



Patient Led Research Hub

Frequently Asked Questions

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UNIVERSITY OF
CAMBRIDGE

NIHR

Cambridge Biomedical
Research Centre



Cambridge Clinical Trials Unit

Who can submit a research idea?

We welcome research ideas or proposals from any rare disease 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. These stakeholders may be interested in sharing their research idea using the community-led Rare Disease Research Network (rd-rn.org).

We will do our best to connect research proposals about common diseases with relevant research teams, but as these are outside of our rare disease remit, we are unable to provide direct support.

What can the idea be about?

Your idea can be about any healthcare topic, condition, or symptom related to a rare disease. It must contain a primary research component (i.e. it must address a unique, unmet need) which can be answered by research involving human participants (i.e. we do not support animal or laboratory-based projects). We do not support education, awareness or marketing campaigns.

If your proposal is outside of our remit, we will do our best to connect you with a relevant research team, but we are unable to provide direct support.

How do I submit an idea?

You can submit your idea online (plrh.org), via email (info@plrh.org), 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. **The PLRH is a free service to UK-based patient groups.**

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. Our staff have limited capacity, so will likely only be able to support one of your ideas at a time.

What makes a good research idea?

People with lived experience have unique insight into what research might improve diagnosis or manage their condition, symptoms, or daily activities. It can be helpful to consider how your idea will help improve quality of life, 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'?

We recognise that very little is known about most rare diseases, however for us to support new research, we must focus on a specific question. We can help you engage with a wider patient community (e.g. people with a diagnosis but not in your support group or charity) and healthcare providers with relevant clinical expertise to prioritise areas of interest and unmet need. We can work with you to refine these suggestions into a research question that's most important to your group. This early 'exploratory' work can also benefit funding applications.

A good starting point for many rare disease groups is a patient registry. A registry is usually an online database which people consent to join, agreeing to share their personal and medical records. With appropriate permissions, a registry can collect healthcare data from each person's NHS record across various timepoints; other information, for example quality of life assessments, can also be added. Although not a research project in itself, a registry can be an excellent source of data that can be used by multiple researchers for long into the future. It can be a first step into understanding how a rare condition develops, potential complications, and the effectiveness of different treatments. The PLRH cannot help you set up a registry, but we can talk to you about different options and sign-post you to service providers.

What's a feasibility assessment?

Our feasibility assessment will help us decide if it's possible to turn your idea into a research project. We typically consider the following:

- What is already known about the topic?
- Is it ethical?
- Will healthcare professionals support this idea?
- How many participants will the study need and is it possible to recruit them?
- Is the proposed treatment or device available in the UK?
- 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 with existing research teams or ongoing projects: we will do our best to connect you to these teams. Proposals that are not feasible 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 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:

- Laura Cowley (PLRH Research Lead): lbm28@cam.ac.uk, 01223 274570
- Dr Rona Smith (PLRH Medical Director): rms50@cam.ac.uk, 01223 336817
- Louise Stockley (CCTU Operational Director): l.stockley@nhs.net, 01223 348179
- Dr Amanda Stranks (NIHR Cambridge Biomedical Research Centre Patient and Public Involvement & Communications Lead): a.stranks@nhs.net, 01223 348980

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

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

The main reason proposals are not feasible is because they are submitted by an individual without the support of a patient organisation, or by groups which do not have a UK-base. 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 will send a summary of the existing research to the patient group)
- The idea is not technically feasible
- The idea is outside of our remit (e.g. does not focus on a rare disease, or is for laboratory work instead of involving human participants)
- The idea is a marketing, awareness, or educational campaign (i.e. it does not address an unmet need or have a primary research component)
- The patient group cannot commit to the lifespan of the project

Will you fund my research?

No. The PLRH is not a funder. To develop a research idea we must receive external funds from a public, charity, or industry funder. We will collaborate with healthcare professionals, research experts (e.g. grants officer, statistician, health economist, etc.), and you as patient partners, to compose a competitive funding application. We expect at least one member of the patient organisation to be a co-applicant on the funding application and will support you throughout this process. However, please note, medical research funding is very competitive, particularly in rare disease, and we cannot guarantee your application will be successful.

If your project is awarded a grant, how the funding is processed will depend on the specific project and research team. Clinical studies (e.g. prospective observation or interventional trials) almost always require a research organisation to 'host' the study and take legal responsibility, including managing finances. This role is typically filled by a university or hospital. Smaller studies (e.g. patient surveys or service evaluations) can usually be managed by research or patient groups, and it may be possible for your charity to receive and administer the funds.

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

As part of a funding application, we can request costs to pay for your time and expenses. We can also request funding to support involvement and engagement activities for other members of your patient group. In some cases, it may be possible to apply for 'upstream' patient and public involvement funds, which will allow us to pay for your time and expenses prior to a formal funding application. This early funding can help support exploratory work that would benefit your proposal, but it is not guaranteed. We will discuss available funding options with you as soon as we have completed your feasibility assessment.

How am I involved if the research is taken forward?

You join the study 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, helping with recruitment and interpretation, and sharing the results once it's all complete. **You can decide how you'd like to be involved;** the workload required will depend on the specifics of the research question, study type, and funder terms and conditions. We encourage patient members to share their experience living with a diagnosis, but also welcome expertise and skills developed through your personal life or career.

Who else will be on the study team?

With nearly 11,000 different rare diseases, our core PLRH team will most likely not have expert knowledge of your condition. As such, we reach out to relevant medical and research experts for their insight; you're welcome to make recommendations! We usually form a 'multi-stakeholder' team with the following people:

- Patients, family members, carers, advocates, or employed staff from the patient group
- PLRH staff (e.g. research methodologist, project manager)
- Clinical experts (e.g. consultants, registrars, allied health professionals, medical students)
- Non-clinical experts (e.g. scientists, academic researchers)

- Research experts (e.g. medical librarian, grants officer, statistician, health economist)
- Industry experts (e.g. pharmaceutical or biotechnology representatives)

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 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 support an application to the most appropriate funding programme for the research idea. This could be public (e.g. National Institute of Health and Care 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 can take up to 6 months to agree contracts with the funder and research teams, receive the funding, 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 results might be published (e.g. medical journal, clinical guidelines). We expect that at least one member of your patient group will be involved in writing and reviewing the report, and will be included as co-author. We are also happy to support your group with sharing the results publicly (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 are happy to share relevant training and events.

How is the PLRH funded?

The PLRH is funded by the Cambridge NIHR Biomedical Research Centre and Cambridge University School of Clinical Medicine. 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. However, we are pleased to accept research ideas from anywhere within the UK.

Did we miss something?!

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