



A Practical Guide to PPI

Information for professionals

thelilyfoundation.org.uk



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Introduction

Here at The Lily Foundation, we believe in the democratic principle of ‘nothing about me, without me’. This means that people who are affected by mitochondrial disease have the right to have a say in the research going on into their condition. In recent years there has been a growing appreciation of the importance of including the patient perspective in all research activity.

Patient and public involvement is increasingly becoming an expected requirement of several research funders, and ethics committees will ask you to detail your plans for involvement as part of their assessment process. This is very important, as patient involvement can help to ensure that your planned research is ethical, relevant and acceptable to the community the research stands to benefit.

The Lily Foundation’s **IMPACT** (Mitochondrial Patient Advisory Committee) is designed to involve people with lived experience of mitochondrial disease, providing opportunities for patients, families, researchers and clinicians to work alongside each other to help shape mito care and research.

IMPACT is open to patients and family members of those living with mitochondrial disease, as well as those who have lost loved ones to the condition, and who have expressed an interest in being involved in research. As IMPACT is open to our entire Lily community across the UK, it is a virtual committee with most activities taking place online. Participants can choose the projects that they would like to be involved in, and researchers will be matched with a diverse group of participants according to their requirements when they apply.

Before you start...

The Lily Foundation’s IMPACT committee is a great way to involve patients, parents and caregivers with direct experience of mitochondrial disease in your research project. However, it’s important to understand that whilst the Lily team are happy to facilitate patient involvement opportunities, PPI must primarily be a partnership between the researcher and the people directly affected by mitochondrial Diseases.

In order to approach IMPACT, you must have a genuine interest in and motivation to involve patients in your research, and you must demonstrate a plan for your patient involvement opportunities that is meaningful and well thought through. We hope this practical guide will be helpful in assisting you to plan your patient involvement activities before you apply to IMPACT.

Involvement, Engagement or Participation?

Before you apply to IMPACT, it's worth first checking that you are definitely looking for involvement rather than participation or engagement. These terms are often used interchangeably but describe three distinct concepts.

Whilst participation involves people actively taking part in your research study, and engagement relates to the sharing of knowledge or information about your research, involvement is defined by the NIHR as research that is carried out 'with' or 'by' people, rather than 'to', 'for' or 'about' them. It is an active partnership where patients, carers and the public work alongside researchers to help influence and shape research.

The Lily Foundation has a comprehensive PPIE strategy that encompasses all three elements of Participation, Involvement and Engagement which you can learn more about through our '**Be Part of Research**' webpages.

The logo for IMPACT features a stylized icon on the left consisting of a circle with a vertical line through its center, and the word "IMPACT" in a bold, sans-serif font to its right.



What are the benefits of involving patients in your research?

There are several benefits to involving patients in your research:

- Taking into account the needs of the mito community can help to improve the relevance of your research, identifying a wider set of research topics than may have been generated by yourselves as researchers and healthcare professionals. It also helps to ensure that your research is focused on what really matters most to patients – for example, by prioritising research that focus on the symptoms that are most debilitating to mito patients.
- People who have been affected by mitochondrial Disease, either personally or through caring for a loved one, may have direct lived experience and knowledge of your research topic. Involving patients and the public can bring a different perspective to your research and can help to reclarify and reshape your ideas.
- Involving patients can also help to empower people by providing them with the opportunity to influence research that is directly relevant to them.
- Involvement helps to ensure that research is outward-facing and focuses on outcomes that are important to those directly affected by the disease.
- It is also a good way to ensure that your research is tailored to the specific needs of the community; for example, by asking patients to be involved in the design of your study, this can improve recruitment and retention to your study by ensuring that your research methods are sensitive to the needs and circumstances of patients.

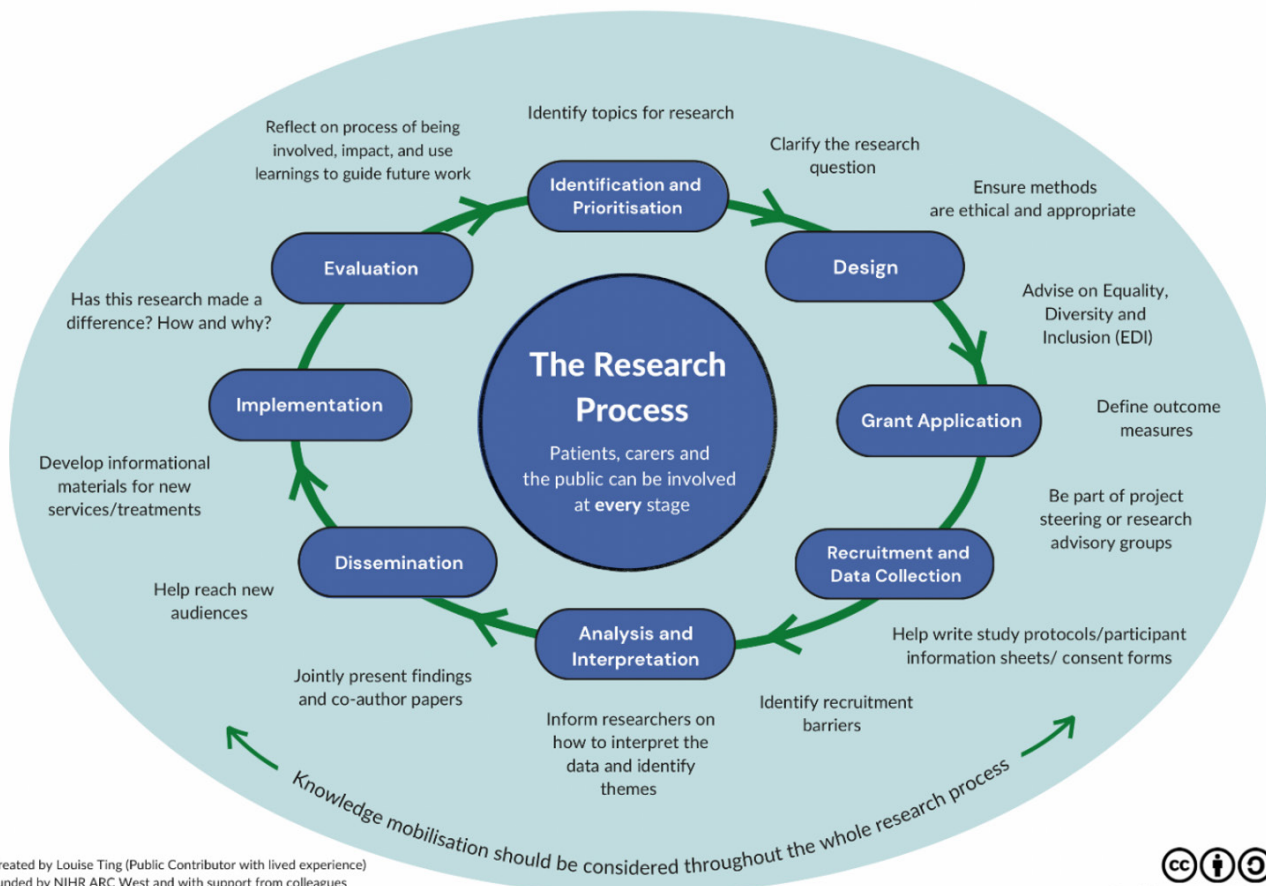


How can IMPACT help you with your research project?

When planning for PPI in your research project, it is important to remember that patients, parents and caregivers can be involved in the various stages of the research cycle, from the planning and design stages, throughout the implementation and management of the study, and all the way through to the evaluation and/or dissemination of the research findings.

In fact, engaging with patients early on and making sure that they continue to be involved all the way through the research process can help ensure that your study remains patient-focused throughout and avoids patient involvement becoming tokenistic, or a 'box-ticking exercise'.

The following diagram is a handy tool to help researchers identify how they can embed public and patient involvement at every stage of the research cycle:



There are several ways that the IMPACT committee can get involved with your research project.

For example:

- Helping to identify research priorities for the mito community. (Please note that The Lily Foundation was among several charities involved in the mitochondrial Disease Priority Settings Partnership (PSP), set up to identify the top research priorities for patients with a mitochondrial disease diagnosis and the healthcare professionals who provide their care).
- Providing input on study design and whether this is practical, manageable, reasonable and relevant to patients.
- Commenting on and developing patient information leaflets or other research materials to ensure they are written in plain English and are understandable to people without a scientific background.
- Acting as project advisors on the study or sitting as part of a steering committee.
- Assisting in research delivery, for example by co-ordinating focus groups or hosting interviews.
- Advising on the best way to disseminate results to the mito community, helping you to think about what the study results mean from a patient perspective.



Key considerations

Before approaching IMPACT to ask for their involvement in your research, there are some key questions you should be prepared to answer when making your application:

Who is your ideal group of participants?

Would you like to engage with a particular subsection of the mito community, such as adult patients or parents/caregivers, or those who have experience with a particular syndrome or genetic diagnosis? It's important to also think about the possible implications of involving patients at this stage who could go on to become research participants, and any potential ethical challenges or conflicts this may bring. Other things to consider include whether it is important to you that people have been involved in research in the past? Do they need to have been living with the disease for a number of years, or does it not matter? Including a diverse range of voices can help to ensure a variety of lived experiences and perspectives.

Why are you looking to involve patients and how will their input influence your project in a practical sense?

It can be helpful to think of some key areas or questions you would like to explore with them and some goals that you would like to achieve together.

It's also important to ensure that you are in a position to actually implement any suggested changes before asking for their input to ensure involvement is meaningful— so please consider early involvement and be mindful of ensuring that you allow time for changes to be made before any funding submission deadlines.

What do you want the involvement to look like?

Would you like group members to participate in a focus group or 1:1 discussion, or would you like them to complete a questionnaire or give feedback via email? Do you have study documents such as a Participant Information Sheet or a protocol / schedule of assessments that you would like reviewed? There may be various levels of involvement opportunities.

What do people need to know to participate in a meaningful way?

Is there any pre-reading, teaching or training on the topic that would help inform the discussion and if so, how will you build this into the PPI activity? Would it be helpful to spend some time explaining complex medical concepts or terms in a simple way? Could a glossary of terms be helpful to aid understanding?



How many people would you like to be involved?

Are these the same people throughout or would you like different people to be involved at different stages?

How often would you like to engage the committee and what does their involvement look like?

Think ahead and be clear about the level of commitment required from patients and the public – is their involvement going to be a one-off or are you looking for members who can give up more time to be part of your project at various stages of the life cycle of the research project? Depending on their circumstances, people will be able to commit different levels of time to a project so it's important that this is clear from the outset. At the end of each activity, think about **what happens next**. If you are planning a future PPI activity, make sure to let the group know when to expect to hear from you again. If this is the end of their involvement, how will you provide feedback and ensure you keep them informed about the project in terms of next steps.

Practical and emotional considerations

In addition, you should consider practical issues, such as timing of meetings, being sensitive to the needs of people you are working with, any ethical requirements and safeguarding the individuals involved. Also think about any potential barriers to involvement, such as visual or hearing impairment or other physical or cognitive disabilities and how you plan to address any challenges to make your activity as inclusive as possible.

Being involved in discussion groups may also present emotional challenges as you are asking people to recount individual experiences of their own healthcare journey that may be distressing or emotional. Be prepared to spend time listening to people's personal stories, and to moderate the discussion to ensure the original topic is covered whilst being sensitive to people's individual circumstances.

PPI budgets and financial considerations

It is good practice to budget for patient involvement when planning a study.

The NIHR have full and comprehensive guidance relating to this topic which we would encourage you to review, and which can be found at [nihr.ac.uk/payment-guidance-researchers-and-professionals](https://www.nihr.ac.uk/payment-guidance-researchers-and-professionals).



Included is guidance which sets out the following rates, which can be used as a guide / benchmark for your involvement activity:

- **£12.50** - For involvement in a task or activity such as reading and commenting on a document which equates to less than half an hour. For example, reviewing a patient information leaflet, lay summary or abstract.
- **£25** - For involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less. For example, participating in a focus group to provide feedback on a proposal.
- **£50** - For involvement in a task or activity likely to require some preparation and which equates to approximately two hours of activity. For example, a teleconference with related papers to read or review a few short documents.
- **£75** - For involvement in a task or activity where preparation is required and which equates to approximately half a day's activity. For example, participating in a meeting to interview a small number of candidates who have applied to join a committee or panel, participating in a focus group, or delivering training.
- **£150** - For involvement in all-day meetings. For example, attending a committee or panel meeting as an observer prior to becoming an active public member of a committee/panel.
- **£300** - For involvement in all-day meetings that require substantial preparation. For example, when chairing or co-chairing a meeting or when carrying out other discretionary work, which requires additional responsibilities.

We understand that if engaging early with patients and the public (e.g. before research funding is granted) you may not yet have a budget for PPI. This is not necessarily a barrier to involvement as many people want to take part for altruistic reasons or because they are generally interested in research.

It's also important to give people the choice about whether or not they would like to be reimbursed for their time. Some people may prefer alternative (or additional) means of recognition, such as a letter of thanks, a certificate or a personal reference from a researcher (this can be helpful to young people thinking about applying for college or university).



Providing feedback

Providing regular, detailed feedback about how input from patients and the public has helped to guide and refine your research is crucial to good practice in patient involvement. It is important to remember that members of IMPACT give up their time and effort to help researchers understand what really matters to people living with mitochondrial disease, often whilst coping with the demands of the condition on themselves or family members. It is important to recognise and acknowledge the added value that their perspectives have brought to your research so that they feel that their involvement has been worthwhile.

Before beginning to undertake PPI work, it is worth planning ahead to think about the duration of the patient involvement and how you will keep the group informed about how their feedback is shaping your research at every stage. Some people find it helpful to use the “You said, we did” approach, a simple format to show practical examples of areas where their suggestions have been taken forward and implemented. Another good way of measuring the impact of your PPI work is to keep a PPI activity log. You will find some template examples of ways to demonstrate impact and provide feedback at the end of this guide, but these are by no means the only way you can collect and share feedback.

There may be times where it may not be possible to implement patient feedback or suggestions; for example, if it is not practical or ethical to implement a change proposed by a patient group. It is good practice in these cases to spend some time explaining and justifying areas where their feedback has not been taken on board, particularly if you are able to give a good reason as to why it has not been possible to implement their changes.

With this in mind, please think carefully about asking for patient involvement if you already know that you are not in a position to implement any changes to your proposed research. For example, if your patient information leaflet has already been approved by ethics, there will likely be limited changes you can make based on patient feedback at this stage. For this reason, we would always encourage engaging with IMPACT as early as possible, and where possible even before the grant approval stage. Early engagement allows PPI contributors to be involved in every aspect of the research cycle, from the initial idea through to the dissemination of results, and ensures truly meaningful patient involvement at every stage.

Part of providing feedback involves also sharing updates when outcomes are negative; for example, if funding is not approved or if the research study is ultimately unsuccessful. Our contributors expect to be kept up to date on ‘what happened next’ with the research they have been involved in, even when the news isn’t good. Helping people to understand the impact that their contributions have had despite a negative outcome overall can be really helpful in keeping them motivated to stay involved in future research.



Frequently asked questions

Do I need ethical approval for Patient and Public Involvement?

No. You do not need to submit an application to a Research Ethics Committee in order to involve the public in the planning or the design stage of research, even if the people involved are NHS patients. Please note that by 'involvement', we are not referring to research participants taking part in a study.

How early should I make contact about patient involvement in my research?

As early as possible! We would advise giving us as much notice as possible (at least 4-6 weeks) if you would like to meet with the IMPACT committee. This will give us a chance to work with you to schedule a meeting at a mutually convenient time and will also allow time for any background work / preparation to be done before the meeting.

Where can I find extra resources to help me with my PPI?

The NIHR have a fantastic range of resources and guides to help you involve patients and the public in your research. In particular the following pages can help:

- [Briefing notes for researchers](#)¹ – public involvement in NHS, health and social care research provides comprehensive briefing notes about various aspects of Patient and Public Involvement and includes the UK standards for Public Involvement.
- [Resources for PPI](#)² – includes links to documents regarding co-production in research, payment and recognition for PPI and general guidance on how researchers can involve patients and the public in research.
- Within the [NIHR-funded Biomedical Research Centres](#)³ are dedicated PPIE teams who can provide additional resources, training and advice, so it's worth connecting with your local team.
- Elsewhere, the [Plain English Campaign](#)⁴ is a helpful resource that can help to ensure you are communicating clearly to your intended audience and without the use of jargon. A [plain English summary](#)⁵ is a requirement of NIHR funding applications, more details of which can be found here.

1 - <https://www.nihr.ac.uk/briefing-notes-researchers-public-involvement-nhs-health-and-social-care-research>

2 - <https://www.nihr.ac.uk/ppi-patient-and-public-involvement-resources-applicants-nihr-research-programmes>

3 - <https://www.nihr.ac.uk/about-us/what-we-do/infrastructure/biomedical-research-centres>

4 - <https://www.plainenglish.co.uk>

5 - <https://www.nihr.ac.uk/plain-english-summaries>



Next steps

I am interested in getting involved but I have more questions – who should I ask?

If you would like to discuss how to involve patients and the mito community in your research, please contact Katie Waller (Head of Patient Programmes) at katie@thelilyfoundation.org.uk.

How do I apply?

You can apply to approach the IMPACT committee using our online web form. Once we have received your application, we will review it and then we'll be in touch to discuss it with you. Once applications are approved, we will ask you to sign an agreement with The Lily Foundation that outlines our terms for working with IMPACT, and then we will begin the process of identifying suitable members of our IMPACT committee who may be interested in getting involved with your project. We will then work closely with you to arrange your PPI activities and act as moderator between you and the committee.

Name of Lead Researcher	
Title of Research Project	

[illegible]



Appendix B - You Said, We Did Template

Example - You said that our patient leaflet had too much complex medical jargon and felt that a diagram could help to explain

You Said...

We did...



IMPACT

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