



## **Participant Information Sheet For Biomedical Researchers**

UCL Research Ethics Committee Approval ID Number: \_12303/002\_

### **YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

**Title of Study:** Characterising researchers who use human samples in Europe

**Department:** Division of Surgery and Interventional Science

**Name and Contact Details of the Researcher(s):**

Emma Lawrence [e.lawrence@ucl.ac.uk](mailto:e.lawrence@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:**

Dr Amir Gander [a.gander@ucl.ac.uk](mailto:a.gander@ucl.ac.uk)

#### **1. Invitation Paragraph**

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take the time to read the following information carefully. Contact us if there is anything that is not clear or if you would like more information.

#### **2. What is the project's purpose?**

Human tissue samples are a vital foundation of medical research, however, until now the policy and processes that determine the funding and usage of these samples have not always been founded on evidence. In 2018 we ran a study to find out more about human samples users in the UK.

The aim of this study is to better understand the use of human tissue samples in biomedical research in the rest of Europe. The study will consist of a survey to better understand when human samples are used, what the motivations are for using them and if there are any barriers to accessing and using human samples in Europe currently. The research will be conducted from Oct 2020 to Jan 2021.

#### **3. Why have I been chosen?**

All Biomedical research professionals of post-PhD level are invited to participate in this research. This includes the private and public sector. We are hoping to get as many responses as possible in order to make the results as representative as possible.

**Inclusion Criteria:** All Post-PhD Biomedical researchers based in Europe are invited to partake in this study. 'Biomedical' refers to the study of any area of science with a basic or translational medical application.

**Exclusion Criteria:** If you don't have a PhD, are based outside of Europe or study plant or environmental Biology you are excluded from this study.

**4. Do I have to take part?**

It is up to you to decide whether or not to take part. You can keep this information sheet and can stop completing the survey without giving a reason and without it affecting you. You cannot withdraw information as your data is anonymous.

**5. What will happen to me if I take part?**

The survey will take approximately 7 minutes to complete.

**6. What are the possible disadvantages and risks of taking part?**

The survey will take 7 minutes of your time to complete. It may require some thought about your research protocols and questions.

**7. What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those people participating in the survey, it is hoped that this work will go on to inform human sample acquisition and funding policy in the future. Other potential benefits for you include improving the mechanism through which you locate existing sample resources.

**8. What if something goes wrong?**

If you have a complaint about the way you have been treated during this research please contact Dr Amir Gander – [a.gander@ucl.ac.uk](mailto:a.gander@ucl.ac.uk)

Should you feel that your complaint has not been handled to your satisfaction you can contact the Chair of the UCL Research Ethics Committee – [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

**9. Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

**10. What will happen to the results of the research project?**

A report will be generated for the BBMRI-ERIC Common service IT. Results will be published in an open access peer review journal. You can also check for updates on our work on our website: <https://www.bbmri-eric.eu/> Results should be published by the end of 2021. You will not be identifiable in any report or publication. Data collected during the course of the project might be used for additional or subsequent research.

**11. Local Data Protection Privacy Notice**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice - for participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The categories of personal data used will be as follows: none.

The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest.

*Your personal data will be processed so long as it is required for the research project.*

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

***If you choose to share your email address for future updates or participation in our user forum this may be shared with other member of the CS IT and BBMRI ERIC. Data will not leave the EEA.***

**12. Who is organising and funding the research?**

This work is being performed at UCL and is funded by the BBMRI ERIC common service IT, find out more at <https://www.bbmri-eric.eu/>

**Contact for further information**

Dr Emma Lawrence

e.lawrence@ucl.ac.uk or [contact@biobankinguk.org](mailto:contact@biobankinguk.org)

020 3549 5849

**Please save a copy of this information sheet for your future reference.**

**Thank you for reading this information sheet and for considering to take part in this research study.**

**We will assume that you consent to the above by completing the survey.**