

Patient Led Research Hub

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At the Cambridge Patient Led Research Hub, our aim is to provide the resources, expertise and infrastructure to turn patients' own research ideas into high-quality clinical projects.

www.plrh.org



Aim

Patients understand their disease and needs better than many medical professionals do. They may also have important ideas about what research would be most beneficial to their lives. However, due to the complexity and cost involved in running clinical trials, the majority of research originates with the pharmaceutical industry or academic researchers. The Cambridge PLRH supports patient led research, working in partnership with patient groups to deliver clinical studies based on their own research questions.

About us

The PLRH was established in 2015 by members of the Cambridge Clinical Trials Unit (CCTU) from the University of Cambridge and the Cambridge University Hospitals NHS Foundation Trust. We have expertise in the design and delivery of large and complex

national and international clinical trials. The PLRH is led by Dr Thomas Hiemstra, a clinical trialist and honorary consultant nephrologist at Addenbrooke's Hospital. Importantly, we do not have a specific research focus, allowing us to support research proposals from any patient group, on any topic.

Please navigate to our website plrh.org for more information about the PLRH, our research projects and publications, news and events, and an online submission form for your research ideas. Read our open-access commentary 'Inverting the patient involvement paradigm: defining patient led research' for a detailed review of the PLRH model.

Where do I start?

You are welcome to contact us directly for more information about the PLRH and research process. However, we request that where possible, research ideas and proposals are submitted through your patient organisation.

What to expect?

We will arrange a meeting with you to discuss your proposal in person. The first step will be to assess whether your proposal is feasible and practical. For feasible projects, we will work with you to develop a funding proposal and design the study. You will become part of the study team and remain involved throughout the whole process, from initial development through reporting the study results. We recognise that your ability to commit may fluctuate, so a representative from your patient group can help with this role.

Setting up a clinical research project can take a long time, often years. Studies can require an extensive amount of background work, device development, and collaboration between

organisations before data collection even commences. As the study progresses, funding external to the PLRH will be required. Although we endeavour to successfully secure a grant for your project, we can only assist in the application process, and cannot guarantee funding will be achieved.

What if I don't know anything about research?

Don't worry! We don't require you to have any knowledge of the research process. We provide the medical and research expertise, and you provide the idea and life experience. Both are equally important to developing clinical trials.

Involving people with 'lived experience' from the onset of research greatly improves the quality and credibility of research. You will be able to contribute invaluable knowledge to patient-centred design, communication, and outcomes, and ensure that the recommendations from your study reach all members of your patient organisation.

Key considerations:

- Is this a patient-centred question with clinical relevance?
- Does any current research address this question?
- Will the study outcomes be helpful to a patient group?
- Are study outcomes likely to be sustainable and easy to implement?

Governance

The PLRH is part of the CCTU, and its strategy and governance are reviewed by the Cambridge Biomedical Research Centre (BRC) and the Cambridge University Health Partners' (CUHP) Patient and Public Involvement Research Oversight Committee. Patient organisations maintain a study-specific partnership and oversight role once a research proposal has been submitted.

Support

The PLRH receives indirect funding from the NIHR via the CCTU. The CCTU is a UK Clinical Research Collaborator and a member of the Cancer Research UK CTU group, with accreditation based on a quality management system covering all aspects of clinical trials conduct. The East of England Research Design Service has contributed funds to developing patient involvement, co-production, and patient led research.

Contact us

Please email us at plrh@hermes.cam.ac.uk or telephone 01223-274570. We aim to respond to all queries in a timely manner. Follow us on Twitter @PLRH_Cambridge for our latest news, events and study progress. If you have any queries or concerns about Patient and Public Involvement in research, the PPI in Research Oversight Committee can be contacted at ppi@addenbrookes.nhs.uk.

External links

INVOLVE is a national advisory group funded by the NIHR, with the aim of advancing public involvement to an essential role within the research process.

People in Research is for members of the public who would like to find out more about public involvement in the NHS, public health and social care research. You can register for involvement opportunities [here](#).

UK Clinical Trials Gateway provides easy-to-understand information about clinical research trials running in the UK. It hosts a large range of information, and is designed to link patients and their clinicians with trials of interest.

The James Lind Alliance is a not-for-profit initiative designed to bring patients, carers and clinicians together in Priority Setting Partnerships, to identify and prioritise research questions.

UKCRC Registered Clinical Trials Units Network is designed primarily for investigators based in the NHS, academia, and industry wishing to develop new trials, or seeking advice on a current project.

International Clinical Trial Center Network aims to improve clinical research by fostering collaborations worldwide, forming a unique network of leading trial centres with a global reach.