

Cambridge Biomedical Research Centre

Cambridge University Hospitals' (CUH) Patient and Public Involvement (PPI) Panel

A guide for Research Readers

Welcome. Thank you for your expression of interest in joining the CUH Patient and Public Involvement Panel. This guide has been written to help answer any questions you may have about becoming a Research Reader. If, after reading it, you still have further questions, please do not hesitate to get in touch.

Who are our Research Readers and what do they do?

Our panel of Research Readers are volunteers who review research documents, providing insights and points of view that may not have considered. It is not necessary to have been a patient, or to have any medical knowledge, to join the panel as a Research Reader, as all perspectives are valued. We welcome new members from all backgrounds over the age of 16 years.

People join us so they can:

- Collaborate with researchers to improve health research
- Improve patients' experience of taking part in future research
- Discover more about the world-renowned research conducted on the Cambridge Biomedical Campus
- Contribute to innovative pioneering research work
- Learn and develop new skills



How does it work?

Readers receive research documents to read and review via email from the panel coordinator. A brief introduction to the study with information detailing what is required accompanies each request. This usually takes the form of a question, or set of questions, from the researcher together with a deadline within which to respond (usually two weeks). Research Readers choose which document(s) to read/comment on, depending on individual interest and available time.

Confidentiality

Your contact details will not be passed on to researchers without your express permission. When you join, you will be asked to sign a confidentiality agreement. You will not, in any circumstances, be sent any personal information relating to patients or study participants.

It's a very flexible, worthwhile way to volunteer your time

- You don't need to travel
- You select which pieces of research to comment on, depending on your time and individual interests – so you're always in control of your time and do not feel burdened
- You will receive regular feedback from researchers so you know your input is worthwhile
- You can withdraw from the panel at any time and you are under no obligation to review any particular study or number of studies

“Don't be intimidated by the fact that you are helping very brilliant medical researchers. You have a value to them, and the reason you exist in this role is because you have insights and skills that they don't have”. *Panel member*

Readers may be asked to read and comment on:

- Plain English summaries – a brief summary that has been written for members of the public rather than specialists. It should be written clearly and simply, without jargon and with an explanation of any technical terms that have to be included
- Patient information sheets – to give potential participants research study information to help them decide whether or not they want to take part
- Patient consent forms – for potential participants to complete once they've decided they'd like to take part in a research study
- Patient & Public Involvement (PPI) sections of funding applications – description of how the research project plans to use PPI
- Study protocols – a full description of the research study, including a detailed set of activities for the study

What impact does our panel of Research Readers have on research?

'I went through all the suggestions one by one and systematically applied changes to the documents. The documents read a lot better after the edits.'

Dr Gaby Captur Clinical Lecturer and NIHR Rare Diseases Translational Research Fellow

'Your comments have been incredibly useful – in particular pointing out parts of the summary that are confusing. I have now extensively revised this based on your advice, and the advice of other groups. Many thanks to all of you.'

Mr Stephen Price Consultant Neurosurgeon

'All the feedback was very helpful and I expect it to impact positively on the study.'

Dr Audrey Melvin Clinical Research Fellow University of Cambridge

The National Institute of Health Research (NIHR) has developed Learn Zone, an online resource full of learning and development tools for members of the public getting involved in research. Visit <http://www.nihr.ac.uk/patients-and-public/learn-about-research/learn-zone/>

How we support and communicate with our Research Readers

We provide:

- Regular (optional) meetings, enabling members to hear the latest news from researchers as their studies progress
- Learning opportunities for those who wish to develop their skills and share knowledge and expertise with staff and volunteers
- A short monthly e-newsletter to keep everyone up to date, including a feedback report from our researchers, and a calendar of other events and talks

Cambridge University Hospitals' Patient and Public Involvement Panel coordinators are here to help.

Contact: Anna Ellis

anna.ellis@addenbrookes.nhs.uk

or ppi@addenbrookes.nhs.uk

Telephone: 01223 254620

Website: cambridgebrc.nihr.ac.uk

“Try and imagine the practicalities of the research study. Imagine the people who will be participants. If it were you, or someone for whom you cared, what would be your thoughts? What would you want to happen to agree to participate?”

Panel member

CUH Patient and Public Involvement

Research Reader Ros with her dog Penny

'I enjoy the flexibility of being able to work in my own time, with no pressure, and without having to attend meetings. The feedback from researchers proves how valuable the work of panel members is. Give it a go. You will definitely enjoy it. There is always help/advice should you need it'.



Ros

Research Reader Jeremy

'I find the work stimulating engaging and highly enjoyable. I commend Public and Patient Involvement to all who have the time and desire to make a positive contribution to those whose wish it is to make the experience of being a patient a better one'.



Jeremy

Professor John Bradley

Director of the NIHR Biomedical Research Centre

"If you involve people, and you involve them early, you will reap the benefits as a research programme evolves."



John Bradley

For more information call 01223 254620 or email ppi@addenbrookes.nhs.uk
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