

Understanding Longitudinal Population Study Data and the Law

UK Data Protection Laws

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

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

UK Data Protection laws regulate the use of **personal data** (data which can identify a person) across all data use. This includes organisations, businesses, the government as well as university and NHS-led research.

Your standard rights under these laws are:



to be informed about how your data is being used



to be able to access your data



to have your data corrected



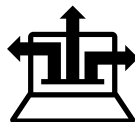
to ask for your data to be destroyed



to restrict the use of your data



to object to the way your data is used



to move your data to another organisation



rights related to automated decision-making, including profiling

Not all these rights apply to research

Why? Because they can harm ongoing and future research if applied.



Exemptions are in place for research

Why? So that research data can continue to improve and save lives.



Longitudinal population studies must protect the confidentiality, integrity and availability of personal data.

Confidentiality

Your data is kept confidential and secure, there is no unauthorised access and researchers only access pseudonymised¹ data.

Integrity

Data is accurate, consistent, reliable and only used for research. Your study has to provide you with information on how your data is used.

Availability

Approved researchers apply to access data and show they are trained to work with data. If granted access, they are given the minimum amount of data needed for their project.

¹ Data where the information that can identify a person has been removed and replaced by a research identifier (ID) or "pseudonym", typically random codes that make no sense.

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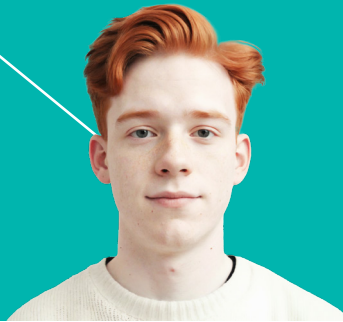
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“I’m a longitudinal population study participant², how do the exemptions for research under the UK’s Data Protection laws affect my rights?”

“My study may **not allow data to be erased**, as it could seriously impair previous and current research. But almost all longitudinal population studies give you the **right to stop** your data being used **from the point you tell** them you want to do so.”



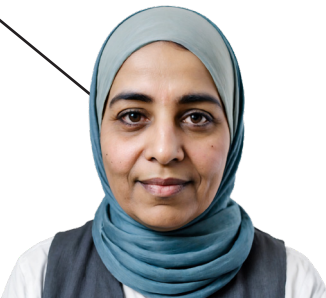
“**Exemptions** to my rights depend on the longitudinal population **study**. They’re not applied automatically, my study will carefully consider what exemptions apply.”



“I **can’t have** my study **data corrected** but I can ask for my **name and address** to be **updated**.”



“I **can’t transfer** my study **data** to another study as they may record data differently and collect different types of data, making this a complex process.”



“**Accessing my individual study data may not be possible**. It raises ethical issues and can create scientific bias³.”



Longitudinal Population Studies



Do respect your right to be informed



Do allow you to restrict the way your data is used



Do stop collecting data if you object

2 A person who voluntarily joins a study where their personal data is collected over time for the purposes of longitudinal research. For example, filling out questionnaires or attending clinics for measurements such as height, weight or providing blood samples.

3 When the way in which research is carried out may lead to results that are not objective or accurate.

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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