



ExPAT research study, LCRC: Research Privacy Notice

Information you need to know:

The Leicester Cancer Research Centre (LCRC) is part of the University of Leicester. Further information on the institution can be found here: <https://le.ac.uk/>.

This privacy notice explains how we use your personal information and your rights regarding that information. For the ExPAT study, The University of Leicester will act as the Data Controller.

The Data Protection Officer is: Parmjit Singh Gill, Data Protection Officer, University Of Leicester, and University Road, Leicester, LE1 7RH. Email: dpo@leicester.ac.uk.

What information are we collecting?

As part of the ExPAT study, we are specifically collecting the following information:

- Full name
- Gender
- Date of birth
- Ethnicity
- Home address
- Telephone number
- Medical history (including diagnoses, surgical history, treatment history, medical interventions, current medication, tumour pathology, body mass index and smoking status).

Why are we collecting your data?

We are collecting your personal data to record all trial and research outcomes relating to the ExPAT research study.

- To identify the right treatment for each cancer case.
- To Monitor progress and correlate with any research we do on samples that you will donate to prevent or treat cancer.

We will use your personal and medical data to research and identify why some people respond better to some treatments than others.

How we will use this data?

We will use this information:

- To monitor your progress, analyse and correlate with any research we do on your samples.
- To contact you about the research study, and make sure that relevant information about the study is recorded for your care,
- To oversee the quality of the study.
- For auditing purposes.

Please note, regulatory organisations may look at your medical and research records to check the accuracy of the research study.



What is the legal basis for processing the data?

The University of Leicester legal basis upon which we will process your personal information for research activity is public task and this is set out in Article 6 of the GDPR;

“Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller”

Please note the official authority to carry out research is expressed in the University Charter in section 13 (b).

In addition, our research is carried out in the public interest as results may be used for the advancement, publication and dissemination of the findings of discoveries.

In some cases research activities may require processing of special category data. Depending on the research activity and the data which will be collected the University may process it under Article 9 paragraph 2(a) which refers to consent as the legal basis or Article 9 paragraph 2 (j) which refers to archiving purposes in the public interest, scientific or historical research purposes or statistical purposes as the legal basis.

If we are sharing your data with others who are we sharing it with?

The research team is comprised of The University of Leicester and University Hospitals of Leicester approved staff, who will use your data to conduct the study and to monitor your wellbeing

Only approved members of the research team will have access to your information and identifiable samples. All records and samples will be fully anonymised before they are shared outside of the research team for analytical or auditing purposes

How long we will process your data for?

We will retain your data for 5 years from the study end date. After this period, all information held about you for the purpose of this research study, will be securely destroyed.

What are your rights and how to enforce them?

As a research Participant you have the following rights ;

- Right to access, if you wish to request copies of your personal data.
- Right to rectification, if you think the data we hold about you is incorrect.
- Right to restriction, if you believe we are over processing your data.
- Right to objection, if you believe that any of the data we hold is incorrect.

Please note:

It is also important to understand that these rights will only apply to identifiable data.

You may withdraw from the study at any point where we hold identifiable data, however where your information has been completely anonymised, your information is no longer accessible and is therefore not classed as personal data for the purposes of the Data Protection Legislation.

How to complain to the Information Commissioner's Office?

The Information Commissioner can be contacted on:

Post: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK95AF.

Tel: 0303 123 1113.

Email contact can be made by accessing www.ico.org.uk