

PARTICIPANT INFORMATION SHEET

Understanding Body Donation

We are inviting you to take part in a research study. Please take time to read the following information carefully and discuss it with others if you wish. Before you decide whether to take part, it is important for you to understand why the project is being done and what it will involve. Please ask if there is anything that is unclear, or if you would like more information. Take time to decide whether you wish to take part.

1. What is the purpose of the study?

In the United Kingdom each year around 1,300 donors are accepted for body donation. This gift enables vital training for medicine and healthcare. There is little known about what is widely thought about body donation, who might use the body, what might happen to it. The specific aims of the study are as follows:

- To understand what the public know and think about body donation.
- To understand what the public think about who can use donated bodies.
- To understanding what the public think donated bodies can be used for.

These will then help us to improve how we communicate the options of body donation and will inform development of practice.

This is a study with a single part. Participations will be invited to take part in an anonymous online questionnaire. This should take no longer than 15 minutes to complete.

2. Why have I been invited to participate?

The study is looking for a really broad range of views on body donation and hence you have been invited because you have heard/seen about this study. The only inclusion/exclusion criteria for this study is that you are over 18 and consent to take part.

3. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to confirm that you have read the consent statements and consent to being a part of this study at the start of the online questionnaire. As you will be anonymous you will not be able to request to withdraw your data after you have submitted it.

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

If you chose to be a part of the study, you can access the online questionnaire. You will have to read the consent information and then tick to say that you are happy to consent to the study at the top of the questionnaire. You will then be able to complete the online questionnaire anonymously which should take approximately 15 minutes.

5. What are the possible benefits of taking part?

There are no direct benefits for you in taking part in this study. However, the study may help further our understanding of body donation. We anticipate a deeper understanding of body donation and how the sector can continue to engage with all different groups who work with donors and how we might better communicate with donors.

6. Are there any possible disadvantages or risks of taking part?

There are no significant disadvantages or risks associated with taking part in the study. We anticipate that once you have read this information sheet and the consent information that the questionnaire should take approximately 15 minutes of your time. The topic of body donation may be sensitive for some. Because this study is nationwide and we are not recording your names or details, if this raises any concerns for you, for example if the study raises a medical question about your own health please follow the NHS guide to access to [services](#). If the study raises a question about body donation please use the [Human Tissue Authority guide](#) to help you.

7. What about confidentiality?

All information collected about the individual ('personal data') will be kept confidential (subject to legal limitations) to ensure compliance with data protection legislation that researchers need to understand and follow. You, and your data, will be assigned a unique identifier that will be used to name the files. Outputs arising from the research (e.g. scientific publications) will not contain any personal data that would permit identification. No names or contact details will be recorded.

8. What will happen if I don't want to carry on with the study?

Once you have submitted any data, because it is anonymous, it is not possible to withdraw from the study.

9. What should I do if I want to take part?

If you wish to participate then please read the consent page and click proceed to start the survey.

10. What will happen to the results of the research study?

It is anticipated that the results will go on to be published in a peer reviewed scientific journal. Any publication based on the results of this study will be announced via the Brighton and Sussex Medical School twitter account will be freely available to download.

Data will be retained for 5 years whilst it is relevant and after that will either be deleted or moved to the university archives.

11. Who is organising and funding the research?

This study is being conducted and funded by the Brighton and Sussex Medical School anatomy department.

12. Who has approved this study?

This study has been approved by the Brighton and Sussex Medical School Research Governance and Ethics Committee (RGECE/BSMS3867/18)

13. Who is responsible if something goes wrong?/What if there is a problem?

If you have any concerns about any aspect of this study or about the way you have been approached or treated during the study, or how your information is handled during the course of the study you should contact the lead researcher who will do their best to answer your questions. Their contact details are provided at the end of this Sheet.

Alternatively, you may wish to contact the University of Sussex Research Governance Office via: rgoffice@sussex.ac.uk.

14. Contact for further information?

Contact information for the lead researcher for any questions, concerns or comments:

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15. Insurance

The Universities of Brighton and Sussex have insurance in place to cover their legal liabilities in respect of this study.

Thank you for taking the time to read this information sheet, we hope that you will chose to participate in this study.