

What is the UK LLC?

- The **UK Longitudinal Linkage Collaboration** (UK LLC), established in 2019 for COVID-19 research, now also supports diverse health and social research across the UK.
- The CSS Biobank will partner with the UK LLC, meaning **data will be used:**
 - Safely**
 - Responsibly**
 - For **public interest research**

[Video: What the UK LLC is and how it works](#)

Who Runs the UK LLC?

- Core leadership:** University of Bristol and University of Edinburgh
- Data infrastructure, security & data processor:** Swansea University
- Environmental data expertise:** University of Leicester
- The **NHS** and the **Office for National Statistics** (ONS)
- The UK LLC's activities are reviewed by: a panel of **data experts, data owners, and public contributors**.

[Website: UK LLC public involvement](#)

Who Funds the UK LLC?

- UKRI:** UK Research and Innovation
- ESRC:** The Economic and Social Research Council
- MRC:** The Medical Research Council

5 Key Promises for Data Handling

- 1 Involve **study participants**
- 2 Work to **high standards**
- 3 Trusted Research Environment (TRE) does not:
 - **hold personal identifiers**
 - **allow removal of data**
- 4 **Not to sell data**
- 5 Always **respect relationships**

[Website: 5 key promises](#)

Why Combine Data via the UK LLC?

- Brings together **anonymised** data from **>20 UK longitudinal studies**, including the CSS Biobank, into 1 **secure system**, helping researchers:
 - Study **long-term health and well-being**
 - Link information across systems** (e.g. health and education)
 - Answer **big questions** that no single study could explore alone

Who Can Apply to Use the Data?

Only **UK-based researchers** can apply for anonymised, linked data, and they must have:

- Accreditation** by the Office for National Statistics (ONS)
- Approval** by the UK LLC access panel
- Approval** by the CSS Biobank study team
- Research that will **benefit the public**

Researchers must go through a **strict approval process** by the CSS Biobank data access committee to use **unlinked study data**.

[Website: Data Use Register](#)

How is Data Protected?

All data are **stored securely in a TRE**, ensuring:

- Researchers never see **names** or **personal identifiers**
- All **CSS Biobank data** shared with UK LLC is **pseudonymised** with **access strictly controlled**, with projects using this data **reviewed and approved**

What will Data Linkage be Used For?

Researchers will be able to **understand more about:**

- The **short- and long-term effects of COVID-19**
- How people **used health services**, and where **support was missing**
- How people's **life situations** have affected their health
- How to **design public health support** that works better **for everyone**

What Information might the CSS Biobank Collect from Health Records?

Health records include:

- Records held by your General Practitioner (GP)
- Hospital records
- Mental Health Data
- Cancer Registrations
- Mortality Data

Your **name is never linked** to the information taken from your records

Your **patient health information** includes:

- Details of **visits to your doctor**, diagnoses made and any treatments
- Hospital visits**; why you were there & what happened, including visits to **A&E**, being admitted to hospital for **inpatient and outpatient** care
- Details of **community care**, for a particular illness or for your mental health.

Participant Rights

Participants always have the right to:

- Know **how** their data is being used
- Ask questions** or request changes
- Withdraw from future use** of their data at any time

We only **link** participants' CSS Biobank data with health records through the UK LLC if they've **given consent when joining the Biobank**.

Participants can:

1. **Withdraw consent** to use their CSS Biobank data for health record linkage
2. **Withdraw** from the CSS Biobank all together

[Website: Contact point to withdraw](#)