

New research proposal: summary sheet

This worksheet is intended as guidance only; it's designed to provide helpful prompts as you think about your research idea. Its completion is not necessary to collaborate with the Patient Led Research Hub. Contact info@plrh.org to discuss your idea in more detail.

Tell us about yourself:

Name:

Email address and/or phone number:

Are you contacting us on behalf of a patient group or charity? Which one?

Tell us about the condition:

What's the clinical diagnosis? What are the main symptoms?

Who's usually affected?

Roughly how many people are diagnosed in the UK? Roughly how many people are diagnosed worldwide?

What charities or patient support groups are available in the UK? Are there other similar rare conditions, 'umbrella' groups or charities that you could partner with (if so, please list)?

Tell us about the question:

What new information is required?

How would this benefit people affected by the condition and their families?

How would this benefit healthcare professionals and the NHS?

Briefly describe existing or ongoing research in this area (specific to your question) that you're familiar with.



Can your patient group/charity help fund this research? Are you aware of any other potential funding opportunities?

Tell us about the research plan:

Will the study be an observation (collect information on existing treatments or care pathways) or intervention (test a new dose, treatment, or device)?

What will the study measure?

How many people in the UK do you think would participate in the study?

Briefly, what would participants have to do? How long would they have to participate?

Tell us about the research team:

Is there anyone you think is essential to have on the research team?

Are you familiar with a relevant specialist that could be approached about this idea?

Does your patient group/charity have a medical advisory board, or work closely with any medical or research experts? What support can your patient group/charity offer?

How would you like to be involved in the study?

Tell us anything else you think we need to know: