West Midlands SECURE DATA ENVIRONMENT

Part of the NHS Research Secure Data Environment Network



# West Midlands Secure Data Environment (West Midlands SDE)

Introduction to the West Midlands SDE





#### What's this about?

The West Midlands Secure Data Environment (West Midlands SDE) is new. It will improve healthcare and support health innovation by making better use of health data for research and care planning.

You might be asked about the West Midlands SDE by people you provide care for.

This information will help you understand what the West Midlands SDE is, what it's for and what it means for everyone living in our region.

It will give you the details you need to explain where people can go for more information and how, if they so wish, they can opt out of their health data being used in this way.

So please take the time to get to know a little bit about the West Midlands SDE. For you, your family and those you provide care for.







#### What is the West Midlands SDE?

The West Midlands SDE is an NHS-led West Midlands initiative that allows researchers to analyse health and social care information without it leaving the secure environment, making it much safer.

Researchers will use this data to discover new medicines and treatments – faster and more efficiently than ever before.

The SDE will also enable care service planning to be better informed through data, supporting innovative advances in how care and treatment are provided.

By linking primary and secondary care data, the SDE will provide a more complete picture of people's health.

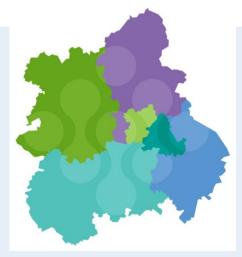




#### Local to you

The SDE covers six integrated care systems (ICSs) in the West Midlands, with a total population of 6.2 million and 848 health and social care partner organisations. An ICS is the partnership of those organisations in your local area.







Shropshire, Telford and Wrekin ICS

- Staffordshire and Stoke-on-Trent ICS
- Black Country ICS



Birmingham and Solihull ICS

- Herefordshire and Worcestershire ICS
- Coventry and Warwickshire ICS







#### Data saves lives



COVID-19 highlighted the importance of research being delivered quickly. A government strategy called <u>Data Saves Lives</u> was created to make sure the work in this area continued following the pandemic. The strategy's aim is to bring about health and care improvements through better use of health and care data, digital technologies and safe, ethical research.







#### The role of SDEs



Secure data environments are a critical part of the strategy.

Information about the care we receive can make a real difference to our family, friends, and neighbours. It can save lives – including our own.

The West Midlands Secure Data Environment will give authorised, trained researchers and care planners the ability to analyse the health and social care information from across our region in one, NHScontrolled environment. They will use this larger, regional pool of data to find ways to improve care for everyone, helping to reduce health inequalities.







### Who else is involved?

- Health and research organisations from across the West Midlands
- Patients and the public from our local communities
- The West Midlands SDE is part of the NHS Research Secure Data Environment Network covering the whole of England
- University of Birmingham; the University of Warwick; Keele University; Aston University; and the University of Nottingham









Is it safe?

The West Midlands SDE is part of a national programme run by the NHS, under strict levels of privacy and security:

- · people's information will be protected to ensure their confidentiality
- it will use the highest level of cyber security
- researchers and care planners, and their reasons for using people's health and care data, will be strictly vetted
- it will allow researchers and care planners access only to the information they need to answer their research or care planning question, and only in secure and controlled settings
- · local people are involved in overseeing the whole process.









### The Five Safes Framework



Safe data: protected to ensure people's confidentiality



Safe projects: only approved projects with clear public benefits



Safe people: only accredited, authorised, trained researchers and care planners





Safe settings: data used in secure environment only

Safe outputs: use of data is checked to ensure it protects privacy The Five Safes is the West Midlands SDE's guiding framework. It means the West Midlands SDE will be used only:

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

The Five Safes is considered best practice in data protection.





#### The benefits

Every x-ray, blood test result, GP appointment or experience of care we have is logged in our records, along with personal details such as our age and ethnicity. This wealth of information that exists about us all is incredibly valuable for:

- understanding what treatments and care work best, based on the experience of others
- · discovering how to prevent diseases so everyone can benefit
- reducing health inequalities in our local communities
- finding out how our genes and lifestyle affect our health
- improving how we detect, diagnose and treat diseases
- enabling us to offer innovative treatment and care sooner.







## Opting out

Our health and care information can play a vital part in helping with problems that affect the whole population – and those rare health conditions suffered by small groups of people.

Those who are happy for their health and care information to be used for research projects and care planning supported through the West Midlands SDE do not need to do anything.

#### Local Data Opt-Out

Anyone wanting to opt out of West Midlands SDE-supported research projects and care planning can download and complete an opt-out form from the Local Data Opt-Out page of our website.

This can then be emailed to <u>WMSDEOptout@uhb.nhs.uk</u> or sent to the postal address on the web page. There is also an opt-in form for anyone who changes their mind.

We will post details <u>on our website</u> soon for those who would prefer us to fill in the form for them over the phone.

#### National Data Opt-Out

It's also possible to opt out of **all** health research and care planning projects by visiting the national data opt-out service website at:

www.nhs.uk/your-nhs-datamatters/manage-your-choice/.







### How people can get involved

People who live in our communities are essential to decision making for the West Midlands Secure Data Environment. We want them to help us develop it, make sure it operates as it should, and hold us to account if needed. We want to listen to their views and act on their feedback.

There will be lots of chances to be involved. For instance:

- we've set up a Patient and Public Advisory Group
- people from our local communities will be members of the groups managing all our different areas of work
- we're holding engagement events across the region.

Anyone who'd like to get involved can email us at <u>WMSDE@uhb.nhs.uk</u>.









#### For more information...



#### Visit the West Midlands SDE website



www.WestMidlandsSDE.nhs.uk