

## West Midlands Secure Data Environment NewsBytes

September 23

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 the patient and public involvement, communications and engagement workstream, the national network launch event and a piece about the benefits of the WMSDE for the West Midlands.



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 patient and public involvement, communications and engagement workstream

The Patient and Public Involvement, communications and engagement workstream works alongside the six other workstreams in the WMSDE to ensure we are involving, communicating and listening to our stakeholders and the public. The purpose of the workstream is to:

- ensure patients and the public are always seen, heard and involved in decision making
- keep partners and the public updated on key developments
- answer questions from patients, the public, partners and the media.



We believe patients and the public are essential to all decision making for the programme. Therefore we have set-up a Patient and Public Advisory Group (PPAG) ) to support this and are actively encouraging volunteers to [get involved](#). We would like to ensure our PPAG is diverse and representative of the region's population. The PPAG involves ordinary people who have experienced being a patient, carer, or a service user.

Alongside the development of the PPAG we will be embarking on a stakeholder engagement campaign to ensure our different audiences are fully informed on the WMSDE developments and the opportunities to be involved. Our audiences include:

- health and care staff within the partner organisations across the six ICS regions
- data providers
- data users.

We will also be providing support to the planned deliberative engagement campaign with the aim of discussing with our population the purpose of having a regional data environment for

research and what anticipated benefits this could bring to individuals, communities and the region as a whole.

The PPI, communications and engagement workstream is co-chaired by Steven Blackburn and Charlie Wonders. Steven is Lead for Public Involvement in Research, NIHR Research Design Service and Institute for Applied Health Research at University of Birmingham and Charlie is Head of Communications and Engagement for NHS Arden and GEM Commissioning Support Unit and strategic communications lead for the programme. Steven and Charlie bring a very different and unique set of skills to the programme.



Charlie Wonders



Steve Blackburn

Steven said: “I am really pleased to be involved in this programme of work and the real opportunities it has to offer with involving patients and the public in key data research development. To undertake engagement on such a large scale is unique in the research environment and will offer many opportunities and challenges. It is key that not only do the public understand what we are developing but also the why. The PPAG will have real opportunities to involve and inform on behalf of the wider population.”

Charlie said: “This is a great opportunity to have the wider discussion about data for research and the power of NHS data. From a communications perspective we need to ensure that all our communications are in plain English and accessible to all. We must respect there are multiple audiences that we will be talking to and ensure we tailor our communications accordingly. We are due shortly to launch the WMSDE website which will provide a central focus point for data users, data providers and the general public.”

The membership of the PPI, communications and engagement workstream includes PPIE leads, communications leads and engagement leads from across the region, PPAG representatives and representatives from advisory bodies. If you would like to be considered for membership of the workstream then please contact [WMSDE@uhb.nhs.uk](mailto:WMSDE@uhb.nhs.uk)

## PPI, communications and engagement monthly update

The PPI, communications and engagement workstream held its first workstream meeting on Thursday 7 September. The meeting was well attended with representatives from NHSE, HDRUK and several of the ICS regions. The meeting was an introduction to the WMSDE, the workstream, the objectives and some of the challenges. There were some lively discussion points and an acceptance that the first phase of stakeholder engagement may take longer than initial timelines suggested. There was an ask around: the benefits of local endorsement; a supporting toolkit; identification of quality improvements; a need for use cases; and, one voice across the region. The feedback will be included into the workstream workplan.

The first Patient and Public Advisory Group (PPAG) meeting will take place on Monday 2 October 12-2pm. It will be a face-to-face meeting in Birmingham with the ambition to give members the opportunity to meet one another and get to know the programme and the role of

PPAG. The session will be interactive with many opportunities for round table discussions. Speakers will include Programme and workstream leads who will set the scene for the workshop.

## NHS Research SDE Network launch event

On Friday 15 September the NHS Research SDE Network held a launch event in Oxford. There was good representation from across the National SDE and the regional SDE Network. The key speakers and panellists included Professor Sir John Ball, Tim Ferris and Claire Bloomfield.

The day opened exploring the fact that we don't really use data well except for when we are in a crisis such as COVID-19 and then we know how to use it. This is one of the challenges the SDEs face – how to collate and present the data so it can be used better. Claire Bloomfield highlighted there are 3 Cs to deliver:

- Confidence – in how we are doing this
- Collaboration – between SDEs as well as private and public sector
- Co-ordinated approach.

The Health Research Authority outlined the support they can provide to SDEs around standardising governance around the Confidentiality Advisory Group (CAG) and the Research Ethics Committee (REC) requirements. They also held a workshop on IG in the afternoon.

Professor Emily Jesson, CTO Health Data Research UK then introduced the room to the concept of a single front door for research data which can be connected/embedded into existing SDE websites. A further session in the afternoon reviewed some of the challenges/opportunities of a single front door.

There was a great deal of optimism in the room and the belief that we can deliver this and the network is working together to achieve the end goal.

A post-event pack will be made available from the event organisers which we will share in the next NewsBytes edition.

## The benefits of a West Midlands-wide SDE

The WMSDE will create better patient outcomes by increasing the scale of health and care research in the region, according to information governance and ethics workstream leads Professor Liz Sapey and Dr Masood Nazir.

There are examples of individual excellence across the West Midlands, but WMSDE will bring that work together for the first time.



Professor Liz  
Sapey



Dr Masood  
Nazir

Liz said: "There's never been a significant drive across the region to bring data together for research and innovation before.

“Everybody’s been doing it on their own and they’ve all been doing it well, but the WMSDE will bring that learning together so we can answer questions in a more holistic way, meaning the answers will have more impact for our patients.”

If an organisation is currently investigating a rare illness they may have access to data for a few hundred patients in their local population, but across the region that data could be enriched by possibly two or three times.

Further insight from those findings can highlight significant differences, such as backgrounds, experiences and local service provision.

Masood said: “We need to constantly be examining services to look at how they can improve. Sometimes doing that can reinforce how well you’re doing, but it can also highlight when there are ways of doing things better. Having access to data on a larger scale will improve this process and lead to better outcomes.”

Another benefit from this increased scale is that it could also increase data security.

Liz added: “People’s data will be accessed through WMSDE in a de-identified way.

“When researchers are working with larger data sets, as the WMSDE will provide, the chances of an individual being re-identified are much smaller.”

## Personalised type 2 diabetes support – powered by NHS data series

The latest video in the national ‘powered by NHS data’ series is called ‘navigating life-changing diagnoses: empowering patients with NHS data’.

It shows how, based on evidence that personalised diabetes support makes a difference to patients, an online tool was developed to give patients the tools and help they need to manage their condition while living their lives.



You can watch it on the [NHS Digital website](#).

## HDR UK news

### Digital leaders' network launches

HDR UK Midlands has launched a new NHS digital leaders' network across the East and West Midlands to drive digital transformation across the health and care system. The new Midlands Chief Clinical Information Officers' (CCIO) Network brings senior clinicians together from across the region. More information is on the [HDR UK Midlands website](#).



### HDR UK Midlands on social media

HDR UK Midlands has launched accounts on various social media platforms, including:

- [Twitter](#)
- [LinkedIn](#)
- [YouTube](#).

Follow the accounts to keep up to date with the latest news, events and opportunities.

## 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](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