


Saving lives in the West Midlands

Why we're all part of a
bigger health story



A smiling male doctor with a beard and stethoscope, holding a tablet, interacting with a patient. The doctor is wearing a light blue striped shirt. The patient is partially visible on the left, wearing large hoop earrings. The background is a bright, modern clinical setting with a green plant.

**Did you know,
every time you
visit your local
doctor or hospital,
you could be
helping save
someone's life?**

You might not realise it, but every x-ray, blood test and treatment you have could make a difference not only to your own health, but to that of other people as well – including your family. You too could benefit from what's learned from other people's care.

Our health information has been used to help others as well as ourselves for many years. It has led to the better care and longer lives we have now.

The role of research

Researchers from the NHS, universities and charities, along with the companies that make medicines and develop new healthcare technologies, find answers to important questions.

They do this by using the health and care information doctors and nurses collect from us and store in our health records. Over decades, researchers' work has brought about enormous changes. Here are just a few examples of what we've gained from health research.

- The number of women who survive breast cancer has doubled in the past 50 years.
- CT scans, first carried out in 1971, and MRI scans, introduced in 1980, are now everyday tools for checking what's happening inside our body and showing doctors if we have a disease or injury.
- Two drugs were found to treat COVID-19 infections, saving millions of lives. As did a brand new vaccine that researchers worked hard to develop quickly when we urgently needed it.

Research is what made all these amazing successes possible. Along with the knowledge gained from the information we help create when we receive care.

Health data saves lives. We can all contribute to it and we all benefit from how it's been used by researchers over many years – often before we were born.



A safer way with better results

Now the NHS is creating a new way in which this research will be carried out.

The West Midlands Secure Data Environment (West Midlands SDE) will bring together people's health and care information from across the whole region, keeping it safely within the NHS. Having such a large amount of knowledge will help researchers learn more about the health conditions that affect lots of us – and the less common ones suffered by just a few.

Working with the NHS, researchers will also be able to discover ways to help people living in areas of the West Midlands where health is poorer and lives are shorter. The West Midlands SDE will make this possible thanks to the large amount of useful information researchers will be able to study.

Having a much better picture of the health of people in our region will mean researchers will be able to find new medicines and treatments, while reducing the side effects of those we already have.

We'll also see new ways of working that will be better for our care. People who plan our health and care services will be able to use the SDE to learn if those services are still right for people living in our local communities. Having that understanding will show them what might need to change, and how.

Just like our family members before us, our health data and the way we're cared for will become part of a bigger story. Joined together with that of other people living in the West Midlands, it will help bring about new or different ways of caring for us, our family members, and future generations.

We operate under s251 regulations with support from the HRA (for research) and the secretary of state for health and social care on advice from the Confidentiality Advisory group (CAG). This allows us to link patient information from different resources for specific healthcare and research purposes. When data is requested or used, it is always provided in an anonymised form, meaning no personal details that could identify you are shared.

How safe will it be?

The West Midlands SDE will be used only:



by the right people – researchers and health and care service planners wanting to improve health and care



doing the right thing – carrying out research and service planning carefully and safely



in the right way – in secure and controlled settings



for the right reasons – to make a difference to people in the West Midlands.

How do we know that? Because:

- the West Midlands SDE is owned and run by the NHS
- we use the strictest, most up-to-date security
- we'll very carefully check researchers and health and care planners and why they want to use the West Midlands SDE
- we'll allow researchers and health and care planners to see only the information they need to answer their research and health and care planning questions, and only in secure and controlled settings
- local people, like you, will be involved to make sure the West Midlands SDE stays safe and private, and that the research and health and care planning the West Midlands SDE supports will help solve health problems for people in our local communities.

Get involved

There'll always be ways for you to take part in the West Midlands SDE's work, from having a say in how it develops to giving opinions on how health information should be used.

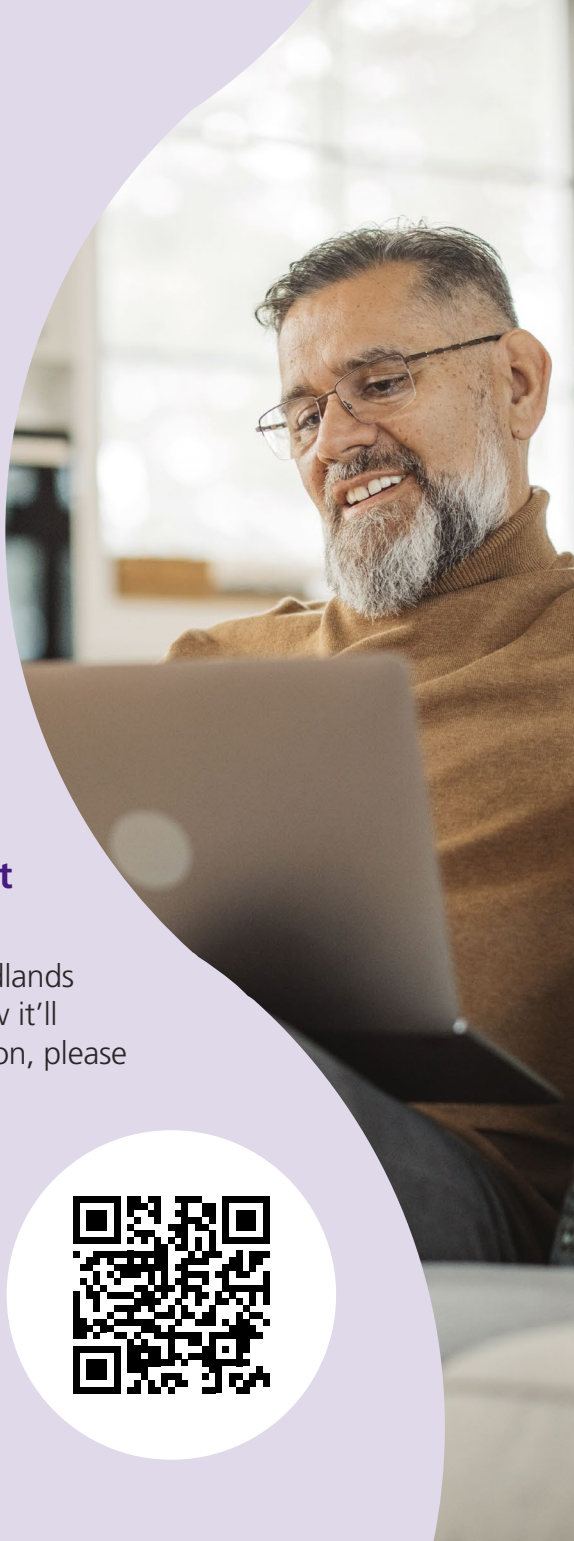
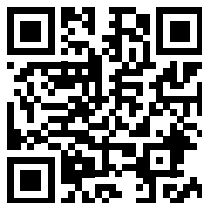
To find out more about, for example, membership of our Patient and Public Advisory Group, or the events we'll be running across the West Midlands, please email us at mlcsu.involvement@nhs.net

Want to know more about the West Midlands SDE?

To learn more about the West Midlands Secure Data Environment and how it'll benefit everyone living in our region, please visit our website at

www.westmidlandssde.nhs.uk

Scan me to
be directed to
our website





If you don't want researchers and health and care service planners to use your health information

We need researchers to keep trying to find new, life-saving medicines and treatments, especially for our biggest health problems such as cancer and dementia. They can only do this if we allow them to carry on using our health information in the way they've done for many years.

We also need to understand more about what everyone living in the West Midlands needs to live a healthier, longer life. What we can learn from people's information will help us plan health and care services that work better for them.

Only accredited, trusted researchers and health and care planners will be allowed to see information through the West Midlands SDE – and only for work that will make things better for us.

However, if you'd like to opt out of allowing your health information to be used for research and health and care planning, you can find out how to do so on the next page.

How to opt out

West Midlands SDE only

If you want to opt out only from West Midlands SDE-supported research projects or care planning, please download and complete a form from our website's Local Data Opt-Out page at <https://westmidlandssde.nhs.uk/your-data/local-data-opt-out/>.

You can email this to us at WMSDEOptout@uhb.nhs.uk, or post it to:

**West Midlands SDE
R&D
1st Floor
ITM
Heritage Building
Queen Elizabeth Hospital
Birmingham
B15 2TH**

If you would like to opt back in, you can do so at any time using the opt-in form at <https://westmidlandssde.nhs.uk/your-data/local-data-opt-out/>. You can download, complete and return this in the same way as for opting out.

If you would prefer us to complete the form for you, we will soon be able to do this by phone. We will publish more details on our website page at <https://westmidlandssde.nhs.uk/your-data/local-data-opt-out/> when this service is available.

If you would like this information in an alternative format, (for instance, braille, audio, easy read or your spoken language) please email WMSDE@uhb.nhs.uk.