

West Midlands Secure Data Environment NewsBytes

September 24

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



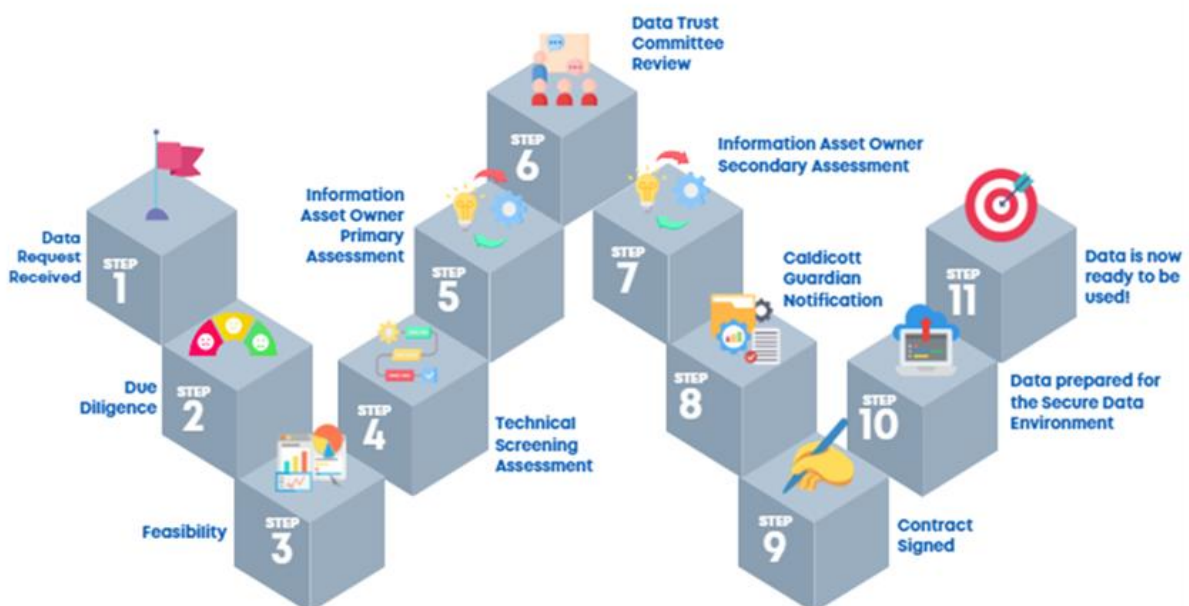
This month we outline our Data Access Request process, share another PPAG vlog and look at how the West Midlands SDE is supporting a major new research initiative aimed at improving diagnosis, treatment and care for prostate cancer patients.

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](#).

Data Access Requests – how are they reviewed and approved?

Data access requests for the West Midlands SDE follow a rigorous review process before researchers can use the platform.

An 11-step process, shown below, protects health and care data on the West Midlands SDE. This ensures data is always being used for the right reasons and by the right people. It also identifies early on whether the platform can deliver what researchers need.



The amount of time the process takes will depend on each individual request, based on the level of complexity involved.

Crucially, however long it takes, each step must be passed to ensure the West Midlands SDE follows the [Five Safes Framework](#).

This process has been designed following national guidance on data access and previous work to support research.

The Data Trust Committee and Patient and Public Advisory Group have also had input into this process and what the initial data access request form covers.

A step-by-step breakdown:

1. **Data access request received – a request** is submitted to use the West Midlands SDE and is ready for review. Researchers can either get to this point independently or involve the West Midlands SDE team earlier on if they need advice to complete the request.
2. **Due diligence** – the West Midlands SDE team completes due diligence to check whether requestors are responsible partners. They also review the proposed research to ensure it has enough potential to deliver public benefit.
3. **Feasibility** – this is an early check to ensure the West Midlands SDE can facilitate requests.
4. **Technical screening assessment** – once a request is seen as feasible, the technical aspects of pulling the required data together is looked at more closely. This helps to streamline the process later as the team will know exactly what they need to do.
5. **Information asset owner – primary assessment** – the governance team reviews the request to make sure the right ethical frameworks are in place for the research to proceed.
6. **Data Trust Committee review** – the Data Trust Committee will then review and make final decisions on data requests, ensuring transparency throughout. The Data Trust Committee consists of 13 members of the public who hold exclusive voting rights.
7. **Information asset owner – secondary assessment** – this second governance check makes sure once again everything is aligned before applications enter the final stages.
8. **Caldicott Guardian notification** – The Caldicott Guardian will review the requests and make decisions or give guidance, referring to the Caldicott principles. [Caldicott Guardians](#) are senior people responsible for protecting the confidentiality of people's health and care information and making sure it is used properly. All NHS organisations and local authorities providing social services have Caldicott Guardians.
9. **Contract signed** – contract negotiation is ongoing from start to finish. Once all steps have been successfully completed, contracts are signed.

10. **Data prepared by the SDE** – the West Midlands SDE prepares the data in the platform for researchers to use.

11. **Data is ready** – researchers are given access to the platform and can begin using the West Midlands SDE’s analytical tools to work with the de-identified data.

Several data access requests are currently working through this process, with the Data Trust Committee set to have its first review meeting in September.

Amy Gosling, West Midlands SDE Programme Manager, said: “It’s really important that we follow this process to release data for research purposes. We want to support secure access to data for innovative projects, while at the same time being transparent about what we’re doing and why we’re doing it.”

If you have any questions about data access requests or have a research idea you would like to pursue through the West Midlands SDE, please email WMSDE@uhb.nhs.uk. Our team members are always happy to talk this through and help if they can.

Patient and Public Advisory Group (PPAG) vlog

Our latest PPAG meeting focused on the information governance protocols protecting people’s data on the West Midlands SDE.

Information Governance Officer, Stephanie Kabare, gave a presentation before answering PPAG members’ questions.

You can watch our second [PPAG vlog](#) to find out more about the meeting.

Keith Fielding, PPAG member and vlog presenter, said: “It was very important to me and the other members that we received reassurance on how well controlled it is. The main thing I took from it was how secure data is in the environment.”



Joining PPAG

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.



- 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.

West Midlands SDE supports new data-driven approach to prostate cancer

The West Midlands Secure Data Environment (SDE) is supporting a major new research initiative aimed at improving diagnosis, treatment and care for prostate cancer patients.

In the first inter-SDE collaboration, West Midlands, North West and London SDEs are working with charity Prostate Cancer Research.

More widely, the NHS is joining forces with Prostate Cancer Research to provide unique access to healthcare data for research that could transform patient care and treatment of the disease.

The initiative, known as Prostate Progress and backed by actor and broadcaster Stephen Fry, has been selected to take part in NHS England's Data for Research and Development Programme. It is the first of a series of 'driver projects' that will support innovative uses of health data.

The project will provide safe and secure access to the clinical data of prostate cancer patients who agree to take part, alongside data the patients directly input – such as how they are feeling and the real-life effects of their cancer and its treatment.

Researchers hope to gain unique insights into prostate cancer by combining the two sets of data to understand more about the disease, develop new treatments and tests to improve diagnosis, monitor the safety of treatments, and plan new NHS services.

Stephen Fry, who has previously had prostate cancer surgery, is keen to encourage others living with a diagnosis to get involved with the project. Speaking of his support for Prostate Progress, Stephen Fry said:

“Prostate Progress represents a beacon of hope in the fight against prostate cancer, a disease that impacts countless lives globally.

“By harnessing the power of our own health information, we empower researchers to unlock vital insights, leading to groundbreaking advancements. We can bring the world closer to a future where this disease is no longer a threat, where early detection and effective, humane treatment saves lives.

“I am excited to be part of Prostate Progress and urge others to join me.”

Anyone diagnosed with prostate cancer, either recently or in the past, is being encouraged to take part in Prostate Progress. You can find out more information and sign up at www.ProstateProgress.org.

Dr Vin Diwakar, National Director of Transformation at NHS England, said:

“This unique collaboration with Prostate Cancer Research will provide new insights into prostate cancer and improve care for patients.

“The NHS Research Secure Data Environment Network allows us to link data and enable research at a scale not previously possible, while maintaining the highest levels of security.

“Researchers will benefit from the rich picture provided from NHS clinical data as well as information from patients who volunteer to take part and share their experiences.

“I’d encourage anyone who has had prostate cancer to sign up for Prostate Progress and help improve the lives of people with the disease.”

Oliver Kemp, CEO of Prostate Cancer Research, said:

“Prostate Progress puts data back into the hands of the patient, allowing them to record and track the impact of prostate cancer on their day-to-day lives.

“Putting patients at the heart of research and bringing the data they contribute together with clinical data will be massively powerful. It will be the key to driving forward scientific discoveries and innovations to deliver tests and treatments that meet patient need.

“We are delighted to be working in partnership with NHS England and look forward to working alongside our NHS colleagues as we reap the promised benefits for patients and the NHS.

“We are tremendously grateful to all those who have contributed to the work that has gone into designing and developing Prostate Progress and, most especially, to men diagnosed with prostate cancer, who have given freely of their time and energies to support this groundbreaking initiative.”

More information and videos can be found on the [Prostate Progress website](#).

There is also [a video of Stephen Fry](#) encouraging people to take part in Prostate Progress.

HDR UK News

Four new members join Health Data Research Alliance

Four organisations have joined the Health Data Research Alliance, including National PET Imaging Platform and the Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences. More is 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.

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