

# UK Longitudinal Linkage Collaboration Survey - longitudinal study data, laws and safeguards

## Which organisation is asking me to complete this survey and what do they do?

UK Longitudinal Linkage Collaboration (UK LLC) is the national Trusted Research Environment (TRE) for the longitudinal research community. UK LLC securely holds linked longitudinal data from many of the UK's most established longitudinal studies and participants' NHS, socio-economic and environmental records. It allows applications to access the linked data – within the TRE - for research in the public good.

UK LLC is led by the Universities of Bristol and Edinburgh, in collaboration with University College London, Swansea University and the University of Leicester and works with four nation NHS authorities and the Office for National Statistics.

## What is the purpose of this survey?

UK LLC's Public Advisory Group and members of the UK LLC team are co-producing a series of infographics to explain the various laws and safeguards that govern how longitudinal study data is used, who is allowed to use it and for what purpose. The results of the survey will inform part of this co-produced work. Don't worry if this is a subject where you don't know much about the questions being asked. Understanding what you know and what you don't know will help us when creating the infographics.

## What is a longitudinal study?

Longitudinal studies gather data about people's lives over time. This data is made available for research in the public good and can lead to discoveries that improve people's lives. People who volunteer to join a longitudinal study are called study 'participants' or 'volunteers'.

## Will I be paid for completion of this survey?

Yes. You will be offered payment of an e-voucher of £15 for completion of the survey. Section 3 of the survey has a link that you need to **copy and open in a separate window** - this is how you can claim your payment. **You will need to then make sure you have returned to this survey and clicked 'submit'**. This step is needed to keep your responses anonymous from your payment.

## How long will this survey take to complete?

We expect this survey to take around 15 minutes to complete.

## When does the survey need to be returned?

Please complete the survey by Monday 29th January 2024.

## Will I be able to see the infographics that have been created?

Yes. The infographics will be published on UK LLC's website (<https://ukllc.ac.uk>) when finalised and will be publicly available for other organisations and individuals to read and download free of charge.

- If you have any questions or concerns about any of the content of this survey, please contact us at [comms@ukllc.ac.uk](mailto:comms@ukllc.ac.uk)
- For more information on UK Longitudinal Linkage Collaboration (UK LLC) visit our website: <https://ukllc.ac.uk/>
- UK LLC's Privacy Policy – <https://ukllc.ac.uk/privacy-policy/>
- UK LLC's Promises to Study Participants - <https://ukllc.ac.uk/our-promises/>

\* This form will record your name, please fill your name.

## 1. Are you a longitudinal study participant? \*

☐ Yes

☐ No



2. If yes, how long have you been a longitudinal study participant?

- ☐ 0-2 years
- ☐ 3-5 years
- ☐ 6+ years
- ☐ Can't remember

3. Are you a public contributor/patient partner/lay representative/expert by experience? \*

- ☐ Yes
- ☐ No

4. If yes, how long have you been a public contributor/patient partner/lay representative/expert by experience?

- ☐ 0-2 years
- ☐ 3-5 years
- ☐ 6+ years
- ☐ Can't remember

5. Have you heard of any of the following laws and safeguards? (tick all those that apply) \*

- ☐ Common Law Duty of Confidentiality
- ☐ Section 251 of the NHS Act 2006
- ☐ Digital Economy Act 2017
- ☐ UK General Data Protection Regulation (GDPR)
- ☐ Control of Patient Information (COPI) Regulations 2002
- ☐ Human Rights Act
- ☐ Mental Capacity Act
- ☐ Human Tissue Act
- ☐ Data Protection Act 2018
- ☐ I have not heard of any of these laws and safeguards



6. Out of a score of 6 (where 1 is no knowledge and 6 is detailed knowledge) where would you say your level of knowledge sits on each area of laws and safeguards? \*

|                                                                   | 1                     | 2                     | 3                     | 4                     | 5                     | 6                     |
|-------------------------------------------------------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Common Law<br>Duty of<br>Confidential-<br>ity                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Section<br>251 of the NHS<br>Act 2006                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Digital<br>Economy Act<br>2017                                    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| UK General<br>Data Protection<br>Regulation<br>(GDPR)             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Control of<br>Patient<br>Information<br>(COP) Regulations<br>2002 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Human Rights<br>Act                                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Mental Capacity<br>Act                                            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Human Tissue<br>Act                                               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Data Protection<br>Act 2018                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



7. Without looking up information about the laws and safeguards, read the following quotation and select the law or safeguard you think it relates to.

*"...allows the common law duty of confidentiality to be lifted temporarily to enable disclosure of confidential patient information for medical purposes." \**

- ☐ Common Law Duty of Confidentiality
- ☐ Section 251 of the NHS Act 2006
- ☐ Digital Economy Act 2017
- ☐ UK General Data Protection Regulation (GDPR)
- ☐ Control of Patient Information (COP) Regulations 2002
- ☐ Human Rights Act
- ☐ Mental Capacity Act
- ☐ Human Tissue Act
- ☐ Data Protection Act 2018
- ☐ Not sure

8. Without looking up information about the laws and safeguards, read the following quotation and select the law or safeguard you think it relates to.

*"Where information is given in circumstances where it is expected that a duty of confidence applies, that information cannot normally be disclosed without the individual's consent." \**

- ☐ Common Law Duty of Confidentiality
- ☐ Section 251 of the NHS Act 2006
- ☐ Digital Economy Act 2017
- ☐ UK General Data Protection Regulation (GDPR)
- ☐ Control of Patient Information (COP) Regulations 2002
- ☐ Human Rights Act
- ☐ Mental Capacity Act
- ☐ Human Tissue Act
- ☐ Data Protection Act 2018
- ☐ Not sure



9. Without looking up information about the laws and safeguards, read the following quotation and select the law or safeguard you think it relates to.

*"Personal data shall be processed lawfully, fairly and in a transparent manner in relation to individuals." \**

- ☐ Common Law Duty of Confidentiality
- ☐ Section 251 of the NHS Act 2006
- ☐ Digital Economy Act 2017
- ☐ UK General Data Protection Regulation (GDPR)
- ☐ Control of Patient Information (COP) Regulations 2002
- ☐ Human Rights Act
- ☐ Mental Capacity Act
- ☐ Human Tissue Act
- ☐ Data Protection Act 2018
- ☐ Not sure

10. Without looking up information about the laws and safeguards, read the following quotation and select the law or safeguard you think it relates to.

*"Information held by a public authority in connection with the authority's functions may be disclosed to another person for the purposes of research which is being or is to be carried out." \**

- ☐ Common Law Duty of Confidentiality
- ☐ Section 251 of the NHS Act 2006
- ☐ Digital Economy Act 2017
- ☐ UK General Data Protection Regulation (GDPR)
- ☐ Control of Patient Information (COP) Regulations 2002
- ☐ Human Rights Act
- ☐ Mental Capacity Act
- ☐ Human Tissue Act
- ☐ Data Protection Act 2018
- ☐ Not sure



11. Some participants lose the capacity to make consent decisions, for example, people with dementia. If they had already been taking part in a longitudinal study, do you think it would be appropriate to carry on using their data? \*

- ☐ Yes
- ☐ No
- ☐ Not sure

12. In relation to your answer to Question 11 about whether or not you feel it is acceptable to continue to use data provided by participants who have lost their capacity to give consent, how strongly do you feel about this?

Select the relevant response depending on whether you answered 'yes' or 'no' to Q11. If you answered 'not sure' you can leave this question blank.

|                                 | Neutral               | Moderate              | Strong                |
|---------------------------------|-----------------------|-----------------------|-----------------------|
| I answered 'yes' to Question 11 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I answered 'no' to Question 11  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

13. In relation to your answer to Question 11 about whether or not you feel it is acceptable to continue to use data provided by participants who have lost their capacity to give consent, what would be needed to make this acceptable to you?

14. After a participant has died, if they had already been taking part in a longitudinal study, do you think it would be appropriate to carry on using their data? \*

- ☐ Yes
- ☐ No
- ☐ Not sure

15. In relation to your answer to Question 14, where you indicated whether or not you felt it was acceptable to continue to use the data of a longitudinal study participant after they have died, how strongly do you feel about this?

Select the relevant response depending on whether you answered 'yes' or 'no' to Question 14. If you selected 'not sure' to this question you can leave this question blank.

|                                 | Neutral               | Moderate              | Strong                |
|---------------------------------|-----------------------|-----------------------|-----------------------|
| I answered 'yes' to Question 14 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I answered 'no' to Question 14  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



16. In relation to your answer to Question 14, where you indicated whether or not you felt it was acceptable to continue to use the data of a longitudinal study participant after they have died, what would make this acceptable to you?

17. Would it be a surprise to you to learn that in the event of a major emergency, there is legislation that allows confidential patient data to be used for the purposes of research to aid the major emergency? For example, during the coronavirus pandemic, confidential patient data was used to enable researchers to aid the understanding, diagnosis and treatment of COVID-19. \*

☐ Yes

☐ No

18. Would it be a surprise to you to learn anonymous data can be used without people's knowledge or consent? \*

*Anonymous data is information that has had personal identifiers, such as name and date of birth, removed – meaning that no individual can be identified*

☐ Yes

☐ No

19. Would it be a surprise to you to learn that health treatment groups, for example cancer registries, can be compelled to provide data into research resources? \*

☐ Yes

☐ No

20. Would it be a surprise to you to learn that there are committees appointed to make decisions about what research is in the public interest and fair (equitable) - and that these committees can allow people's data to be used without consent on the understanding all reasonable efforts are made to inform people and let them opt-out? \*

☐ Yes

☐ No

21. Do you know how to exercise your right to sign up to the National Opt-Out (England only)?

☐ Yes

☐ No



22. Do you know how to exercise your right to withdraw/opt-out from your longitudinal population study?

Only answer this question if you answered 'yes' to Question 1 where we asked if you are a longitudinal study participant.

☐ Yes

☐ No

23. Do you know how to exercise your right to request a partial withdrawal/opt-out from your longitudinal population study? For example, remaining within the study but withdrawing consent to sharing data with commercial organisations?

Only answer this question if you answered 'yes' to Question 1, where we asked you if you are a longitudinal study participant.

☐ Yes

☐ No

24. Individuals have the right to choose whether their personal data is used in research, does it matter to you if this was done through an opt-in or opt-out mechanism? \*

☐ I would prefer to opt-in

☐ I would prefer to opt-out

☐ I don't have a preference

25. In relation to the answer you provided in Question 24, about whether you would prefer to opt-in or opt-out of your personal data being used for research, how strongly do you feel about this?

Neutral

Moderate

Strong

I answered that I would prefer to opt-in

☐

☐

☐

I answered that I would prefer to opt-out

☐

☐

☐

26. In relation to Question 24, where we asked if you would prefer to opt-in or opt-out of having your personal data used for research, if you have indicated a preference, what are the factors driving this?





27. It is known that making contact with some groups of people to ask for an opt-in consent is particularly hard (for example, children in the care system, homeless people, people with mental ill-health) which means the research can be biased and not be able to help some vulnerable communities. Do you think there should be a way to enable research to be representative of all groups and include seldom heard communities where appropriate safeguards exist? \*

- ☐ Yes
- ☐ No
- ☐ Not sure

28. In relation to Question 27 where we ask you if there should be a way to enable research to be representative of all groups and include seldom heard communities where appropriate safeguards exist, how strongly do you feel about this?

|                                 | Neutral               | Moderate              | Strong                |
|---------------------------------|-----------------------|-----------------------|-----------------------|
| I answered 'yes' to Question 27 | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I answered 'no' to Question 27  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

29. In relation to Question 27 where we ask you if there should be a way to enable research to be representative of all groups and include seldom heard communities where appropriate safeguards exist, what safeguards would be needed?



## A short section to complete about you, as the person completing the survey.

### Why are we asking for this information?

We are asking for this information to understand if the surveys have reached a representative group of our population, or not, and if any responses reveal a pattern that show a different level of understanding among groupings of people of the laws and safeguards relating to the use of longitudinal data. This information will not be shared outside of the UK LLC co-production team.

### Will sharing this information mean I can be identified?

No. The information we collect in this section of the survey **will not be used to contact you** in the future and **will not be used in a way that can identify you** and connect you with your responses. If you have any concerns about providing this information, you can select 'prefer not to say' for any question or leave this section blank.

### 30. What is your age group?

- ☐ 18-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ Over 65
- ☐ Prefer not to say

### 31. What gender do you identify with?

- ☐ Man
- ☐ Woman
- ☐ Non-binary
- ☐ Prefer not to say
- ☐ Prefer to self describe (type in box below)
- ☐ Other

### 32. Do you have a long-term physical or mental health condition or illness, lasting or expected to last 12 months or more?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say



**33. In which country do you live?**

- ☐ Scotland
- ☐ England
- ☐ Wales
- ☐ Northern Ireland
- ☐ Elsewhere
- ☐ Prefer not to say

**34. Please select the highest level of education that you have attained**

- ☐ No qualification
- ☐ NVQ1/SVQ1
- ☐ O-Level/GCSE/NVQ2/SVQ2/Scottish Intermediate
- ☐ Scottish Higher, NVQ3, City and Guilds, Pitman
- ☐ A-Level, Scottish Advanced Higher
- ☐ Higher vocational training (e.g. Diploma, NVQ4, SVQ4)
- ☐ University degree
- ☐ Postgraduate degree (e.g. Masters or PhD), NVQ5, SVQ5)
- ☐ Prefer not to say



35. **What is your ethnic background? Choose from one option that best describes your ethnic group or background.**

- ☐ Asian/Asian British - Indian
- ☐ Asian/Asian British - Pakistani
- ☐ Asian/Asian British - Bangladeshi
- ☐ Asian/Asian British - Chinese
- ☐ Asian/Asian British - Other Asian background
- ☐ Black/Black British - African
- ☐ Black/Black British - Caribbean
- ☐ Black/Black British - Other Black Background
- ☐ Middle-Eastern
- ☐ Mixed/multiple ethnic groups - White and Black Caribbean
- ☐ Mixed/multiple ethnic groups - White and Black African
- ☐ Mixed/multiple ethnic groups - White and Asian
- ☐ Mixed/multiple ethnic groups - Other mixed/multiple ethnic background
- ☐ White - English, Welsh, Scottish, Northern Irish, Irish
- ☐ White - Other white background
- ☐ Other ethnic group - Arab
- ☐ Other ethnic group
- ☐ Prefer not to say



## Claiming your £15 e-voucher

Please copy (not click) the link below and **open in a separate window** for details of how to claim your e-voucher.

Then **come back to this form and make sure you click 'Submit'**

<https://forms.office.com/e/muNRetqYw6>

This is necessary to make sure your survey answers are anonymous and you can still claim your e-voucher.

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