**Liverpool University Biobank Privacy Notice**

**Who will own my data once I’m consented?**

Data will be collected and owned by the University of Liverpool Biobank (LUB).

**Why do you need my data/information?**

Your data/information is being collected to help us understand the various mechanisms of pathophysiology along with the therapeutic responses which may differ amongst ethnic populations and males and females along with disease patterns. The data set has been designed to capture relevant clinical data (diagnosis, treatment history, medical history and results of laboratory tests) and demographic data (name, gender, ethnicity, DOB, GP details, occupation, NHS number and hospital unit number).

**What allows you to use my data/Information?**

You will have consented for your personal data as described above. If we wish to use the data/information you have provided to us for new or different purposes, other than for which it was originally supplied, we will request your written permission first. Your consent may be withdrawn at any time by contacting the Liverpool University Biobank Manager.

**Who will my data be shared with?**

All information that is collected will be held in accordance with data protection laws in the UK. Only a small number of Biobank staff who are professionally bound to maintain your privacy, would have access to demographic data identifying you personally. This information will be stored securely and your name, address and other personal information will not be provided to researchers using your samples. You will not be able to be identified by the researcher. All your data/Information is anonymised before being released to researchers. We will ensure that your personal data will not be disclosed to other organisations institutions and authorities unless required by law.

**Do I have to provide this information and what will happen if I don’t?**

No one is required to provide their data to be used by the biobank, however, without the accompanying data the samples that you have donated will not be of use to researchers. All information will be treated with the strictest confidence and held securely within LUB. This information is essential to help researchers understand what your illness was like and relate what is found in the laboratory to what happens to patients.

**What rights do I have when it comes to my data?**

Under the General Data Protection Regulation, you may have the following rights with regards to your personal data:

* The Right to subject access – you have the right to see a copy of the personal data that the University holds about you and find out what it is used for
* The Right to rectification – you have the right to ask the University to correct or remove any inaccurate data that we hold about you
* The Right to erasure (right to be forgotten) you have the right to ask the University to remove data that we hold about you
* The Right to restriction – you have the right to ask for your information to be restricted (locked down) on University systems
* The Right to data portability – you have the right to ask for your data to be transferred back to you or to a new provider at your request
* The Right to object – you have the right to ask the University to stop using your personal data or to stop sending you marketing information, or complain about how your data is used
* The Right to prevent automated decision making – you have the right to ask the University to stop using your data to make automated decisions about you or to stop profiling your behaviour (where applicable).

Please note that not all rights apply in all situations. To find out more about your rights under the GDPR, please visit the Information Commissioner’s website.

To request a copy of your data or ask questions about how it is used, contact:

Dan Howarth, Data Protection Officer

Email: [**legal@liverpool.ac.uk**](mailto:legal@liverpool.ac.uk)

Post: Legal & Governance, University of Liverpool, Foundation Building, 765 Brownlow Hill, Liverpool L69 7ZX.

**Who can I complain to if I am unhappy about how my data is used?**

You can complain directly to the University’s Data Protection Team by writing to:-

Dan Howarth, Data Protection Officer

By email: [**legal@liverpool.ac.uk**](mailto:legal@liverpool.ac.uk)

Post: Legal & Governance, University of Liverpool, Foundation Building, 765 Brownlow Hill, Liverpool L69 7ZX.

**You also have the right to complain to the Information Commissioner’s Office using the following details:**

The Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF

Telephone: 08456 30 60 60 or 01625 54 57 45

Website: www.ico.org.uk