

Public and patient views of laboratory grown red blood cells

**Participant Information Sheet (Patient focus groups)**

This document is to explain more about the research we are doing. When you’ve read this, have a think about whether you are happy to take part (or if you want, discuss it with someone else).

**Why are we doing this research?**

We are interested in your views on laboratory grown red blood cells and immortalised stem cell lines, that is cells kept alive in the laboratory indefinitely. Scientists are growing red blood cells using stem cells obtained from donated blood for new treatments. They are also growing red blood cells from stem cell lines. We want to know your views on these techniques. This research project is trying to find out what patients think about the use of laboratory grown red blood cells and stem cell lines for blood transfusion.

**How are we doing the research?**

We want to talk to some small focus groups of people who have received blood products to find out what their views are about the development of these new techniques for producing red blood cells. We are asking you to be in one focus group (with 5-10 other patients), where we will ask things like ‘what do you think about growing red blood cells in the laboratory’? The focus group will be held in in the Bristol area. We will ask your permission to audio record the group discussion. The focus group will last about 1-1.5hrs. When talking about things like health people sometimes remember, or talk about, experiences that may have been upsetting for them or still are. There will be two people running the group so if you become upset for any reason someone can go out with you, and also make sure you know where to find help. Mostly though these kinds of groups give people a chance to discuss their ideas and views and get them heard. It may give you a chance to influence the way policy and the science conducted around these new treatments is developed in the future.

**Why have you been asked to take part?**

We are asking you to take part because you have experience of being someone who has received a blood product or are a family member of a person who has received blood products. Taking part is voluntary and this information is to help you decide whether or not you want to take part. If you change your mind that is fine – no problem- or indeed if you want to change your mind before the focus group takes place that is ok too. We will ask you to sign a form saying you are happy to be involved – but again you can still change your mind. We will ask again before the group discussion begins if you are still happy to take part, just to make sure. You can leave the discussion in the focus group at any time, but we won’t be able to remove what you have already said from the recording and the information you have given cannot be withdrawn because we won’t be able to identify your voice easily in the recording. We hope being in the focus group will be an interesting experience and we will really value your views. We will reimburse your travel expenses.

**What will we do with the information you give us?**

What is said in the group will be audio recorded and transcribed, without your name on it so that no one outside the research team knows who took part. We ask you not to talk about other patients in the group without their agreement as they may tell you something they don’t want shared outside the group. During the project only the research team will have access to the full transcripts but we will share extracts from the data with members of a public advisory group who will be asked to comment on our analysis of the data. You will not be identifiable to the advisory group and when we write about the research you will remain anonymous.

**What will happen when the research ends?**

We will store the written copies of the focus group discussion and audio recordings on the UWE secure server which is password protected. For two years, only the research team will be able to read or listen to these but we will keep them for up to five years after this project has finished in order to give us time to write about what we find out. We are also asking for your permission to archive (store) the anonymised (unnamed) data in a UWE university repository (digital storage) so that we may share the data with other researchers if they wish to use it for their research. This is what the University expects us to do in order to follow the law on Data Protection and offering to share data is expected by the research funder to get the best value from research.

**Who is doing the research?**

This study is being funded by the National Institute for Health Research and is part of the work of the Blood and Transplant Research Unit (BTRU) in Red Blood Cell Products. The researchers conducting this study are from the University of the West of England (UWE). The research has been approved by NHS Research Ethics Committee and the UWE Faculty Research Ethics Committee. Rachel Hale, is the researcher who will lead the focus group. Professor Julie Kent is the project manager and will also attend the focus group.

If you are willing to take part in the research or have any questions about the research please contact Rachel Hale on rachel.hale@uwe.ac.uk or Professor Julie Kent on Julie.kent@uwe.ac.uk or 0117 32 82356.

If you want to complain about the research for any reason then please contact the Associate Dean, Professor Jenny Ames, Faculty of Health & Life Sciences, UWE on Jenny.Ames@uwe.ac.uk

**Thank you very much indeed for your help.**

The Blood and Transplant Research Unit (BTRU) in Red Blood Cell Products is part of and funded by the National Institute for Health Research (NIHR) and is a partnership between the University of Bristol and NHS Blood and Transplant (NHSBT) in collaboration with the University of Warwick, the University of Bath and the University of the West of England

