

**Public**



# UK Longitudinal Linkage Collaboration: Study Prospectus

---

**Public**

Version 1.2

27 February 2025



Funded by  
ESRC  
and MRC

# Contents

---

<b>0</b>	<b>Purpose</b>	<b>3</b>
<b>1</b>	<b>Introduction to UK LLC</b>	<b>3</b>
<b>2</b>	<b>UK LLC: Our promises</b>	<b>5</b>
<b>3</b>	<b>Benefits of joining UK LLC</b>	<b>5</b>
<b>4</b>	<b>Data we offer</b>	<b>8</b>
<b>5</b>	<b>How does it work?</b>	<b>8</b>
<b>6</b>	<b>What is the Vanguard group?</b>	<b>11</b>
<b>7</b>	<b>LPS eligibility requirements</b>	<b>12</b>
<b>8</b>	<b>Public &amp; Participant Involvement and Engagement</b>	<b>14</b>
<b>9</b>	<b>Legal Status &amp; Intellectual Property</b>	<b>14</b>
<b>10</b>	<b>Appendix</b>	<b>16</b>

# 0 Purpose

---

This document provides information to UK **Longitudinal Population Studies (LPS)** who are interested in the **UK Longitudinal Linkage Collaboration (UK LLC)** and the services and benefits it can provide.

The document describes the UK LLC and provides information about how LPS can apply to join the collaboration, the on-boarding process and explains the role and responsibilities which come with membership.

**UK LLC is run by the Universities of Bristol and Edinburgh, in collaboration with UCL, Swansea, City St George's, University of London and University of Leicester. This work is funded by UK Research and Innovation (UKRI). UK LLC uses data provided by LPS participants collected through LPS, or as part of their healthcare, interactions with wider government departments and environmental data about the property, neighbourhood and wider environment in which they live.**

# 1 Introduction to UK LLC

---

The **UK LLC** is a transformational resource that for the first-time links data from many UK Longitudinal Population Studies (LPS) with participants' NHS records and environmental exposure data. It hosts these data within a national Trusted Research Environment (TRE) and provides a secure centralised analysis platform for pooled investigation of data by the UK's interdisciplinary longitudinal research community. As such, UK LLC provides record linkage as a service to its contributing LPS and manages all centralised aspects of the governance of the resource and the curation of the data.

The UK LLC was developed as part of the UK's Chief Scientific Advisor's **National Core Studies (NCS)** to conduct COVID-19 pandemic research and to develop UK data science capabilities. Within these, the **Longitudinal Health & Wellbeing NCS (LHW NCS)** uses UK

LPS to provide unique insights into population health, behaviours and wellbeing. In October 2020, the LHW NCS commissioned new COVID-19 relevant data collection from LPS participants and designed and built the UK LLC to systematically link participant data with routine health, environmental and administrative records.

The UK LLC, led by the University of Bristol (UoB, Director Andy Boyd), in partnership with the University of Edinburgh (UoE, Co-Director Robin Flaig), integrates data from >20 major UK LPS, and has established data and governance pipelines to link LPS participants to their health, environmental and administrative records. All data are held in a centralised research resource which is independently audited and certified as a Trusted Research Environment (TRE)<sup>1</sup>. The UK LLC TRE is hosted by Swansea University's Secure eResearch Platform (SeRP UK) and uses NHS Digital Health and Care Wales (DHCW) as a Trusted Third Party (TTP) for record linkage processing. Swansea University are academic collaborators who contribute to the data processing, development and academic outputs of UK LLC and provide the SeRP infrastructure. Collaborators at the University of Leicester's Centre for Environmental Health and Sustainability provide modelled environmental exposure data and address geocoding services.

UK LLC hosts more than 20 LPS with approximately 320,000 LPS participants. These LPS bring exceptionally detailed and broad varieties of LPS data collected over many years and pandemic follow-up data. UK LLC has systematically linked these LPS data to NHS Digital, Welsh (NHS DHCW/SAIL) and environmental exposure records and will soon link to administrative records (Department for Work and Pensions (DWP), Department for Education (DfE) and His Majesty's Revenue and Customs (HMRC)), creating a truly interdisciplinary, cross-cutting capability for longitudinal research. There are ongoing discussions to flow **Scottish** (Public Health Scotland) and **Northern Irish** (Health & Social Care Northern Ireland) **NHS records** into the UK LLC TRE.

[1] UK LLC have **ISO 27001 certification** – certificate number 21069; **NHS Data Security Protection Toolkit** accreditation – reference number EE133799-LLC; Health Research Authority **Research Ethics Committee** approval – reference number 20/NW/0446; Health Research Authority **Confidentiality Advisory Group** approval – reference number 21/CAG/0044.

## 2 UK LLC: Our promises

---

- **We promise** to involve study participants and members of the public across our operations, from important decisions about how we work, to the research we approve and how we communicate with the public.
- We promise to work to high standards. This means being transparent in our methods, securing accreditations from independent ethics committees and auditors, and working to the Five Safes framework to enable data to be used for public good research in the UK.
- We promise that our Trusted Research Environment:
  - Does not hold any personal identifiers. For example, there are no names or full dates of birth. This means it is highly unlikely any one individual can be identified.
  - Does not allow removal of data for analysis. The data stays within the TRE, which is based in the UK and may only be accessed by UK-based researchers.
- We promise not to sell data, ever. In future, we may need to cover the costs of running the service by asking researchers to pay a minimal fee to access the TRE.
- We promise to always respect the relationships between our partner studies and their participants and provide a resource that is tailored to the needs of longitudinal population studies.

## 3 Benefits of joining UK LLC

---

**We are a national TRE**, efficient and compliant with stringent data owner and regulatory requirements, with ISO 27001 Information Security certification and a DEA accredited processing environment. By providing a national TRE as a service, we are removing the duplication of direct and opportunity costs of each study managing their own TRE.

We **provide data linkage as a service**, reducing direct costs to LPS and the burden of arranging and maintaining complex Data Sharing Agreements with diverse data owners. Our model is both secure and efficient and therefore is seen as attractive to both data

owners and regulators. This model is providing effective in opening up transformational linkages – e.g., de novo linkages of LPS to administrative records from DWP, HMRC and DofE in alliance with Administrative Data Research UK.

UK LLC provides a managed application process to provide legitimate researchers with access to pooled and linked data on behalf of LPS yet operate a governance mechanism enabling LPS to always maintain control of application approvals. LPS staff are provided with a dedicated working space within UK LLC to conduct feasibility assessments and LPS descriptive and documentary analyses. LPS PIs and applied researchers are encouraged to apply to use UK LLC (at no cost) to conduct their own research programmes.

We are a linkage expert hub, providing guidance on regulatory requirements, participant fair processing and consent wording, and advocating for development of a facilitatory environment for LPS linkage and wider access within the data science community.

UK LLC offers new scientific opportunities to researchers based on our comprehensive record linkages and by pooling data from many LPS into a single heterogeneous sample with power to assess sub-group interactions and rare exposure/outcomes. Our researchers have access to UK LLC Explore, the UK LLC metadata catalogue. The UK LLC Explore app aids data discovery across all data (Longitudinal Population Studies and linked data) held within the UK LLC resource and enables researchers to build a data request to their specification.

We plan to extend our infrastructure provision to enable 'omic research'. As a whole, this provides LPS with an opportunity to broaden their user base and demonstrate wider value and impact.

UK LLC was established to inform research into COVID-19 but is evolving into a long-term resource for any research investigation requiring LPS data linked to routine records. Administrative data (DWP, DfE, HMRC) will be available for research by the end of 2024. Future plans also include integration of other data e.g. multi-omics data, wider NHS and environmental data. This would provide new scientific opportunities based on pooled heterogenetic sample from many LPS, such as:

- COVID-19 research focused on long-term health and socio-economic inequalities, pandemic outcomes and evaluation of COVID-19 welfare interventions on health
- Priority research questions relating to mental health, outcomes associated with childhood adversity, healthy ageing and neurodegenerative decline, cardiometabolic health, multi-morbidities, respiratory health and multi-omics research
- Life-course measurement of health and socio-economic exposures, covariates and outcomes
- Research on social inequality across generations, the impact of mental ill-health and inequalities on productivity
- Identifying patterns of service utilisation to understand care pathways and health/social intervention take-up to inform policy evaluation and econometrics studies
- Capture of data not readily amenable to direct measurement (e.g., environmental exposures)
- The impact of climate change on health and wellbeing
- Participant follow-up independent of active LPS participation, enabling more inclusive research and the means to quantify and address attrition and attrition bias, assess representativeness and calculate statistical weightings to enable generalisable findings and development of innovative statistical methods
- The study of rare events and outcomes and harder-to-reach population sub-groups, and considering regional effects and issues.

It is recognised and expected that LPS contribute to UK LLC on a non-exclusive basis and will likely continue to offer access to their data via other routes and to contribute to (many) other research initiatives.

## 4 Data we offer

Data are shared with UK LLC by LPS and onwardly shared with researchers by UK LLC as datasets, rather than variable-level data.

### 20+ Longitudinal Population Studies with >280,000 participants

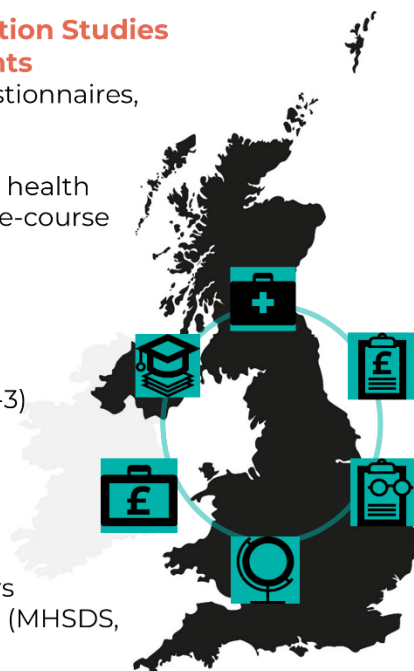
- COVID-19 collections (Questionnaires, Serology)
- SES & demographic
- Baseline physical & mental health
- Baseline family, SES and life-course indicators

### 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

- HMRC
  - DWP
  - DfE
- } Approvals in place

### Environmental & neighbourhood

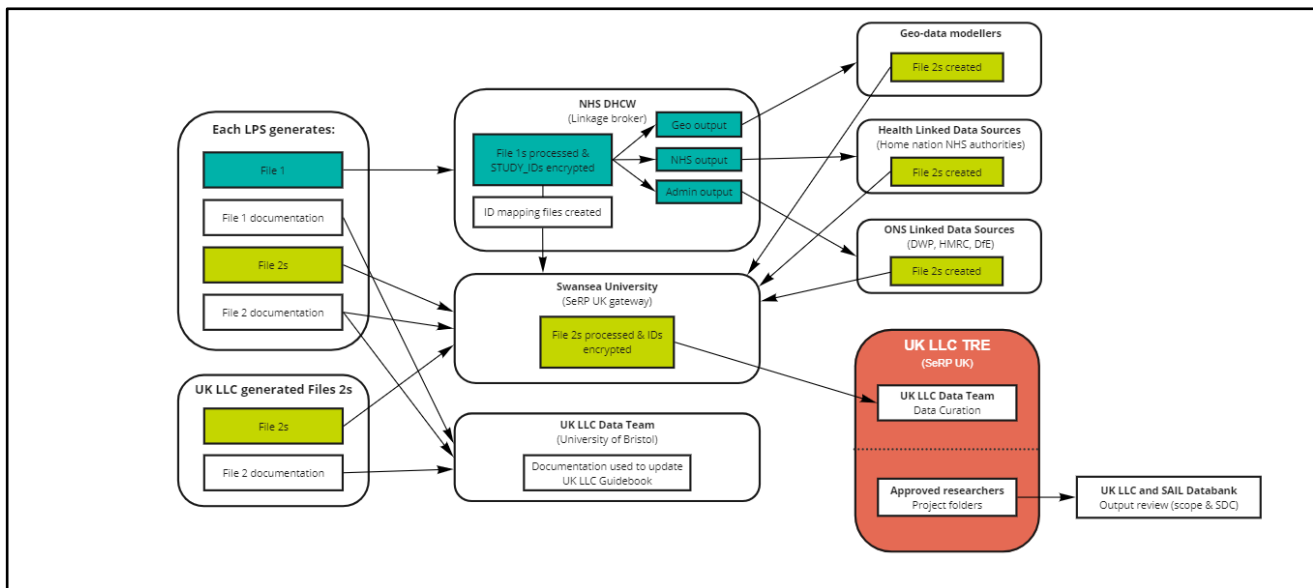
- Air pollution
- Noise
- Greenspace
- SES & demographic indicators
- Service provision
- Property data

## 5 How does it work?

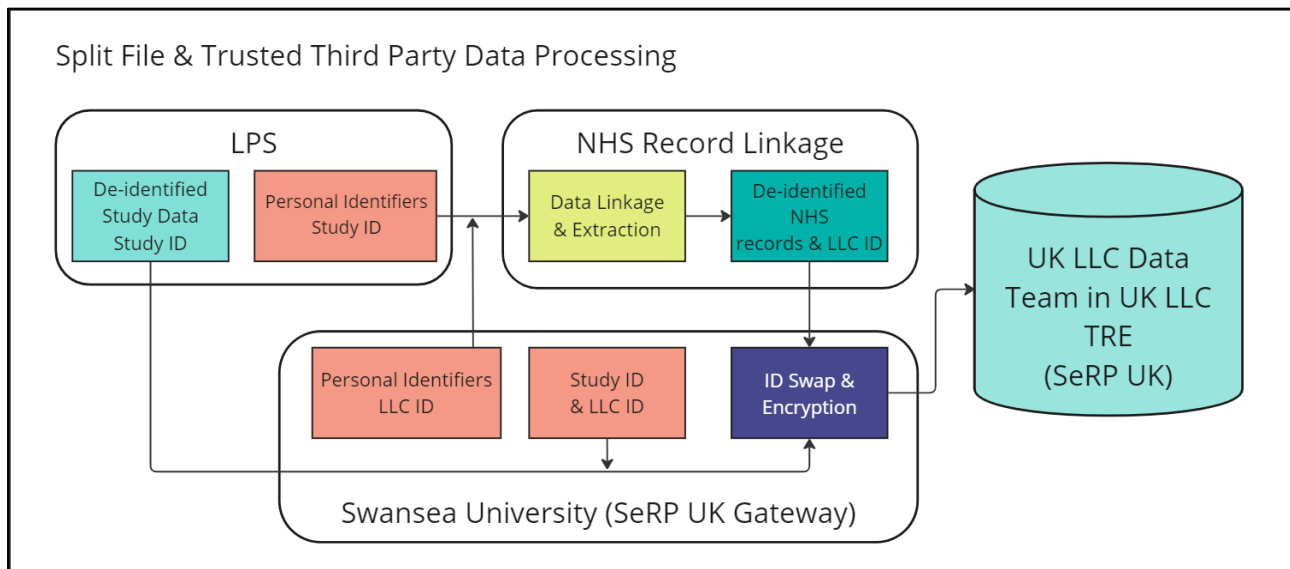
UK LLC is a centralised TRE containing de-identified participant-level data and encrypted address-level data from LPS and linked data sources. UK LLC TRE uses a secure analytical platform provided by Secure eResearch Platform (SeRP UK).

Using a de-identification process involving the use of Trusted Third Parties, the platform acts as a 'Gateway', linking datasets to form a rich database containing de-identified data, where the risk of the re-identification of any individual by UK LLC staff or research users is not considered reasonably likely (meaning it can be considered 'effectively anonymous' under the codes of practice established by the Information Commissioners' Office). All datasets are securely transferred into the UK LLC TRE using a 'split-file' process (Figure 1).



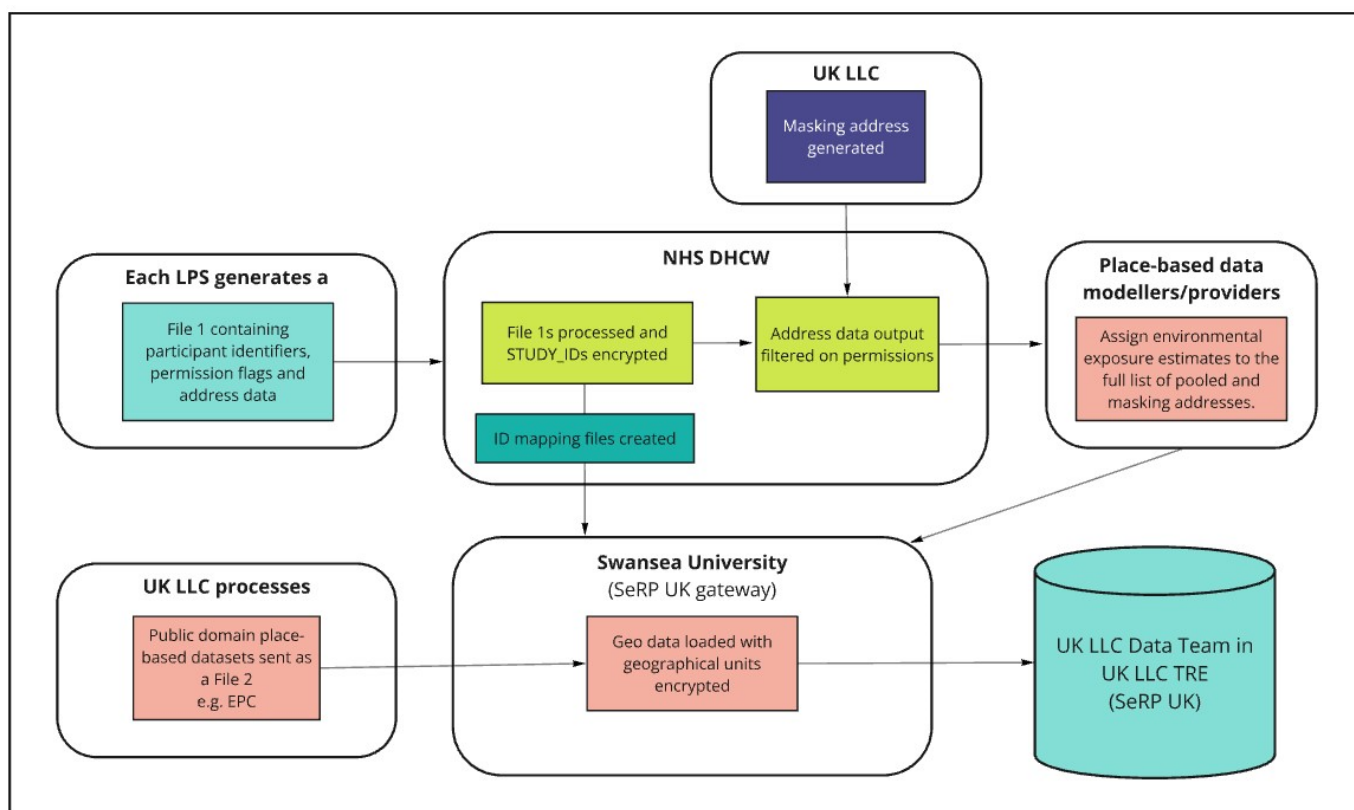


**Figure 1:** A high-level overview of the processors and pathways used to send data to UK LLC TRE – the University of Bristol, as Data Controller, is responsible for all these data flows (at times, with other, independent, Data Controllers).



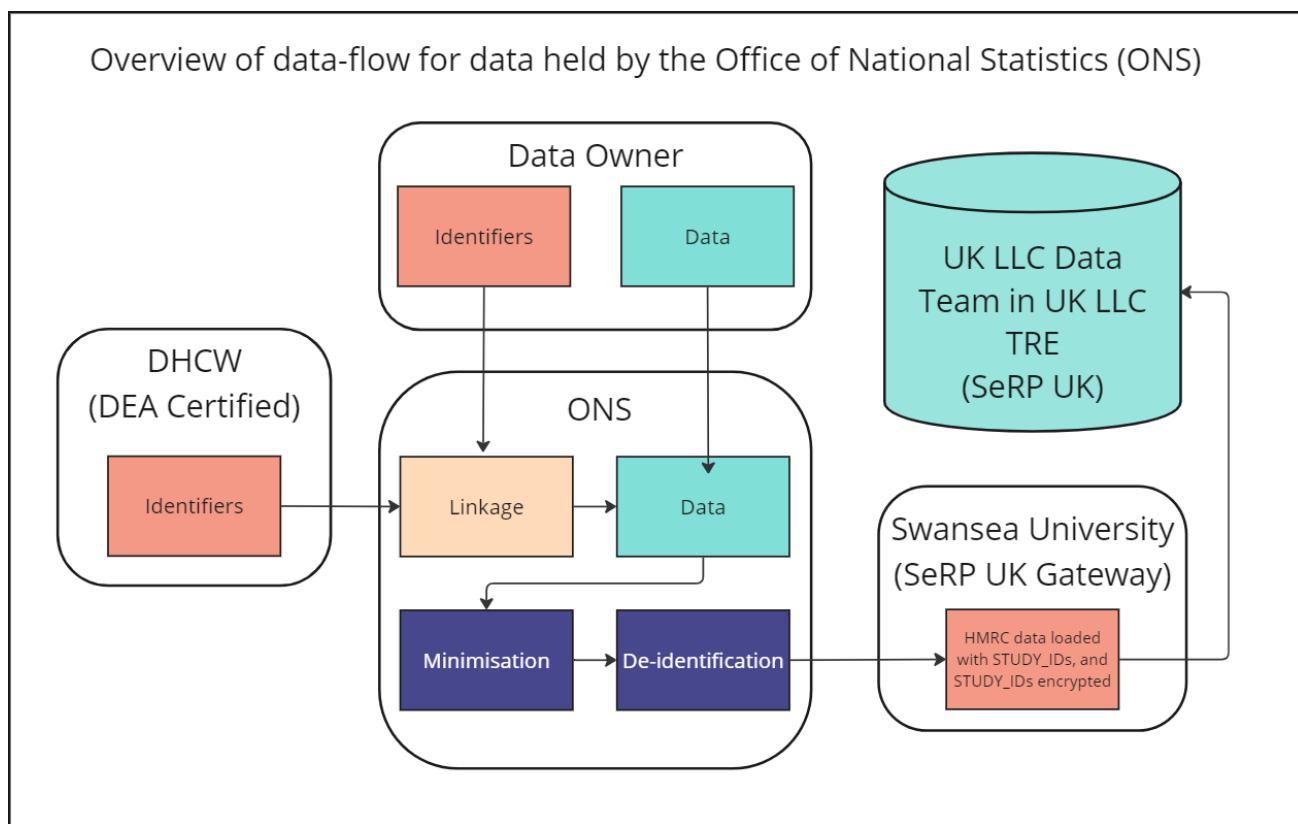
**Figure 2:** Overview of the data linkage methodology and split file & trusted third party data processing.

This ‘split-file’ process ensures that participants' data are only visible to data owners and that all of the data in the UK LLC TRE are de-identified. The approach to record linkage is illustrated below for NHS Record linkage (Figure 2) and Place-based linkage (Figure 3).



**Figure 3:** Overview of dataflow from address or postcode to Place-based data.

Figure 4 displays the indicative approach for linkage to datasets held by the Office of National Statistics.



**Figure 4:** Overview of indicative dataflow of ONS held datasets

## 6 What is the Vanguard group?

We are committed to collaborative endeavour – we are a collaboration of the LPS for the LPS – so decisions are made together with LPS data managers

The UK LLC Vanguard group is comprised of LPS data managers across all collaborating LPS that make up UK LLC, chaired by the UK LLC Director. The Group meets quarterly or as required (with regular updates) to:

- i. Receive progress updates
- ii. Co-develop processes
- iii. Share best practice and expertise
- iv. Share strategic insight

- v. Raise issues or risks.

Meetings help develop ideas which are then taken to UK LLC Senior Management group and/or UK LLC Operational Management Group for decision and action. Issues and risks are noted, added to the risk register and escalated as required.

## 7 LPS eligibility requirements

---

Any LPS is eligible to join where the LPS has/had direct involvement and engagement with their participants and direct collection of primary study data (electronic cohort studies are not eligible). If there is a doubt about your eligibility, please get in touch. We reserve the right to determine eligibility on a case-by-case basis. The stages in the LPS onboarding process are illustrated below (Figure 5).



**Figure 5:** LPS onboarding stages.

As a contributing LPS, you will sign a data deposit agreement (DDA) that will detail UK LLC operating principles, the data to be contributed and the contributions required from the LPS. The agreement should include any special conditions associated with your LPS/participants that you need UK LLC to uphold.

- LPS data managers, through the Vanguard group, shape UK LLC's protocol and design decisions, in alignment with its 'co-design' philosophy
- Each LPS will need to provide:
  - files of identifiers to establish the linkages
  - files of de-identified data to develop the analysis resource
  - quarterly updates on consent status so that withdrawing/objecting participants' wishes can be implemented.
- UK LLC coordinate an application and approvals process to access LPS' data, but LPS approve applications using already established mechanisms and let UK LLC know the outcome within four weeks of receiving the request.
- It is the LPS's responsibility to maintain the underlying governance permissions and legal basis to contribute data into UK LLC TRE for example, an LPS may be required to re-consent participants or pursue Section 251 (England and Wales) to provide an alternative legal basis. UK LLC provides advice and template materials to help establish and maintain the governance permissions and legal basis.

## 8 Public & Participant Involvement and Engagement

---

UK LLC has established a Public and Participant Involvement and Engagement (PPIE) strategy. The formal UK LLC Public Involvement Programme commenced in January 2022 where 25 public contributors were appointed to roles across the Strategic Advisory Committee (SAC), the Public Advisory Group (PAG), the Data Access Public Review Panel (DAPRP), and the Public Involvement Network (PIN). These groups and committees have responsibility for assessing and reviewing specific aspects of data access applications (considering the public benefit of the proposal), co-production of communications materials for the public, input towards our strategic direction and future collaborations, and work to assess the acceptability of data use for COVID-19 research.

We are committed to public involvement in our design, operations and communications. LPS staff responsible for Communications and/or PPIE activity will be invited to attend quarterly meetings as part of the UK LLC Communications Network. Best practice is shared among partner LPS and updates on fair processing and public-facing communications are provided.

## 9 Legal Status & Intellectual Property

---

The University of Bristol owns the UK LLC and is Data Controller for the TRE. University of Bristol have contracted a number of other organisations to contribute to UK LLC – including Digital Health Care Wales, University of Edinburgh, University of Leicester, Swansea University and UCL. These organisations are data processors for UK LLC.

All contributing LPS always remain as Data Controllers for their data. UK LLC can only use LPS data in line with the terms and conditions specified within a data deposit agreement between University of Bristol and the LPS host institution. Importantly, the governance framework for UK LLC ensures that LPS retain control over which users use their data for what purposes. The terms and conditions related to the use of data are developed in consultation with the contributing LPS through the ‘Vanguard’ data managers group.

Approved users are granted a non-exclusive, revocable, non-transferable, licence to use data in the UK LLC for their approved project (subject to approval, so long as the University of Bristol maintains a relevant data deposit agreement/data sharing agreement with the third-party data owner and retains the rights to sub-license the source data). Users do not gain any ownership of individual level data, including derived variables. Users will own the analytical outputs of their research (research findings and tools including syntax, documentation and codelists). However, they are required to provide UK LLC (University of Bristol) with an irrevocable, perpetual, worldwide, transferrable and royalty-free licence to use all user results and tools for research, teaching and other non-commercial purposes. UK LLC publish all outputs into the public domain under a Creative Commons licence which means that LPS have the ability to use these for their research, teaching and other non-commercial purposes.

# 10 Appendix

---

**UK LLC website:** [UK LLC | UK Longitudinal Linkage Collaboration](#)

**UK LLC GitHub:** <https://github.com/UKLLC>

**UK LLC YouTube:** <https://www.youtube.com/channel/UCUX46cVODzgU7FcaZIMCOYA>

**UK LLC Twitter:** [@UKLLCollab](#)

**UK LLC research protocol paper:** UK Longitudinal Linkage Collaboration: The National Trusted Research Environment for Longitudinal Research. <https://ijpds.org/article/view/2468>

**UK LLC Publication Policy:** [Governance | UK Longitudinal Linkage Collaboration](#)

**Data depositing guidance:** HYPERLINK

"[https://uob.sharepoint.com/:f:/r/teams/grp-UK-LLCVanguardcohorts/Shared%20Documents/Depositing%20Data%20\(File%20%26%20s\)?csf=1&web=1&e=n0Jxv8](https://uob.sharepoint.com/:f:/r/teams/grp-UK-LLCVanguardcohorts/Shared%20Documents/Depositing%20Data%20(File%20%26%20s)?csf=1&web=1&e=n0Jxv8)" Depositing Data (File%20& 2s)

**UK Longitudinal Linkage Collaboration**

Population Health Sciences

Bristol Medical School

Canynges Hall

39 Whatley Road

Bristol BS8 2PS

**[info@ukllc.ac.uk](mailto:info@ukllc.ac.uk)**

If you require this document in an accessible format,  
please email [info@ukllc.ac.uk](mailto:info@ukllc.ac.uk)