

Data: saving lives in the West Midlands

The bigger health story

Supporting inclusive research to reduce health inequalities



We're all part of something bigger

Every time you visit your local doctor or hospital, you could be helping save someone's life.

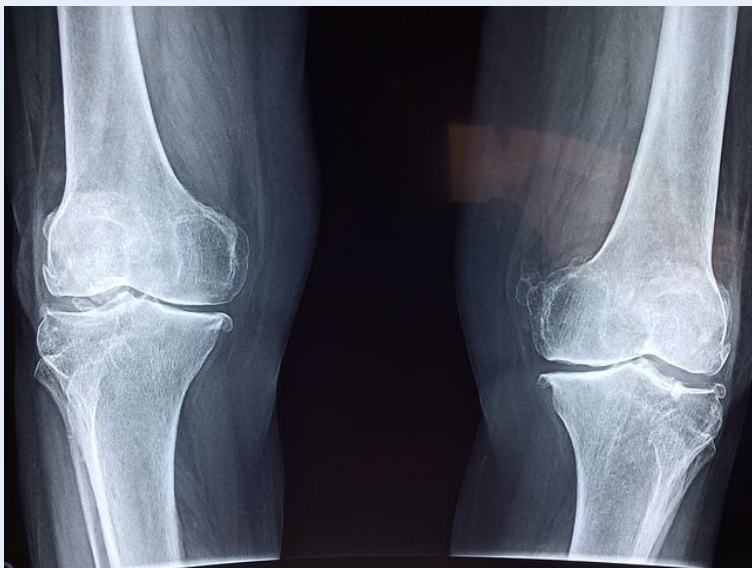
It might be a family member or friend. At some point, care they have might even save you.

That's because the information doctors and nurses collect from us is used to help everyone.

Supporting inclusive research to reduce health inequalities



Our health information saves lives



It's been that way for many years.

Every x-ray, blood test and treatment that we have leads to information doctors and researchers can learn from.

This is how we get new life-saving medicines and treatments. And how we develop new healthcare technologies.



Safer and better



Now the NHS is creating a new way for researchers to carry out this important work. It's called the West Midlands Secure Data Environment – or West Midlands SDE for short.

People who plan our health and care services might also use the SDE to learn if those services are still right for people living in our local communities.

The SDE will keep our health information even safer than it's been before and will give doctors, researchers and service planners much more information to help everyone in our area.

It won't change what happens – just how.



To help us and future generations

The West Midlands Secure Data Environment will join together our health information with that of other people living in the region. Having a much larger amount of information to work with will make it easier to find new or different ways of caring for us and our family members – now and for future generations.



Why health research is important

Research has helped us in many ways. For example:

- Two drugs saved lots of lives during COVID-19. As did a vaccine researchers worked hard to develop when we needed it urgently.
- CT and MRI scans take place every day to check what's happening inside our body and show doctors if we have a disease or injury.
- The number of women who survive breast cancer has doubled in the past 50 years.

Research, along with learning from our health information, made all these things possible.

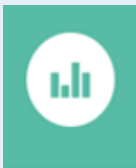


How safe is it?

The West Midlands Secure Data Environment will strictly follow something called the Five Safes framework. It's five things that need to happen to keep people's information as safe as possible.

It means the West Midlands SDE will be used only:

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



Safe data: protection to keep your personal details private



Safe projects: only those that are agreed and trusted to make things better



Safe people: checks on researchers and service planners to make sure they're trustworthy



Safe settings: protecting your information inside the secure environment



Safe outputs: checking researchers' work to make sure it doesn't include your personal details



How can we be sure?

- The NHS owns and runs the West Midlands Secure Data Environment
- We use the best, 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, are involved to make sure the SDE stays safe and private, and that the research and health and care planning it supports will help solve health problems for people in our local communities.



Where it's happening

The West Midlands Secure Data Environment will include health information from people living in these areas



Shropshire, Telford and Wrekin



Staffordshire and Stoke-on-Trent



Black Country



Birmingham and Solihull



Herefordshire and Worcestershire



Coventry and Warwickshire



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.

If you're happy for your health and care information to be used for research projects and care planning supported through the West Midlands SDE, you don't need to do anything.

Local Data Opt-Out

If you want to opt out **only** from West Midlands SDE-supported research projects and care planning, just download and complete an opt-out form from the [Local Data Opt-Out page](#) of our website.

You can then email this to WMSDEOptout@uhb.nhs.uk or send to the postal address on the web page. There is also a form to opt back in if you change your mind.

We will post details [on our website](#) soon for anyone who would prefer us to fill in the form for them over the phone.

National Data Opt-Out

You can also 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-data-matters/manage-your-choice/.





How you can get involved

If you live in the West Midlands, you can have a say in how the West Midlands Secure Data Environment works. We want to hear what you think so we can get it right.

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

- we've set up a Patient and Public Advisory Group
- people like you will be members of the groups managing all our different work areas
- we'll hold events across the region for you to take part in.

GET INVOLVED

Email us at:

WMSDE@uhb.nhs.uk



More information

Visit the West Midlands SDE website



www.WestMidlandsSDE.nhs.uk

