



Understanding Longitudinal Population Study Data and the Law

Common Law Duty of Confidentiality

For more information
ukllc.ac.uk/lps-data-and-the-law

This is a legal principle that means information provided by patients to a health or social care service is provided in confidence. This information can be used for research in certain circumstances.

“As a longitudinal study participant, what is important for me to know?”

“My confidential data will be managed in line with **reasonable expectations**¹ that are **fair and transparent**.”

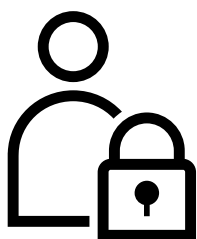
“My **permission is needed** for my confidential patient data to be used.”
(see exemption below)

“I can use the National Data Opt-Out² to say I don’t want my health records shared, **unless explicit consent has been given**.”

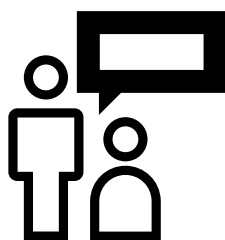
“If I lack capacity to consent, **my rights** under the Common Law Duty of Confidentiality **still apply**, even **after I’ve died**.”



“My longitudinal population study has a responsibility to:”



Protect participants’ confidentiality throughout the research process



Provide participants with updates on how their data is used over time, with an option to object and change their permissions

Exemption

The Digital Economy Act³ and Section 251 of the NHS Act 2006³ allow participants’ data to be used without consent where this will result in benefit to the public. Longitudinal population studies do this to make sure research is accurate and fair to all groups and communities.

¹ Something you’re likely to expect or assume, rather than something that comes as a surprise or seems unrelated.

² Applies to people living in England.

³ See sheet 2 – ‘Digital Economy Act (DEA) 2017’ and sheet 4 – ‘Control of Patient Information Regulations (2002) and Section 251 of the NHS Act 2006’ for more details.

Information correct at time of publication (v1, July 2024). If you have any questions about how your data is making a difference for research, please contact your study team directly.

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