West Midlands Secure Data Environment NewsBytes   July 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 have a special edition focusing on our PPI, communications and engagement activities.

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.

General Election

As you may be aware, ahead of the General Election we had to pause most communications about our work.

This is because the West Midlands SDE is funded by the NHS, which operates under pre-election guidance that covers all public sector organisations.

What the West Midlands SDE means to people: case study

Health research is about finding new medicines, treatments and making health and care services better. The West Midlands SDE makes that easier by providing a larger regional pool of data that can be accessed in one, NHS-controlled environment.

In the previous NewsBytes, we featured Ruth Hereford talking about her experiences with

Ruth Hereford
West Midlands Secure Data Environment (SDE) Patient and Public Advisory Group Member

muscular dystrophy and hopes that the West Midlands SDE can help people like her. Now you can watch Ruth talk about this in our case study video.

Ruth said: "I thought I was on my own for the longest time and it's only now that I see a light and there's a possibility for some kind of a treatment in my lifetime."

Patient and Public Advisory Group vlogs

We are creating a series of video logs – or vlogs – to document what happens at our Patient and Public Advisory Group (PPAG) meetings. You can watch the first one now on YouTube.

These vlogs are led by our PPAG members. They summarise discussion points from the meetings, featuring conversations with key members of our programme operational group.

PPAG member James Whitaker hosts our first vlog. He sits down with Charlie Wonders, who co-chairs the Patient and Public Involvement, Communications and Engagement workstream.

Future vlogs will be shared in NewsBytes as soon as they are available.

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.

Engaging with under-served communities

We are carrying out extensive work with members of our region's under-served communities to inform and engage with them about the West Midlands SDE.

The Patient and Public Involvement and Engagement (PPIE) team has produced an interim report on this work so far. The report summarises findings from 31 face-to-face meetings with communities across the West Midlands. At these meetings, 141 attendees have provided feedback through focus groups, group meetings and questionnaires.

ENGAGEMENT ACTIVITY

931 Stakeholder database contacts

Dedicated Patient and Public Advisory Group

Feedback from:
- Patient and Public Advisory Group
- Under-served engagement – focus groups
- Questionnaire

31 Organisations   **141** Individuals

Below are some highlights from the report.
- Most people wanted more information with examples of the data that would be accessed by researchers.
- People wanted to understand the security measures in place to protect their data in the West Midlands SDE and how this would be regularly monitored.
- Further information was required to reassure people on how data is de-identified.
- People discussed what would reassure them, including but not limited to:
  - being kept informed once data had been accessed and given details of how this had helped researchers or would in the future
  - being given more information on how NHS staff keep data safe in the West Midlands SDE
  - having examples of the data records stored to prove that all data was de-identified.
- Most were reassured that the NHS was leading and managing the West Midlands SDE.
- Although many attendees understood how the West Midlands SDE benefits people using health and care services, the issues of data security and personal information being identified still remained key concerns – they felt they wanted more information in easy read formats, across all languages, and using multiple communication channels.
- Most felt that patients and public representatives should have a role in approving who is allowed to access the West Midlands SDE for research projects.

We thank all those who took the time to be involved.

A further 29 meetings are in the process of being confirmed.

The public at the heart of decision making

People interested in joining our Data Trust Committee (DTC) have now attended welcome meetings and confirmed if they want to become DTC members.

The DTC represents patients and the public in key decision making around future research undertaken through the West Midlands SDE.

Its 13 public members assess researchers' applications and hold exclusive voting rights. They are responsible for making recommendations on data requests, ensuring transparency throughout the process.

It is important that DTC members are given sufficient background information and training to fully carry out these duties. These initial meetings were about laying those foundations.

After hearing more about the Data Trust Committee and the responsibilities and commitment involved, those who attended the welcome meetings were asked to confirm if this was something they still wanted to do. Everyone who attended confirmed they want to become members of the DTC.

Two training sessions are planned for the DTC members over the next couple of weeks. Following the training sessions the first official DTC meeting will take place.

Reaching out to the general public

Plans are well under way for the launch of a public awareness campaign, designed to make more people aware of the West Midlands SDE.

The campaign will highlight how research carried out through the SDE will improve care, save lives and help reduce health inequalities.

We will use the extensive work we have carried out with our PPAG to inform this work.

As a first step towards talking with a wider audience, our team took part in the University Hospitals Birmingham NHS Foundation Trust's (UHB) research showcase.

The event was a celebration ahead of International Clinical Trials Day. Visitors were keen to find out about healthcare research, why it's important and what it does for them.

The West Midlands SDE team had a stand promoting the programme and listening to people's feedback.

Alice Young, West Midlands SDE Project Support Officer, said: "It was such a positive day with lots of interactions with the public and other research staff. We had a lot of people interested in finding out more about our Data Trust Committee and PPAG."
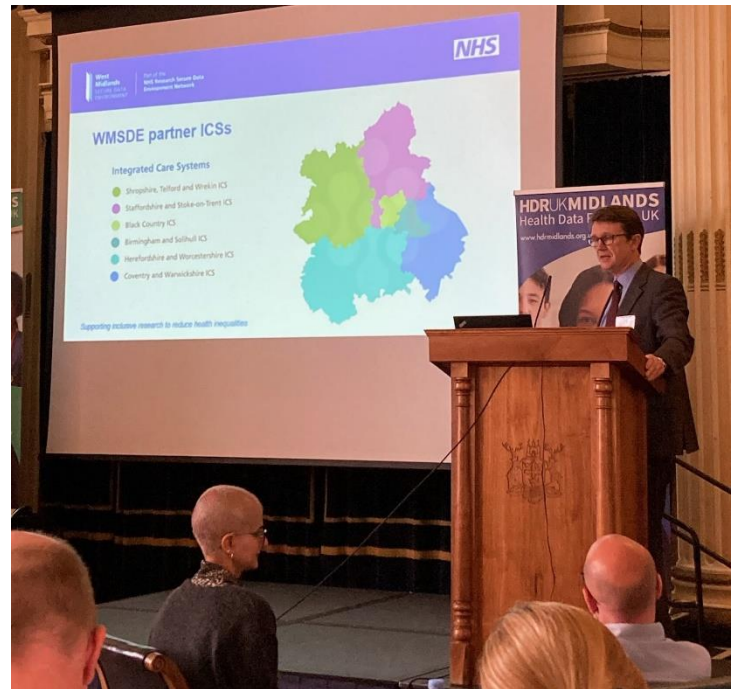
HDR UK Midlands conference

The West Midlands SDE had a strong presence at this year's HDR UK Midlands annual conference.

Around 150 people from the Midlands and beyond attended the event – including delegates from as far as Taiwan and Australia – underlining the region's crucial role in advancing health data research.

The West Midlands SDE was represented in several ways:

- Hilary Fanning, West Midlands SDE Programme Director, provided a national overview as part of her role as Senior Responsible Officer for NHS England's Data for R&D Programme.

- Professor Simon Ball, SDE Senior Responsible Officer, was on a panel discussing the key role secure data handling will play in advancing health research in future. He also gave a presentation on the SDE.

- Lisa Faria, Director of Healthcare Data Research at University Hospitals Birmingham NHS Foundation Trust, took part in a discussion about opportunities for future collaboration. She also presented on the subject of linking patient-level data assets.

The SDE also hosted an exhibition stand at the event showcasing our work and the impact we can make.

Understanding Patient Data

Research, policy and advocacy organisation, Understanding Patient Data (UPD), has published a report on its work focusing on the best language to use when explaining SDEs and TREs to members of the public.

Information about the research project, called 'What Words to Use', can be found on UPD's website, along with links to the report and other materials. UPD says an animation will follow soon, with the aim of it being available by the end of this summer.

Development of public trust metrics

The national SDE programme has developed a benefits realisation strategy to assess the progress of SDEs and support delivery.

Patient and public involvement and engagement (PPIE) and communications work is seen as a core component for building public trust, with a list of key metrics to judge this work:

- **Existence of a PPIE strategy**
- **Progress of a PPIE strategy** – judged by qualitative reports detailing this work
- **Case studies showing PPIE influencing policy**
- **Case studies showing public engagement**
- **SDE public representation**
- **Case studies of the development programme for the SDE public members and their influence.**

Get in touch

West Midlands SECURE DATA ENVIRONMENT

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