BTRU in ODT Patient and Public Research Panel

Useful Information and Common Questions

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Contents

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 and 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 and to 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.
- They consider the potential burden on patients taking part in their research.

- That information about the research is clear, accessible and understandable.
- That the results of the research are appropriately shared with the public.

Key Points

The Patient and Public Research Panel are a group of people, including patients, carers and members of the public, who give researchers feedback on their ideas and project applications. The primary role of a panel member is to read through plain English research documents, prepare feedback and discuss their ideas during our monthly panel meetings. There are other ways to submit feedback if members don't feel confident talking during meetings.

All panel members' experience differs, and you don't need formal qualifications to join the panel. Some members have more general experience of involvement in research as part of charitable or patient organisations, or have personal experience and expertise as patients, donors and carers. Everyone is welcome!

The ideal number of members for the panel is between 10-15, this ensures that all members have the time and opportunity to express their views during our monthly meetings.

Panel members can come from different backgrounds and walks of life. This variety of perspectives ensures our research is of the best quality, has a real impact and reflects the views of the wider ODT community.

You do not need to know anything about organ donation and transplantation or research in general to join. The BTRU is interested in hearing from people who feel confident in expressing their views, who can spare the time and who have an enthusiasm for our research. As you gain more experience, you'll develop the skills, confidence and knowledge you need for the role.

Ideally, we are looking for individuals who can take an active role in the activities of the panel. You should be able to spare 2-3 hours per month to read project information, prepare feedback and attend the panel meeting.

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

Panel members are offered payment for their time and feedback in line with NIHR guidance. If a member accepts payment, we advise them to speak with their local Citizens Advice Bureau, as they can advise members on the potential impact payment may have on their tax and/or benefits. Members who wish to receive payment must complete the required documentation and complete the checks required by Newcastle University's finance team.

As an expert of your own experience, you have something important to share with BTRU in ODT researchers. Sharing your perspective will bring a fresh outlook to our research, which may not have been considered before. 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 and feedback for up to four meetings per year.
- ✓ Multiple methods of supplying feedback on our research. These include a panel meeting discussion, through the Zoom chat function, via email or in a separate one-to-one meeting.
- ✓ Peer-to-peer support.
- ✓ Feedback on how your work has impacted our research.
- ✓ Opportunities to get involved in the wider activities of the Unit.
- ✓ Engagement opportunities.

Is there a Panel Code of Conduct?

We ask all members of the panel to follow a code of conduct. These guidelines outline what is expected of each member and ensure panel discussions are respectful, welcoming, and useful for everyone involved.

As a member, you are expected:

- ✓ To read the project documentation before the meeting and prepare questions and feedback.
- ✓ To let the PPIE Lead know if you cannot attend a panel meeting. To send your apologies, via email, if you cannot attend a panel meeting.
- ✓ To treat all panel members, researchers and BTRU staff and visitors with courtesy and respect.
- ✓ To listen carefully to other panel members and respect their viewpoints, which may differ from your own.
- ✓ Due to limited time, members are asked to keep their feedback short and relevant, and if required, to answer the specific questions posed by the researcher
- ✓ To share your views, positive or negative, but to do so politely and constructively.
- ✓ The role of a panel member is to support, guide and advise.
- ✓ Panel members represent both their own and the wider ODT experience. They are there to make things better for all patients. They must not use meetings or events as an opportunity to advocate for outside organisations or their own research interests.
- ✓ To not use inappropriate language or language that is discriminatory in any way.

- To be patient and respectful of the different ways other panel members or researchers communicate. Allow them to speak without interruption.
- To treat all research documents and panel meetings as confidential. No information should be shared with any third parties.
- To follow online meeting etiquette, for example, to keep microphones muted unless speaking.

What happens if the Code of Conduct is breached?

Members may be asked to leave the panel if any of the following breaches of the code occur:

- If a panel member does not respond to or communicate with the PPIE Lead for three months.
- If a panel member does not provide feedback, of any kind, for three months.
- If a member does not let the PPIE Lead know that they are unable to attend a panel meeting on three consecutive occasions.
- If a panel member deliberately shares confidential information with a third party without the permission of the BTRU in ODT.
- If a member behaves inappropriately
- If there is evidence of harmful or inappropriate behaviour.

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

Or follow us on LinkedIn

Acknowledgements

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The document will be reviewed and if appropriate updated on an annual basis, the next review will take place in January 2027.