



The UK Longitudinal Linkage Collaboration (UK LLC)

Integrating consented and non-consented data for longitudinal population studies.

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University of Bristol
July 2022

A collaboration to benefit public health



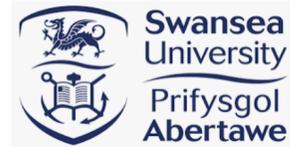
UK LLC led by the Universities of Edinburgh and Bristol



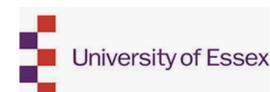
THE UNIVERSITY
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In collaboration with



A work package in the COVID-19 Longitudinal Health & Wellbeing National Core Study



A collaboration to benefit public health



Today's talk:

- Longitudinal Studies
- UK Longitudinal Linkage Collaboration
- Social Licence & 'Consent'
- Q&A

UK Longitudinal Population Studies: Building a 'Bank of Life'



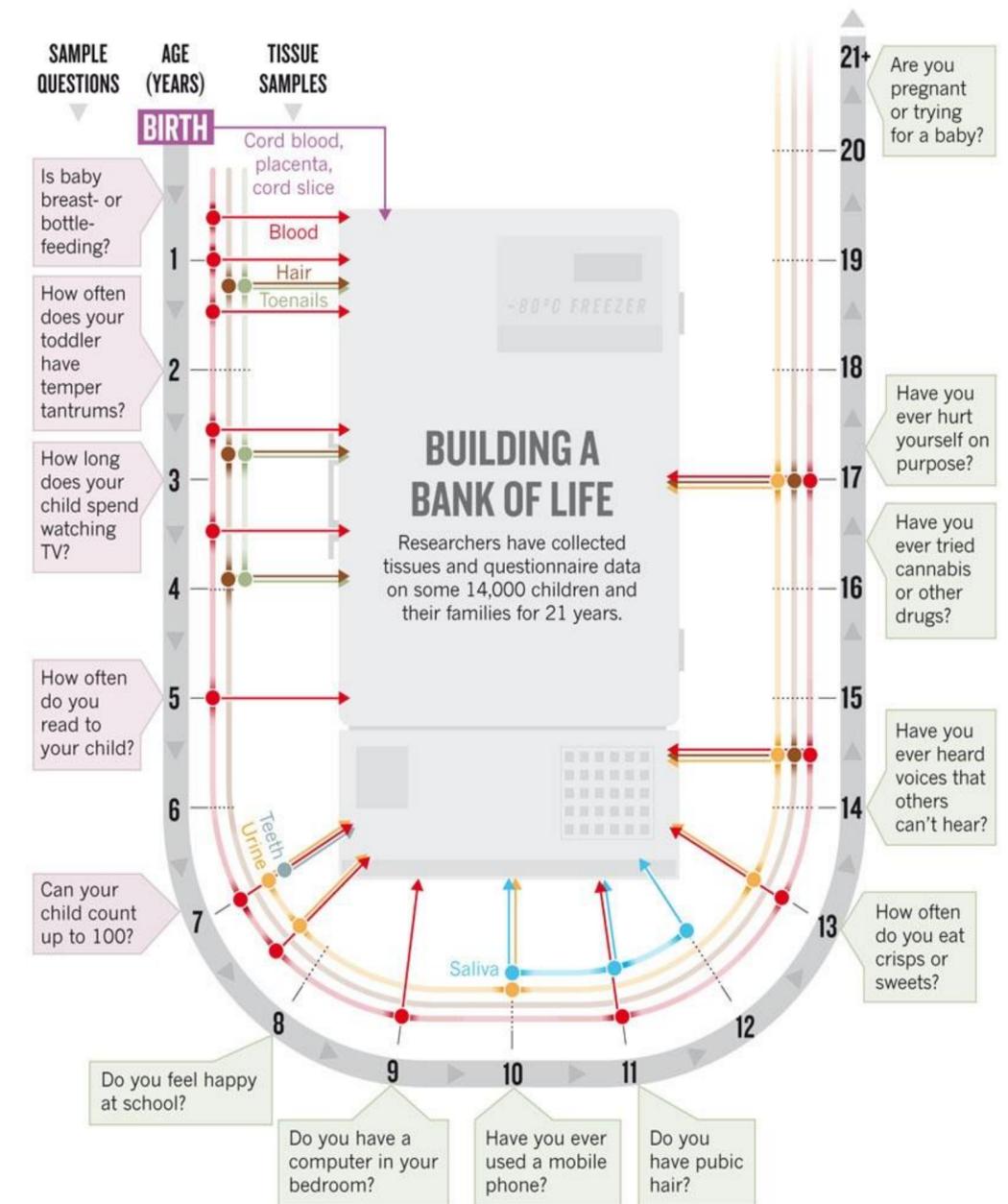
What are Longitudinal Studies?

- A research design where the health, socio-economic and wellbeing events and outcomes of individuals with shared characteristics are followed-up regularly over time: building a 'bank of life'
- 50-100 UK LPS inc. ~2-3 million UK residents
- Data collected directly from participants (surveys and samples) and via 'Record Linkage' to participants' health, administrative geo-spatial and novel (digital footprint, sensor) records.



<https://www.nshd.mrc.ac.uk/>

<https://www.bristol.ac.uk/alspac/about/>



Pearson H. Coming of age. Nature. 2012 Apr 12;484(7393):155.

'Consent' (in the context of longitudinal research)



(Explicit, Opt-in) Consent is not...

- The legal basis for LPS to address Data Protection legislation
- Necessary for the flow and analysis of data
- Always practicable or fair
- A flexible mechanism to manage 'reasonable expectations' in a rapidly changing world

Consent is...

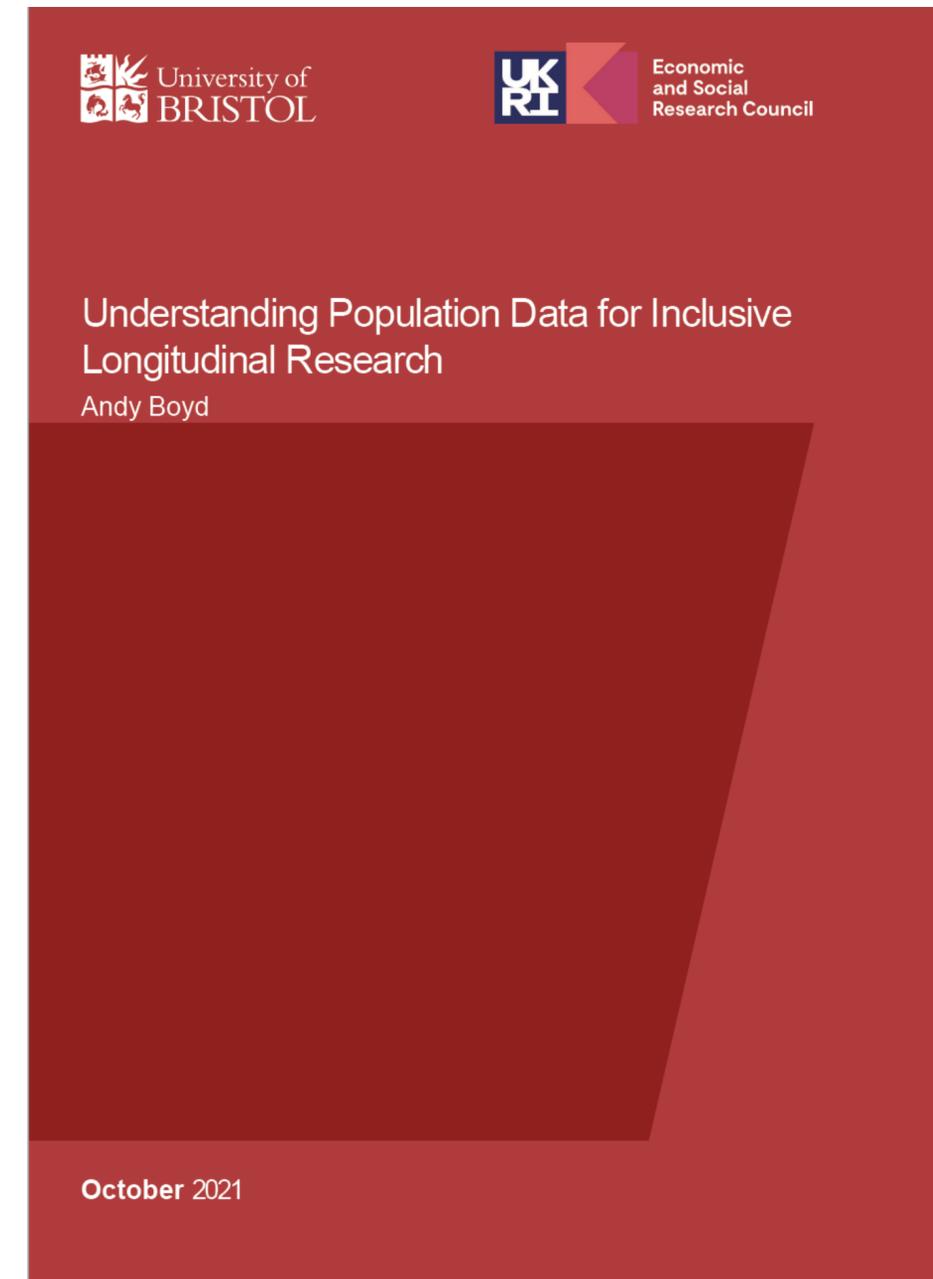
- A critical dimension of research ethics and trust relationships
- A means to address Common Law Duty of Confidentiality (other means exist)
- Highly desirable in terms of ethics, transparency and autonomy

The 'Consented Studies'



Consent can be fragile.

- Validity of 'Consent' is challenged by whether it is 'informed' and the passing of time:
 - Precision of information available at the point of consent
 - Emerging scientific opportunities
 - Changing expectations in best practice
 - Key life stages (reaching majority, loss of capacity, death)
- Potential for bias (in retrospective collection)
- Not all LPS are 'consented' – but strategies need to retain social licence and participant trust meaning they need to be **transparent, fair and respectful of rights.**





The UK Longitudinal Linkage Collaboration (UK LLC)

UK Longitudinal Linkage Collaboration: a national Trusted Research Environment for the Longitudinal Community.



- A four nation TRE for secure cross-cohort analysis of pooled participant data - with regularly refreshed linkages of COVID-19 relevant health and administrative records;
- To align complex and divergent governance frameworks into a streamlined and predictable linkage/access route for NCS researchers.
- A new way of working for record linkage; potential to contribute to any UKRI/WT Population Research UK (PRUK) programme

UK Longitudinal Linkage Collaboration



20+ longitudinal studies with >250,000 participants
A new Trusted Research Environment
Equivalency in study governance & fair processing
Novel NHS Digital data pipeline
Negotiating approvals for administrative data linkages
Public contributors & application panel
Fifteen applications approved & projects underway

ukllc.ac.uk



Using SeRP (serp.ac.uk) secure analysis platform

ALSPAC: Avon Longitudinal Study of Parents and Children

BCS70 British Cohort Study

Born in Bradford

ELSA: English Longitudinal Study of Ageing

EPIC-Norfolk: The European Prospective Investigation into Cancer (EPIC) Norfolk Study

EXCEED: Extended Cohort for E-health, Environment & DNA

The Fenland Study

Generation Scotland

GLAD: Genetic Links to Anxiety and Depression Study

MCS: Millennium Cohort Study

NCDS58: 1958 National Child Development Study

Next Steps

NICOLA: Northern Ireland Cohort for the Longitudinal Study of Ageing

NIHR BioResource_COPING: National Institute of Health Research BioResource, COVID-19 Psychiatry and Neurological Genetics Study

NSHD46: MRC National Survey of Health and Development Cohort/1946 Birth Cohort

TRACK-COVID Study

TwinsUK

Understanding Society - the UK Household Longitudinal Study

A globally unique cross-cutting resource



20+ Longitudinal Population Studies

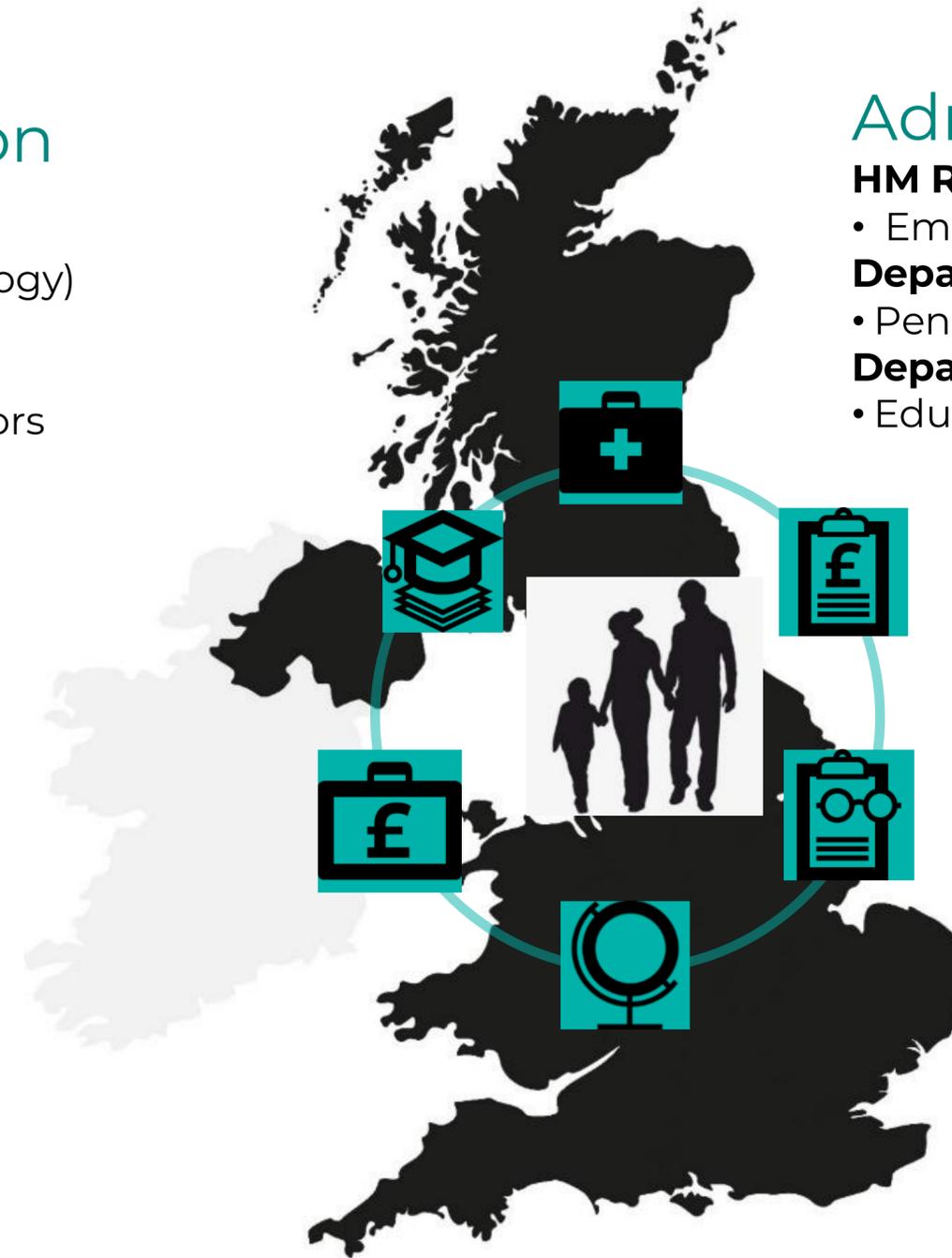
- COVID-19 collections (Questionnaires, Serology)
- SES & demographic
- Baseline physical & mental health
- Baseline family, SES and life-course indicators
- Genetics

NHS COVID-19 datasets

- GP Data
- Vaccinations
- COVID-19 test data (Pillar 1-3)
- Accident & Emergency
- CHES

Wider NHS datasets

- Hospital Inpatient data
- Cancer & mortality registers
- Community Mental Health (MHSDS, IAPT)
- Prescribing data



Administrative records

HM Revenue & Customs

- Employment, earnings & benefits

Department for Work & Pensions

- Pensions & benefits

Department for Education

- Education pathways & attainment

} **Negotiating data access**

Environmental & neighbourhood

- Air pollution
- Noise
- Greenspace
- SES & demographic
- Service provision

} **Modelled & Geocoding underway**

Social Licence



To be seen as publicly and politically acceptable, any data use will need a 'social licence' that is achieved through setting conditions that **extend beyond legal compliance and data protection and encompass ethical standards, the respect of individual rights and the delivery of public benefits.**

The social licence for research: why *care.data* ran into trouble

Pam Carter,¹ Graeme T Laurie,² Mary Dixon-Woods¹

<https://jme.bmj.com/content/41/5/404.short>



<https://www.ukri.org/publications/longitudinal-studies-understanding-population-data-for-inclusive-research/>

A Social Contract with LPS participants

Exemplar from the ALSPAC cohort



[Int J Popul Data Sci.](#) 2020; 5(3): 1728.

PMCID: PMC9053133

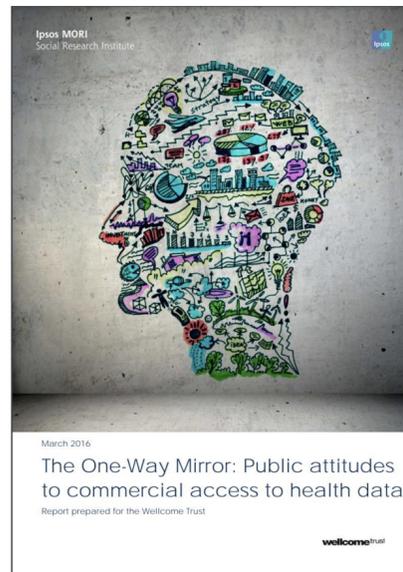
Published online 2022 Mar 16. doi: [10.23889/ijpds.v7i1.1728](https://doi.org/10.23889/ijpds.v7i1.1728)

PMID: [35519823](https://pubmed.ncbi.nlm.nih.gov/35519823/)

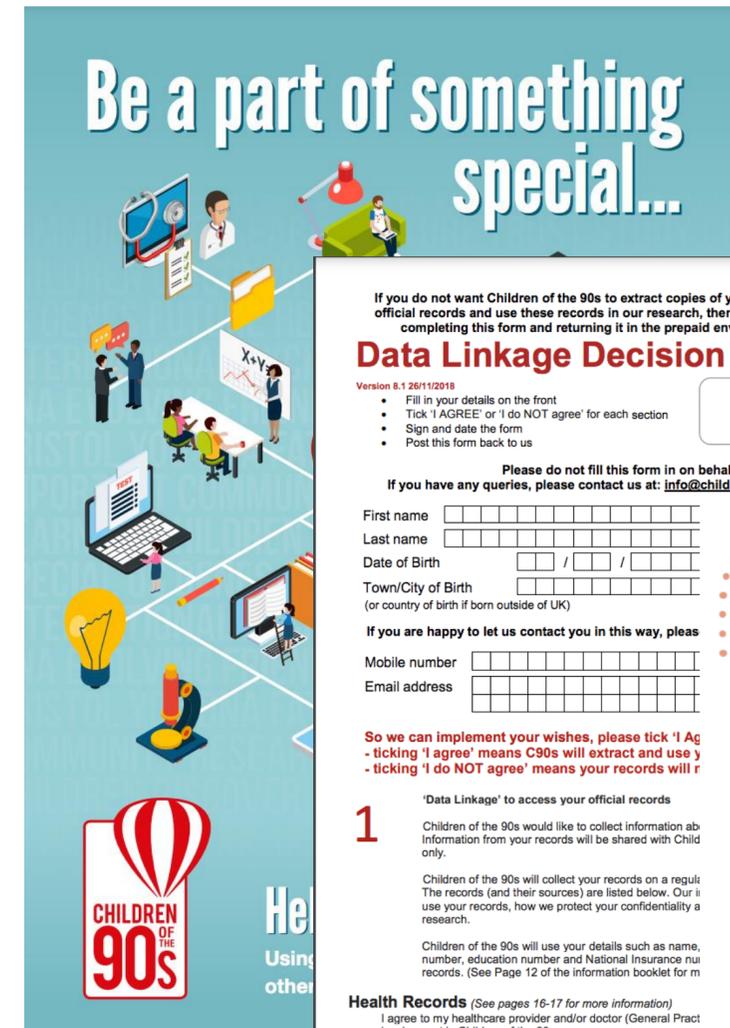
Participant acceptability of digital footprint data collection strategies: an exemplar approach to participant engagement and involvement in the ALSPAC birth cohort study

[Kate Shiells](#),^{1,2,3} [Nina Di Cara](#),³ [Anya Skatova](#),^{1,2,3} [Oliver S.P. Davis](#),^{2,3} [Claire M.A. Haworth](#),^{2,4} [Andy L. Skinner](#),^{1,5} [Richard Thomas](#),³ [Alastair R. Tanner](#),³ [John Macleod](#),^{6,7} [Nicholas J. Timpson](#),^{3,6} and [Andy Boyd](#)^{3,6,8,*}

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9053133/>



<https://wellcome.org/sites/default/files/public-attitudes-to-commercial-access-to-health-data-wellcome-mar16.pdf>



If you do not want Children of the 90s to extract copies of your health and other official records and use these records in our research, then please OPT-OUT by completing this form and returning it in the prepaid envelope provided.

Data Linkage Decision Form

- Version 8.1 26/11/2018
- Fill in your details on the front
 - Tick 'I AGREE' or 'I do NOT agree' for each section
 - Sign and date the form
 - Post this form back to us

Please do not fill this form in on behalf of another person

If you have any queries, please contact us at: info@childrenofthe90s.ac.uk or on 01173 310 010

First name

Last name

Date of Birth / /

Town/City of Birth

(or country of birth if born outside of UK)

If you are happy to let us contact you in this way, please

Mobile number

Email address

So we can implement your wishes, please tick 'I Agree' - ticking 'I agree' means C90s will extract and use your records - ticking 'I do NOT agree' means your records will not be used

1 'Data Linkage' to access your official records
Children of the 90s would like to collect information about your records. Information from your records will be shared with Children of the 90s only.

Children of the 90s will collect your records on a regular basis. The records (and their sources) are listed below. Our use of your records, how we protect your confidentiality is described in the information booklet.

Children of the 90s will use your details such as name, address, date of birth, education number and National Insurance number records. (See Page 12 of the information booklet for more information)

Health Records (See pages 16-17 for more information)
I agree to my healthcare provider and/or doctor (General Practitioner) involvement in Children of the 90s.

and
I authorise my healthcare provider and/or doctor (General Practitioner) to share my health and social care records to Children of the 90s (University of Bristol).

and
I understand that information about my health and social care records, health and social care databases, registers and records maintained by NHS Digital and the Office of National Statistics may be used to provide information about my health status (including consultations, diagnoses and treatments).

If you do not opt-out, Children of the 90s have been given permission to extract and use your official health and other records and retain this information for research purposes.

Our commitment to you:

- ✓ Taking part in the project is voluntary and you are free to withdraw at any time without giving a reason.
- ✓ You will not be identified from the research - researchers do not see your name with your information - they just see your barcode ID number.
- ✓ Every research project is checked to make sure it meets the highest scientific and ethical standards.
- ✓ In the same way as a doctor who treats you is bound to keep your information confidential, Children of the 90s and all the researchers we work with are bound to keep your information confidential.
- ✓ There are independent experts whose job it is to look at what we do and how we do it to make sure your rights are protected.
- ✓ We do not conduct research for commercial gain - all our research aims to benefit society and is not for profit. We are primarily funded by the University of Bristol, the Wellcome Trust and the Medical Research Council.



Professor Nic Timpson
Principal Investigator of Children of the 90s



<https://www.bristol.ac.uk/alspac/participants/using-your-records/>

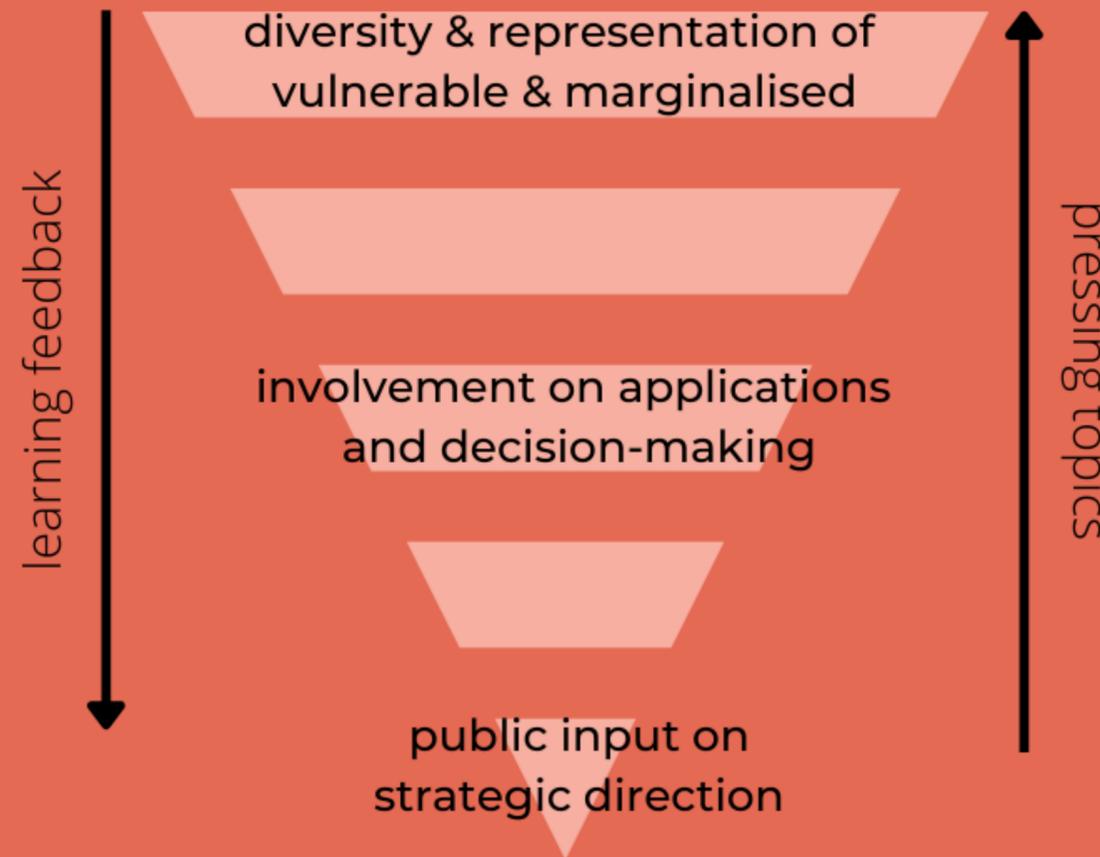
The UK LLC public involvement framework



UK LLC PUBLIC INVOLVEMENT FRAMEWORK



- Public Involvement Network
- Data Access Public Review Panel
- Public Advisory Group
- Strategic Advisory Committee



deeper understanding & sustained commitment

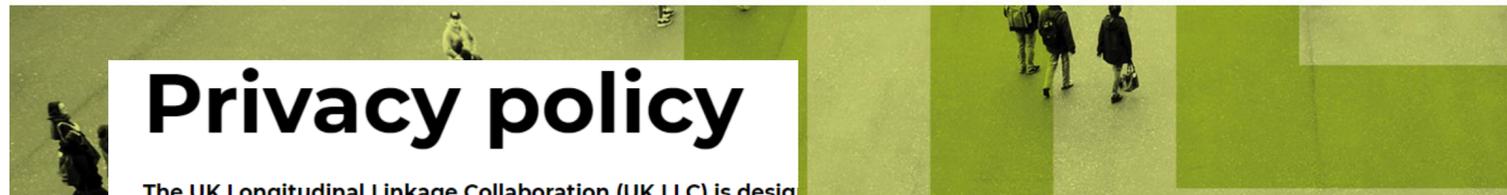


heterogenous views on acceptability and insights into sub-groups

Transparency – UK LLC



HOME ABOUT US RESEARCHERS PATIENT & PUBLIC INVOLVEMENT



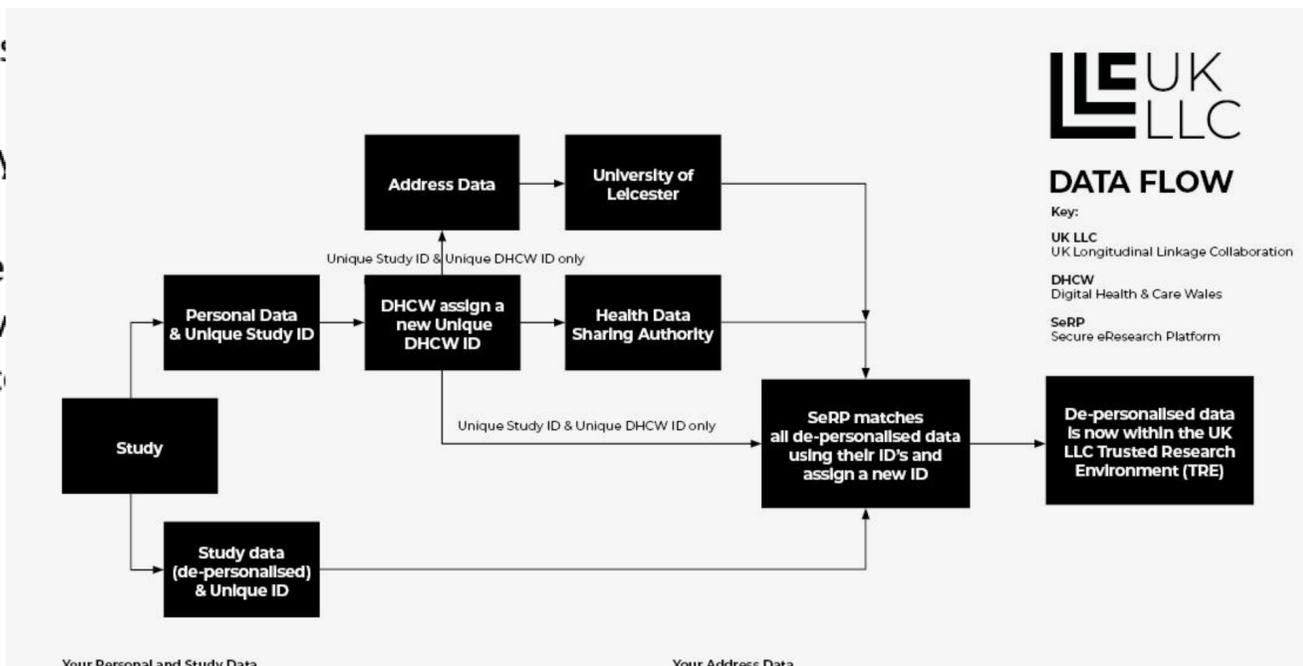
Privacy policy

The UK Longitudinal Linkage Collaboration (UK LLC) is designed to respect

The UK study v health

How We Env acc

Participant Notification Sheet



<https://ukllc.ac.uk/>

UK Longitudinal Linkage Collaboration (UK LLC) : a safe and secure national research resource

Bringing together study data from more than twenty of the UK's top longitudinal studies

What we mean when we say...

Longitudinal studies
 Longitudinal studies work by selecting a group of individuals (collecting data on these people over time). Groups are typically... such as groups of pregnant women in a specific geographical area or in a specific region of study is voluntary.

De-identified
 De-identified: This is data which has had identifying information removed. Data which is de-identified has high levels of security to ensure that individuals cannot be identified.

Secure
 Data will be held and analysed in a safe and secure place to ensure the 'five safes' will be used for research purposes.

Safe
 Studies retain control over their own data for their own purposes.
 Studies inform their participants and provide an opt-out.
 Study participants can change their mind at any time to stop their data being used.
 Strict contracts and security controls.

Frequently Asked Questions

Our Patient and Public Representatives have created the UK Longitudinal Linkage Collaboration (UK LLC). They've helped you have your say and will be...
 info@ukllc.ac.uk

1. The UK Longitudinal Linkage Collaboration (UK LLC) is a safe and secure national research resource.
2. The UK Longitudinal Linkage Collaboration (UK LLC) is a safe and secure national research resource.

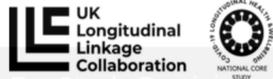
Data Use Register

Our Data Use Register provides information on every application we receive to access data held within the UK LLC Trusted Research Environment. This register is updated monthly.

Click on application ID for more information, including datasets requested, lay summary and results and impact.

APPLICATION ID	PROJECT TITLE	LEAD APPLICANT	ORGANISATION NAME	APPROVAL DATE	APPLICATION STATUS
llc_0014	TRACK-COVID study: a population-based epidemiological investigation of COVID-19 virus infection	Emanuele Di Angelantonio	University of Cambridge	20/05/2022	Approved
llc_0013	Quality checks; curation and methodological enhancement of the UK LLC Partner Studies using linked data	Jamie Moore	University of Essex	31/05/2022	Approved

UK LLC Commitment to Participants



For Study Participants | Our commitment | How we use your data | How we work | How will this make a difference

Our commitment to you

As a participant of one of the studies taking part in the UK Longitudinal Linkage, you have shared data about yourself with your study to help improve health and wellbeing.

Linking the data you give your study with your NHS health records (such as those held by your GP or by the health service) has allowed us to use this data to understand why some people are at higher risk of COVID-19, what factors influence recovery from COVID-19, and how changes about a new GP database have raised concerns about data privacy and use.

We want to be clear – the data you share with us, and any links we make with health records, are not part of your records but do not give study data to the NHS. This may include access to the planned GP database, but changes have been made.

- We never use personal identifiers such as your name or address in any of our research.
- We only use personal identifiers such as your NHS number to link the information you give your study to your health records.
- This de-personalised data is used solely for research in a secure, confidential space, called a “Trusted Research Environment”. Results cannot leave the environment until an independent checker has confirmed that no individual can be identified.
- Approved researchers can only access the Trusted Research Environment once they and their research question have been checked and approved.
- No data is shared for profit making purposes. We do not sell your data, and we never will. Any researcher using your data signs up to this commitment.
- As a community of studies and data scientists we manage your data ourselves. We do not outsource to private companies.
- Our ways of working are reviewed by independent ethics committees and volunteer study members.

<https://ukllc.ac.uk/>

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Conclusions



- UK LPS have 75 years experience of managing ‘consent’
- Consent is fragile but critical to trust relationships
- Consenting can exclude the vulnerable and marginalised and thus bias research and harm the *fairness* of potential public benefits
- This fairness aspect challenges explicit consent as the ‘ethical’ gold standard
 - but opt-in consent should be collected where practicable
 - Where opt-out approaches are used then study objections and National Opt Out must be respected (upholding participant rights)
- Flexible mechanisms are needed to manage ‘reasonable expectations’ over the long-term
- These mechanisms must be co-developed with participants

LPS & UK LLC provide examples as to how ‘consent’ can be managed over long-periods of time, and in relation to new-ways-of-working in a fair, transparent way that uphold rights, autonomy and maintain trust.

A collaboration to benefit public health



Questions?