Patient Led Research Hub

Frequently Asked Questions

21 May 2019

UNIVERSITY OF CAMBRIDGE

NIHR | National Institute for Health Research

CCTU Cambridge Clinical Trials Unit

Who can submit a research idea?

We welcome research ideas or proposals from any patient organisation, patient support group, or charity in the UK.

We do not accept proposals from individual patients, members of the public, community organisations or businesses.

What can the idea be about?

Your idea or proposal can be about any healthcare topic, condition or symptom, but it has to contain a primary research component (i.e. it must address a unique, unmet need; we do not support awareness or marketing campaigns).

How do I submit an idea?

You can submit your idea online (plrh.org), via email (plrh@hermes.cam.ac.uk), over the phone (01223 274570), or in person at an event we're attending. We'll follow up your idea with email correspondence to make sure we have correctly understood what you're proposing.

How many ideas can I submit?

There is no limit, but if your patient group has multiple questions we request that you submit them in order of priority. We may have limited capacity, so will likely only be able to support one of your ideas at a time.

What makes a good research idea?

Patients have a unique insight into what research would help manage their condition, symptoms, or impact on their lifestyle. It may be helpful to consider if your idea will help improve quality of life for a patient population, or if it will help doctors treat or diagnose diseases. Ideally, the outcomes of your research idea will be simple and affordable for patients or healthcare providers to use.

What if I'm just interested in 'more research'?

Most registered patient organisations or charities have a research component: we strongly recommend you seek out an appropriate group to join. However, if you're a patient member of a rare or under-studied disease group, we will consider your request. In some

cases we can connect you with an existing research team that specialises in your field. In other cases, we can work together to formulate a feasible research idea.

What's a feasibility assessment?

A feasibility assessment will determine if it's technically possible to turn your idea into a research project. A feasibility assessment will typically consider the following (for example):

- What is already known about the topic?
- How many participants will the study need and is it possible to recruit them?
- Is the proposed treatment or device available in the UK?
- Will specialist healthcare providers support this idea?
- Is it ethical?
- Are there potential funding sources?

The PLRH aims to support all feasible research ideas. In some cases, feasibility isn't clear and more background work is needed to make a decision – you can help with this process. Sometimes your idea aligns best with specialised research teams or ongoing projects – we will do our best to connect you to these teams. Infeasible proposals will not be taken forward by the PLRH, but you can revise or submit a new idea at any point. We make sure to communicate each process and decision in clear, accessible language. Wherever possible, we invite you to contribute to the work.

What if I'm not happy with your decision?

We will do our best to include you in each decision making process. However, if you are unhappy with our feasibility assessment, we encourage you to contact one of the following:

- Mrs Laura Mader (PLRH Research Lead): lbm28@medschl.cam.ac.uk, 01223 274570
- Dr Thomas Hiemstra (PLRH Director): tfh24@cam.ac.uk, 01223 336817
- Mrs Louise Stockley (CCTU Operational Director): louise.stockley@addenbrookes.nhs.uk, 01223 348179
- Dr Amanda Stranks (Cambridge Biomedical Research Centre Patient and Public Involvement & Communications Lead, and Chair of PPI Research Oversight Committee): amanda.stranks@addenbrookes.nhs.uk, 01223 348980

The PLRH and its activities are monitored by the Cambridge Clinical Trials Unit, the Cambridge Biomedical Research Centre, and the Cambridge University Hospital Partners Patient and Public Involvement Research Governance Committee. We take your concerns or suggestions seriously, and will incorporate your feedback to improve our future conduct and communication.

What are the main reasons that you turn down research ideas?

The main reason proposals are infeasible is because they are submitted without the involvement of a patient organisation. Once the feasibility assessment is complete, we will send you a formal response explaining our decision.

Support may be declined where:

- The idea has already been answered (in this situation we would send a summary of the existing research to the patient group)
- The idea is not technically feasible
- The idea is a marketing or awareness campaign
- The patient group is already well supported by a research team
- The patient group could not commit to the project
- The patient group does not respond to follow-up queries and contacts
- The aim of the proposal is to request funding

Will you fund my research?

No. The PLRH is not a funder. To develop a feasible research idea we must receive external funds from a public, charity, or industry funder. We will collaborate with healthcare experts, research experts (e.g. grants officer, statistician, health economist, etc.), and you as patient experts, to compose a competitive funding application. However, medical research funding is very competitive, and the PLRH cannot guarantee success.

Will I get paid? Will you fund me to conduct the research?

The PLRH will not fund patient groups to conduct their own research. However, it may be possible to request individual payment on an external funding application. The PLRH will reimburse travel and expenses where possible, but only by prior agreement.

How am I involved if the research is taken forward?

You join the Study Management Team and maintain co-ownership of the project throughout its lifetime. Patient groups are heavily involved in designing the research plan, contributing to funding applications and study documents, promoting the study and helping with recruitment, and sharing the results once it's all complete. The type of involvement required depends on the specifics of the research question and the study type. We encourage patient members to share their experience living with a diagnosis, but also welcome expertise developed through your personal life or career.

What do you mean by a 'multi-stakeholder' team?

We receive a wide range of research ideas, many from rare disease patient organisations: it's quite possible that the core PLRH team will not be experts on your exact proposal. As such, we reach out to medical and research experts with a special interest in your field – you're welcome to make recommendations! We usually form a 'multi-stakeholder' team with the following people:

- Patients, carers, or employed staff from the proposing group
- PLRH staff (clinical trialist and research lead)
- Medical experts in your field
- Academic experts in your field
- Research experts (e.g. statistician, health economist, grants officer, regulatory affairs, quality assurance)

How long does it usually take?

We try to set realistic timeframes for each proposal, and will share our estimates with you from the outset. Unfortunately the research process can be very long and slow, especially for PLRH projects that rely on the availability of external experts.

Feasibility

We aim to conduct the feasibility assessment within 3 months of receiving your idea. If the feasibility is uncertain, the background work (e.g. detailed literature review, patient surveys, external consultation, etc.) can take longer, sometimes up to a year, depending on the level of detail required and availability of medical experts.

Funding application

We will apply to the most appropriate funding programme for the research idea. This could be public (e.g. National Institute of Health Research, NIHR), a national charity, or industry. Most funding opportunities are pre-scheduled, so it may be up to 12 months before we are eligible to apply. Some NIHR funding programmes have two stages which are spaced 3 months apart. It can take up to 6 months to receive a funding decision.

Completing the research

If the funding application is successful, it usually takes 6 months to complete the transaction and set up study documentation, ethics, and regulatory approvals. The length of set up is determined by the type of study (e.g. clinical trial, observational study). The actual study can take years, depending on how long we need patients to take the treatment or use a device; some studies also follow patients long-term after they stop the treatment. The exact study design will be determined before we apply for funding.

Will my research be published? How will the results be shared?

We hope so! It depends on what type of study is completed as to how and where the final results might be published (e.g. medical journal, clinical treatment guidelines). We encourage you to be involved in writing the report and will include you as co-author wherever possible. We also welcome your ideas on how best to share the results with patients and families (e.g. community newsletters, patient forums, social media).

What kind of training do you provide?

We do not provide formal training. However, we are closely linked with many local and national patient involvement and engagement groups, and will share all relevant training and events.

How is the PLRH funded?

The PLRH is funded by the Cambridge Biomedical Research Centre, and the University of Cambridge School of Clinical Medicine, this includes indirect funding from the National Institute of Health Research (NIHR). The Cambridge Clinical Trials Unit supports the PLRH with administration and consumable resources.

Where are you based? What area do you cover?

We are based out of the Cambridge Clinical Trials Unit (Coton House) on the Addenbrooke's Hospital campus. We are pleased to accept research ideas from anywhere within the UK.

Did we miss something?!

Please contact us directly at plrh@hermes.cam.ac.uk or 01223 274570 with any further questions. This document is reviewed annually and updated as needed.