

NIHR BTRU in ODT Patient and Public Research Panel

Useful Information and Common Questions

December 2022

What is the BTRU in ODT?

The Blood and Transplant Research Unit in Organ Donation and Transplantation (BTRU in ODT) is funded by the National Institute for Health and Care Research (NIHR).

- The Unit is a collaboration between Cambridge & Newcastle Universities and NHS Blood and Transplant (NHSBT).
- It is dedicated to research into organ donation and transplantation.
- The unit's objectives are to increase the number of organs available, improve long-term outcomes and quality of life for patients after transplantation.
- The Unit also works to understand and overcome the barriers to organ donation and transplantation and improve access to transplantation for all patients.

What is the Patient and Public Research Panel?

The BTRU in ODT is dedicated to placing the patient and public voice at the heart of its research activities.

The Patient and Public Research Panel (PPRP) was created in 2015, when the previous BTRU was established, to fulfil that ambition. The panel brings together the views of patients, carers and the public so that our researchers may better understand the priorities, concerns and needs of the organ donation and transplantation community.

The panel helps our researchers to ensure:

- Their research addresses issues that are important to patients and carers
- That they consider the potential burden on patients taking part in their research
- That information about the research is clear and patients and the public can understand it
- That the results of the research are shared with the public in an appropriate way.

Key Points



The PPRP is a group of people including patients, carers and members of the public who give researchers feedback on their ideas and plans.



All panel members' experience is different but what they share is an interest in organ donation and transplantation research. Some members have more general experience of involvement in research as part of charitable organisations or have personal experience and expertise as patients and carers. However, you're welcome to become a member whether you have direct experience with organ donation/transplantation or not.



The ideal number of members for the panel is between 12-15, this ensures that all members have a chance to express their views during our 45-minute meeting with a researcher.



To make sure research is of the best quality we need to hear from people from a wide range of backgrounds. Panel members come from lots of different walks of life – they have different skills and experiences and have many different points of view.



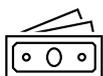
You don't need to have any formal qualifications to be part of the panel, and you don't need to know anything about organ donation and transplantation research before you join. We're interested in your thoughts and your enthusiasm for helping to improve healthcare for everyone.



Each member has a different amount of time they can commit to the panel. Ideally, we are looking for active members who can spare 2 to 3 hours every 3 months to attend an online meeting and read research project information in advance.



Panel meetings take place predominantly online via Zoom usually on a weekday between 9 am-5 pm. However, we know that panel members have busy lives with work, family, educational, community or religious commitments during these hours, so we are flexible and will work to ensure meetings are accessible to all members.



Panel members are offered payment for their involvement in line with NIHR guidance. Members can choose to not be paid and instead will receive a gift voucher at the end of the year to thank them for their involvement or members can choose to receive no payment/reward at all.



As an expert of your own experience, you have something very important to share with our researchers. Sharing your perspective will bring a fresh outlook to our research which may not have been considered. Regardless of your formal qualifications or knowledge of research, your voice is important.

What can I expect as a member of the PPRP?

- ✓ Training to support you in your role
- ✓ Payment for your time (including preparation time for meetings)
- ✓ Support from fellow panel members as well as the Patient and Public Involvement and Engagement Lead and BTRU colleagues
- ✓ Feedback on how your work has improved our research
- ✓ Opportunities for involvement in the wider activities of the Unit e.g., [as a co-applicant](#) on a new research project or as a member of a subgroup helping to develop our teaching or engagement activities.

Panel Code of Conduct

We ask all members of the panel to follow a simple set of guidelines to make sure that discussions are respectful, welcoming, and useful for everyone involved.

- ✓ Treat all panel members, researchers and BTRU staff and visitors with courtesy and respect.
- ✓ Listen carefully to other panel members and respect their viewpoints, which may differ from your own.
- ✓ Each panel member is encouraged to share their honest views, positive or negative, but is asked to do so in a polite and constructive way.
- ✓ Do not use inappropriate language or language that is discriminatory in any way.
- ✓ Be patient and respectful of the different ways that fellow panel members or researchers communicate. Allow them to speak without interruption.
- ✓ During online meetings everyone should keep their microphones muted unless it is their time to speak.
- ✓ Every meeting will be chaired by the PPIE Lead. Please tell the Chair that you want to speak by raising your hand physically or using Zoom emoticons. If more than one person wants to speak at any one time, the Chair will advise on the order and give each person a chance to speak.
- ✓ Treat all discussions with researchers about their work as confidential and treat all documents sent to you as confidential. This means you should not give details or send documents to anyone else who is not a member of the panel or a member of staff of the BTRU in ODT.

Please be aware that members may be asked to leave the panel for any serious or repeated breaches of the code.

What do I do if I have questions?

If you have any questions or would like further information you could do the following:



Email the Patient and Public Involvement and Engagement Lead, Hannah Murray
Hannah.Murray@newcastle.ac.uk



Visit the BTRU in ODT Website: <https://odt.btru.nihr.ac.uk/>



Or follow us on Twitter https://twitter.com/BTRU_ODT

This document was written by Hannah Murray in collaboration with BTRU colleagues and members of our Patient and Public Research Panel in December 2022.

The document will be reviewed and if appropriate updated on an annual basis, the next review will take place in December 2023.