



Participant Information Sheet for UK-based Biomedical researchers

UCL Research Ethics Committee Approval ID Number: 12303/001

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: Barriers to using an online directory to identify human samples for biomedical research

Department: Surgery and Interventional Science

Name and Contact Details of the Researcher(s): Dr Emma Lawrence - e.lawrence@ucl.ac.uk

Name and Contact Details of the Principal Researcher: Professor Barry Fuller - b.fuller@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.

The aim of this study is to better understand the usage of human tissue samples in UK biomedical research. The study will consist of a baseline 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 the UK. The research will be conducted from February 2018 to December 2019.

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 UK based Biomedical researchers 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: PhD students, Non-UK based researchers or plant or environmental scientists 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. If you want to take part you can choose to take part in either the focus group or the survey or both elements. You can keep this information sheet and can withdraw at any time without giving a reason and without it affecting you. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

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

The survey will take approximately 7 minutes to complete. You will be given the option to volunteer to take part in a focus group in the future. **You do not have to take part in the focus group to be included in the survey.** If you opt to participate in the focus group, this will take a further 2-4 hours of your time. The research itself will continue up to December 2019.

6. Will I be recorded and how will the recorded media be used?

Survey participants will not be recorded.

Focus group participants will be audio recorded for analysis. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

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

The survey will take 5-10 minutes of your time to complete. It may require some thought about your research protocols and questions.

Participation in the focus groups will take 2-4 hours of your time. It will require you to discuss your research in a group with other biomedical researchers.

8. 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.

For those partaking in the focus groups, your feedback will be used to develop an online resource for Biomedical researchers. Potential benefits for you include improving the mechanism through which you locate existing sample resources.

9. What if something goes wrong?

If you have a complaint about the way you have been treated during this research please contact Prof. Barry Fuller – b.fuller@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.

10. 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. Confidentiality cannot be guaranteed in a focus group setting.

You will have the option of submitting your email address so that you can be entered into a prize draw or updated on our work.

11. Limits to confidentiality

- Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.
- Confidentiality will be respected subject to legal constraints and professional guidelines.
- Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

- Confidentiality may be limited and conditional and the researcher has a duty of care to report to the relevant authorities possible harm/danger to the participant or others.
- Confidentiality cannot be guaranteed in a focus group setting.

12. What will happen to the results of the research project?

A report will be generated for UK clinical research collaboration (UKCRC) funders. Results will be published in an open access peer review journal. You will be given the option of receiving the results of analysis when they are published. You can also check for updates on our work on our website: www.biobankinguk.org. Results should be published at the end of 2019. 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.

13. Data Protection Privacy Notice

Notice:

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer is Lee Shailer and he can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by selecting the relevant option during the survey (Survey participants) or completing the consent form that has been provided to you (Focus group participants).

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, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

14. Who is organising and funding the research?

This work is being performed at UCL and is funded by the UK Clinical Research Collaboration (UKCRC). This is a consortium of medical research funders consisting of The Medical Research Council, Cancer Research UK, The Wellcome Trust, National Institute for Health Research, British Heart Foundation, Health and Care Research Wales, the Chief Scientist Office and The Public Health Agency.

16. Contact for further information

Dr Emma Lawrence

Email: e.lawrence@ucl.ac.uk or contact@biobankinguk.org

Telephone: 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.