

West Midlands Secure Data Environment NewsBytes

November 24

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



This month we cover the Sudlow Review and the West Midlands SDE's continued growth. We also have the latest in our series of PPAG vlogs.

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](#).

Sudlow Review published

An independent review led by Health Data Research UK's Chief Scientist, Professor Cathie Sudlow, has highlighted the complexities and inefficiencies impeding the use of health data in the UK.

The Sudlow Review - '*Uniting Health Data in the UK*' – says health data should be seen as 'critical national infrastructure' requiring senior leadership and vital investment.

Professor Sudlow was commissioned to lead an independent review of the UK health data landscape, looking at the country's ability to use data to improve healthcare.

She said: "We are simply not maximising the benefits to society from the rich abundance of health data in the UK. Far too often research about health conditions affecting millions of people across the UK is prevented or delayed by the complexity of our data systems. We are letting patients and their families down as a result."

Her final report includes five recommendations that highlight the need to remove barriers, streamline processes, and enable safe and secure data use across the UK:



1. a coordinated joint strategy to recognise England's health data as a critical national infrastructure
2. the establishment of a national health data service with accountable senior leadership
3. ongoing, coordinated, engagement with patients, public, health professionals, policymakers and politicians
4. a UK-wide approach to streamline data access processes and foster proportionate, trustworthy data governance
5. a UK-wide system for standards and accreditation of secure data environments (SDEs) holding data from the health and care system.

Panel members at the launch emphasised the importance of patient and public involvement in being able to realise the benefits of health data.

The full report can be found on the [HDR UK website](#). You can also watch a [recording of the launch event](#), which was held at the Royal Society.

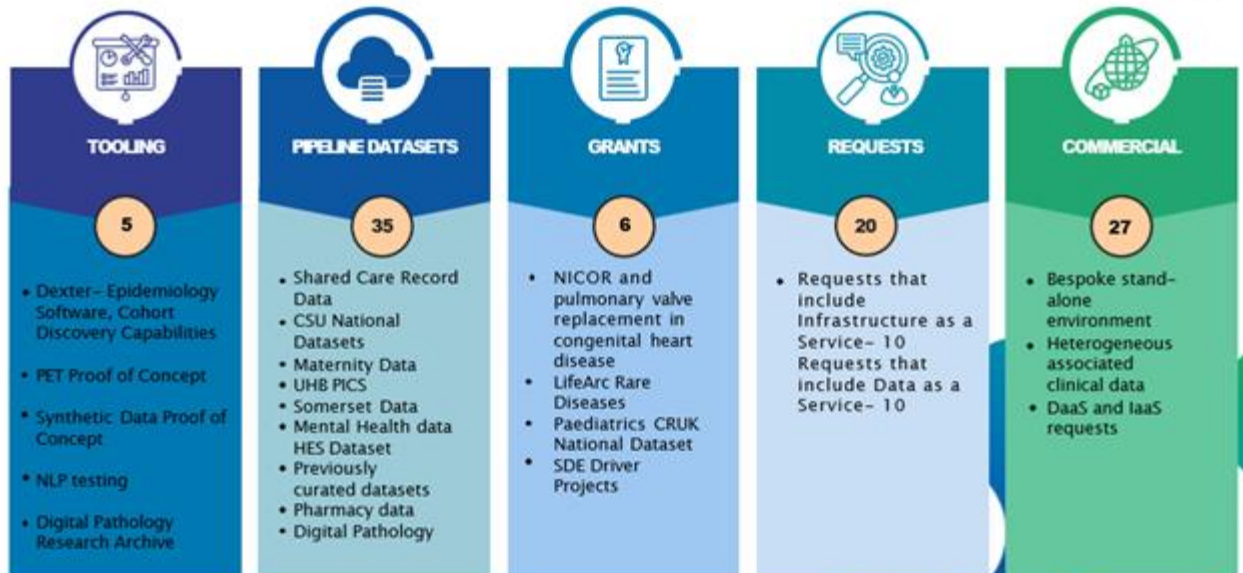
West Midlands SDE continues to grow

The West Midlands SDE is now fully operational, with 93 projects at various stages of development on the platform.

Earlier this year the SDE secured Confidentiality Advisory Group (CAG) and Research Ethics Committee (REC) approvals to process data for research purposes. Data access request protocols and the Data Trust Committee have also now been established. As a result, the West Midlands SDE is now able to start preparing data on the platform to be used for research.

The projects currently being worked on include the preparation of proof-of-concept datasets to demonstrate analytical tools. The SDE is also developing 35 pipeline datasets with partners and processing 20 data access requests.

Below is a breakdown of this work:



PROJECT OVERVIEW

Amy Gosling, Programme Manager, said: “We have an exceptionally talented team that has worked tirelessly for months to reach this landmark moment. We are extremely proud to be working with different stakeholders on several impactful projects and I would like to thank all those involved in getting us here.

“We are focusing on ensuring we work on projects that will support healthcare outcomes for people in the region and will continue to work to achieve our programme milestones.”

West Midlands SDE contact number

The West Midlands SDE programme team can now be contacted by phone as well as email.

The number to call is **0300 0132 181**.

Team members will be available to answer calls during the working hours of 9am to 5pm, Monday to Friday except bank holidays.

At other times, please leave a voice message and a member of the team will return your call the next working day. This information can also be found on the [Contact Us](#) page on our website.

West Midlands SDE brochure launches

Our newly created brochure about the West Midlands SDE is now available to download from our [website](#).

The nine-page document summarises what the West Midlands SDE is, how it works, the services offered and how SDE users can access them.

The brochure is one of many information resources that can be viewed and shared for use from our [website resources page](#).



Data Trust Committee's first meeting

Our panel of 15 Data Trust Committee (DTC) members met for the first time in October and started the process of reviewing applications. They will meet again in November as this work continues.

The DTC's role is to review requests to access data for research on the West Midlands SDE, ensuring data is used only:

- by the right people
- in the right way
- for the right reasons.

DTC members can be from all backgrounds. Specific healthcare, scientific or medical knowledge is not essential. If you are interested in joining, find out more here: <https://nhs.welcomesyourfeedback.net/yhto5a>

Patient and Public Advisory Group (PPAG) vlog

Professor Liz Sapey, Co-Chair of the SDE's Information Governance and Ethics workstream, attended the latest PPAG meeting to give an update on the workstream's work.

Following the meeting, PPAG member Ernest Green and Liz sat down for the latest in our series of PPAG vlogs. Ernest asked Liz how consent and opt outs worked on the West Midlands SDE, as well as how the team ensured data was of a high quality.



Liz told him the model the SDE used meant people's health data would be included unless they told us they didn't want it used for research. The result, she said, would be data that was 'rich and representative' and that research findings would be "much more likely to apply to the whole population".

Liz said: "We need to make as many people aware of this as possible so they know what the SDE is doing and how to opt out if they want to. Hopefully, once we share the benefits of this they will want to keep their data in so it can be used."

You can watch the vlog in full on our [website](#).

Find out more about PPAG

We have created a diverse PPAG that represents the voice of all members of the community. 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.

- To find out more about getting involved, please email: mlcsu.involvement@nhs.net
- More information is also on our [website](#).

SDE's sponsorship looks to the future

The West Midlands Secure Data Environment (SDE) supported an event aimed at increasing the involvement of children and young people in research.

Earlier this month, the Great Ormond Street Hospital Biomedical Research Centre (GOSH BRC) hosted a gathering of patient and public involvement (PPI) leads who work with younger participants.

At the event, researchers and research delivery facilitators shared best practices for engaging children and young people in PPI groups, addressing the challenges of recruiting these important voices.

The West Midlands SDE is working to create similar opportunities for young people in the region.

Amy Gosling, SDE Programme Manager, emphasised the importance of this work.

"Inspiring the next generation to engage with research is a responsibility we take seriously," she said.

"The research we conduct today will shape their future, so it's crucial to ensure their voices are heard. We're excited to support the GOSH BRC event and look forward to learning from its outcomes."

Hilary Fanning announces new role

West Midlands SDE Programme Director, Hilary Fanning, is leaving University Hospitals Birmingham (UHB) to become Director of Discovery at Moorfields Eye Hospital in London.

Hilary, who is currently Director of Research Development and Innovation at UHB, will lead the research and development strategy at Moorfields. She takes up her new post in November.

In addition to steering the development of the West Midlands SDE from its inception, Hilary has overseen a significant research operation at UHB. In 2023, she was awarded an Honorary MBE for her work with the West Midlands Genomic Medicine Centre.



In her new position, Hilary will retain her role as Senior Responsible Officer for the NHS England Data for R&D programme.

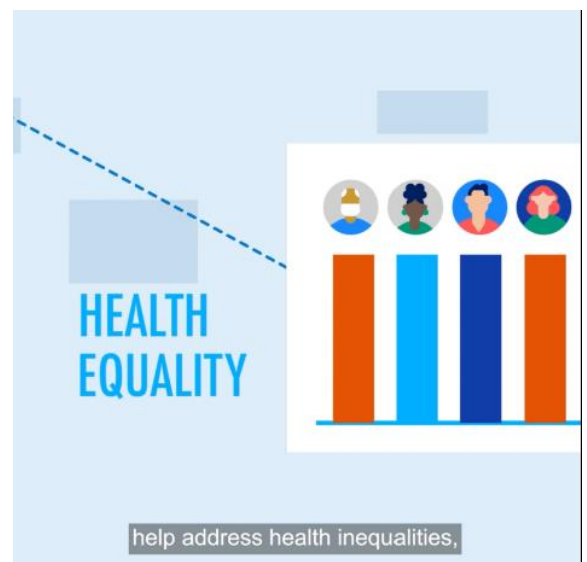
The programme team wishes Hilary all the best in her new endeavour and looks forward to continuing to work alongside her in her national Data for R&D role.

Understanding Patient Data animation

Research, policy and advocacy organisation, Understanding Patient Data (UPD), has produced a new animation explaining how secure data environments work and the benefits they provide.

Using easy-to-understand messages and graphics, the animation also looks at who can access health data through an SDE and the security measures involved.

The animation was co-designed with members of the public during UPD's 'What Words To Use' project, designed to measure public opinion on SDEs and develop resources. You can watch the animation on our [website](#).



There is also a new page on [UPD's website](#) that provides more information about SDEs.

HDR UK Gateway launches

The enhanced Health Data Research Gateway is now live, featuring improved integration with the NHS Research Secure Data Environment Network.



The collaboration between NHS England and Health Data Research UK (HDR UK) is transforming how researchers:

- discover NHS datasets
- navigate data access
- track data use.

Hilary Fanning, Senior Responsible Owner, Data for Research and Development Programme at NHS England, said: "We know that supporting research is key to helping the NHS deliver better patient care and to supporting innovation and growth. Streamlined, secure access to NHS data will enable faster research so that patients can benefit from new treatments and improved care without delay.

"The launch of the improved HDR UK Gateway provides a single front door to NHS data for approved research purposes, enhancing discoverability and speeding up access for researchers."



You can read the full press release on the [HDR UK website](#).

NHS Transformation Directorate statement: "Through our Data for Research and Development programme, we're proud to partner with HDR UK to make NHS data more accessible for approved research while maintaining the highest standards of security and governance."

AI tool identifies people at high-risk for emergency care

Researchers in Scotland are using AI (artificial intelligence) to improve a tool that predicts people most likely to need emergency hospital care. Read more on the [HDR UK website](#).

British Heart Foundation explores potential of AI to improve ECGs

The British Heart Foundation Data Science Centre, led by Health Data Research UK, is challenging researchers to explore the potential use of AI to enhance the use of electrocardiogram (ECG) tests. Read more on the [British Heart Foundation Data Science Centre 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.

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

- Patient and public involvement, communications and engagement
- Information governance and ethics
- Technical design authority
- Data and data standards
- Commercial
- Digital clinical trials