



Summary: Understanding Longitudinal Population Study Data and the Law

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

Longitudinal population study participants provide their study with data about their health and wellbeing that is used for research in the public good.

The laws and legal principles related to the use of this type of data are complex. This series aims to inform longitudinal population study participants how these relate in a way that is easy to understand.

UK Data Protection Laws

(UK General Data Protection – UK GDPR, Data Protection Act 2018 – DPA)



“I know I have data protection rights, but these don’t always apply to me as a participant in a longitudinal population study. This is because some rights could result in stopping the ability to carry out public good research”
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Digital Economy Act (DEA) 2017

“Broader and more in-depth research can be carried out by linking my longitudinal population study data to administrative data, such as my occupation, education, tax and benefits records.”
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Common Law Duty of Confidentiality

“I can expect that my health data – created when I attend health and care providers – is kept confidential, as is my longitudinal population study data. My longitudinal population study should let me know how my data is used, and provide ways for me to object.”
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Control of Patient Information (COPI) Regulations 2002 (and Section 251 of the NHS Act 2006)

“My confidential patient data can be used without my consent but only under strictly controlled circumstances. My longitudinal population study should make best efforts to let me know how my data is being used.”
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If you have any questions about how your data is making a difference for research, please contact your study team directly.