innovation. During those five years its membership has grown to more than 100, it pioneered a data use register standard and it accelerated access to health data for vital research during the COVID-19 pandemic. Find out more on the [website](#).



### **Progress update on addressing NHS winter pressures through health data research**

HDR UK has published an update on 16 projects, funded by the Department of Health and Social Care through the National Institute for Health and Care Research. Among the projects, is a new tool to improve the flow of patients through Same Day Emergency Care, which was led by West Midlands SDE Information Governance and Ethics Lead, Liz Sapey, in her role at the University of Birmingham. Read more about this and the other projects on the [HDR UK 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