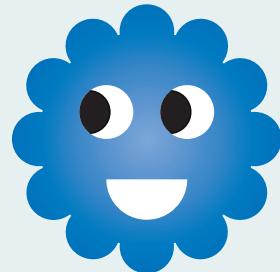


How does the SDE get consent for research?

I understand my health data can help improve healthcare for everyone, but I want to feel protected. Can I choose whether or not to share?

You can opt out through the National Data Opt-Out service, meaning researchers won't have access to your data. Your care won't be affected.





What if I want to share my data for some research projects but not others?

Huge amounts of data exist in different places, making it too hard for researchers to get lots of permissions on a case-by-case basis.



So who gives you permission to access my data without my consent?

Hi! I'm James Batchelor, technical lead for the Wessex SDE project. We ask the NHS Health Research Authority who have the power to approve the safe and secure use of your data for research when asking everyone's permission would not be practical.



How do I know that the research is going to be good for me and society?

The Wessex SDE will have an independent committee, which includes members of the public, who will have the final say on what research can happen.

How do they decide?

The public will help us decide the rules – and all research must be ethical, relevant, and have a clear public benefit.

Your health data can help improve healthcare for everyone. We must also protect your data and respect your choices. The Wessex Secure Data Environment (or SDE) needs consent to access your data. It also needs a trusted way to decide which research projects can happen. Here's how we do this:

The SDE can't ask you individually every time we want to use your data for research—that would be too slow and hard to do. We need to use a lot of data from different places.

Instead, we ask the NHS Health Research Authority for permission. They have a special rule that lets us use your data safely and securely (this is Section 251 of the National Health Service Act 2006). We can only use your data for research that has a clear public benefit and can't be done with anonymous data.

Your data is protected by law in the SDE, for example, by the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. The NHS organisations that share your data with us also have a data protection officer who ensures its safety and appropriate use.

The SDE then has an independent committee that decides which research projects can happen in the SDE. They make sure that the research is ethical, relevant, and has a clear public benefit. The public will help design this committee and be part of it.

You can still choose how your own personal data is used. Anyone can opt-out of their data being used for research and planning that's not about your care using the National Data Opt-Out service. You can also make a choice for someone else like your children under 13. Opting out will not affect your care.



You can find more information on the NHS Digital website.

Credits:

Bournemouth University has produced these toolkit materials for the University Hospital Southampton NHS Foundation Trust, who lead the Wessex Secure Data Environment (SDE) project, part of a national programme funded by the NHS England and the Department of Health and Social Care.

Project led by Professor Anna Feigenbaum.

Design by Open & Honest.