



**Expert Patient Input Committee**  
PPI Guidance for Researchers

# What is EPIC?

The Lily Foundation's Expert Patient Input Committee (EPIC) 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.

EPIC 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. Members have expressed interest in taking part in EPIC as part of signing up to our UK Mito Patient Registry or have approached us directly with a desire to take part. As EPIC is open to our entire Lily community across the UK, this will be 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 need to apply to The Lily Foundation to approach the committee. The application form for researchers can be found [here](#), however we strongly encourage you to read the following guidance before making an application.

Thank you and we look forward to hearing from you.



# Why is it important to include patients in your research?

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.

\*by public we mean carers, family members or those with direct lived experience of the disease



# 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.

# Differences between Participation, Engagement and Involvement

The terms participation, involvement and engagement are often used interchangeably, but they are three distinct concepts:

Participation is where people take part in a research study.

This could be where people are recruited to a clinical trial or research study to test a new treatment. It could also involve completing questionnaires or taking part in a focus group as part of a research study.

The Lily Foundation's '[UK Trials and Research Studies](#)' is a great place to share details of studies that require participation from patients.

Engagement is where information and knowledge about research is provided and shared.

An example of patient engagement would be at [Patient Information Days](#), where researchers talk to patients and families about their work.

It can also include the information that we share across our website and social media pages about the research projects that we currently fund, as well as news articles, interviews with mito researchers and dissemination of your latest findings and results from research studies.

Involvement, on the other hand, 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.

You can involve patients and the public in your research by approaching our EPIC committee.

# How can EPIC help with your research project?

When planning for PPI in your research project, it is important to remember that patients and the public 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.'

There are several ways that the EPIC committee can become involved with your research.

For example:

- Helping to identify research priorities for the mito community.
- 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.

# Consultation, collaboration or co-production?

There are a range of methods for involving people in your research, and these are associated with progressively increasing levels of influence for patients and the public.

How you decide to involve people depends on the nature of your research, as well as the preferences of the people you are involving. If it is the first time you are involving patients and the public in your research, you may want to start with something relatively simple and then build up as you develop the skills and experience in involving patients in your research.

Consultation is where you ask patients and the public for their views and experiences, and then use what you have learned to inform your research. You can consult patients and the public on any aspect of the research process – from identifying research topics through to thinking about the implications of your research findings.

Collaboration is an ongoing partnership between you and the patients you are working with, where decision-making is shared equally. Patients and the public may work with you on a wide range of research activities and across the various stages of the research cycle – from developing the research idea, to forming part of an advisory group, through to collaborating on the dissemination of research findings.

Co-production is where researchers and patients jointly share ownership of a research project and they work together from the start to the end of a project. In co-production, the members work together to design and deliver research, taking into account the equal value of each other's skills, experience and knowledge.

# Practical considerations

When deciding to approach the EPIC committee for involvement in your research, you may want to consider the following:

- What do you want from the people involved and how will their input influence your project?
- How many people affected by mito would you like to be involved? Would you like to engage with a particular area of the mito community, such as adult patients or parents/caregivers, or those who have experience with a particular syndrome or genetic diagnosis. Think about how involving particular groups at this stage might impact later on when you come to recruit participants and any potential ethical challenges this may bring.
- What method would you like to use – consultation, collaboration or co-production? Or are there different stages to your research which would benefit from different levels of involvement?
- What do you want their involvement to look like? Would you like them to participate in a focus group or interview, or would you like them to complete a questionnaire or give feedback via email?
- 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, and how you plan to overcome these challenges.



# Practical considerations

- 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?
- Have you considered whether the members should be reimbursed for their time and, if so, how to do this?
- Who from your team will be responsible for leading on the PPI aspects of your project?
- Do your participants require any prior knowledge or training and, if so, how will you provide this?
- Do you have a PPI budget to cover any costs – such as training, travel expenses (in the case of face-to-face meetings) or reimbursement for their time?
- How will you provide feedback to participants and keep them involved and informed of the research developments?



# Frequently Asked Questions

## Do I need ethical approval for Patient and Public Involvement?

Ethical approval is not needed where people are involved in planning or advising on research, for example taking part in a focus group or developing a questionnaire.

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

We would advise giving us as much notice as possible (at least 4-6 weeks) if you would like to meet with the EPIC 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

## Should I reimburse patients and the public for their time?

It is good practice to budget for patient involvement when planning a study. The NIHR have comprehensive guidance relating to this topic which can be found [here](#).

## I am interested in approaching EPIC but I have more questions – who can I ask?

If you would like to discuss how to involve patients and the mito community in your research, please contact Katie Waller (Science and Patient Engagement Officer) at [katie@thelilyfoundation.org.uk](mailto:katie@thelilyfoundation.org.uk).

# Where can I find other resources that can help me with 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 – 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](#) – 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.
- Elsewhere, the [Plain English Campaign](#) is a really 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 is a requirement of NIHR funding applications, more details of which can be found [here](#).



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