



**Genetic Alliance UK**  
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MANCHESTER  
1824

The University  
of Manchester

## Appendix 1

### Attitudes Towards Donating Human Tissue Samples for Research

#### Participant Information Sheet

We would like to invite you to take part in a research study to help us understand what people think about donating human biological samples, (such as blood, saliva, types of blood tissues such as lung tissue, liver tissue) or tissue (e.g. lung tissue, saliva), or post mortem tissue, for medical research. These samples could be left over from a surgical procedure or they may be donated specifically for research purposes. Currently, we know very little about what people think about this issue. Please take the time to read the following information to help you decide whether you would like to take part.

**Who will conduct this research?** The research is part of the STRATUM project, a project set up to try to increase the effectiveness of tissue sample provision in the UK. It is being conducted with the help of a national charity, Genetic Alliance UK that represents over 150 patient organisations. The Focus Group are a reputable research company helping us to recruit members of the public. This study has received ethics approval from Manchester University.

**What is the aim of this research?** The aim is to understand what people think about donating human tissue samples for medical research.

**Why have I been chosen?** As a member of the public, your views are important. Your views will help us understand people's opinions and ensure that the donation of biological samples for medical research is carried out in a way that reflects people's wishes.

**What would I be asked to do if I took part?** We are inviting you to attend a group discussion to discuss your opinions about donating tissue samples for medical research. Don't worry if you feel you don't know a lot about this topic because discussions will be led by a trained moderator. We have provided some basic information along with this sheet that gives you some background about the topic. There are no right or wrong views; everyone's opinions will be equally valid.

**What happens to the data collected?** The information collected from these discussions will be used to write a report which will be used to influence National policy. The findings will also be used to publish academic papers in journals.



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**How is confidentiality maintained?** Discussions will be digitally recorded so that we can get an accurate account of what was said. However, when these are typed up, all comments will be anonymous and your name will not appear anywhere on the document. The documents will be kept secure on an encrypted hard drive and backed up on an encrypted memory stick which will be kept in a locked office. These documents and the audio files will be kept for 5 years and then destroyed. This information will not be passed on to any other third party.

**What happens if I do not want to take part or if I change my mind?** It is up to you whether or not to take part. If you do decide to take part you will be asked to sign a consent form saying that you have agreed to take part and have the conversation recorded. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself.

**Will I be paid for taking part?** As a thank you for taking part you will be given £50 which will be given at the end of the discussion.

**What is the duration of the research?** There will be between 6-8 people in the group which will last approximately 1.5 hours.

**Where will the research be conducted?**

**What are the benefits from me taking part?** There is no direct benefit to yourself from taking part, but your views will help to shape future policy.

**Who will be running the group?** The person running the focus group is Celine Lewis, who is a researcher with Genetic Alliance UK. If you have any concerns or questions about taking part in this research before the group then please contact Celine on 0207 704 3141. If you have agreed to take part and then find nearer the time you are no longer able to make the group then please contact the person who recruited you directly so that you can be replaced.

**What if something goes wrong?** In the unlikely event that you want to make a complaint about the conduct of the research, or would like help or advice following the discussion, you can contact the head of the project, Julie Corfield:

Email: [juliecorfield@areteva.com](mailto:juliecorfield@areteva.com)

Tel: 0115 812 0008

Many thanks,

**Celine Lewis**