

CLDF Patient and Public Involvement (PPI) and Application Request Guide for Researchers

Contents

What is PPI? 3

Why is involving patients and the public in research important? 3

Involving children and young people 4

How can patients and the public be involved? 4

What do I need to think about before I begin?..... 5

Where can I find support as a researcher/clinician who would like to involve patients?..... 6

Useful Links:..... 8

What is PPI?

The INVOLVE definition of patient and public involvement in research is, “research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.”

Why is it important to involve patients and the public in research?

PPI improves the quality and credibility of your research project

Involving patients in the focus, design and execution of your project can ensure the outcomes are more meaningful and of a higher quality. Involving patients can ensure your research is taken more seriously by funders as patients are at the heart of the project.

Researchers should involve patients at the very start of their project, not when funders require them to on an application form.

Patients can have effective input into all types of research including basic science as well as clinical or translational research.

PPI ensures that your research focuses on what is important to patients

Patients are true experts; they know what it’s like to live with the effects of their condition every day. Sometimes we assume we know what patients would like us to focus research on but when we ask them what would improve their quality of life, the answer can be significantly different. Involving patients makes sure the focus is always on what is most important to them.

PPI enables researchers to have access to real patients to discuss living with their conditions on a daily basis. This can lead research being carried out in different areas or with a different focus to research not utilising PPI.

PPI ensures that your research is conducted in a way that is best for patients

When designing research projects which utilise patient participants (surveys, interviews, changes to clinical practice etc.) patients have a unique insight into their patient journey, when the best time to intervene might be, how best to approach patients or families in difficult circumstances, the best methods to utilise.

Not only does this improve the quality of the research but it can also encourage more individuals to participate within the study.

Patients want to be involved

Many patients want to have an involvement in shaping the research agenda at a strategic level as well as supporting researchers on individual projects. Their involvement can ensure the needs of patients are considered when funding projects or designing individual studies. Those who participate feel that they have a beneficial impact upon health research (Crocker et al 2016) and it provides those living with a liver condition a method of contributing to ongoing research efforts.

Involving children and young people

When research involves children and young people it is beneficial to ensure you consider the best methods for them to participate in the research process. You can find out what is important to young people, how they would like to be involved in a project and ensure the research is focussed on their needs. Many young people are keen to be involved and share their thoughts with you. CLDF can support you in recruiting and involving young people in your study.

- Explanations must be simple and clear and aimed at the age range involved
- The tone must be appropriate but not patronising
- Researchers can be more creative in their methods for involving children and young people

How can patients and the public be involved?

Patients and the public can play key roles at a number of different stages including:

- Setting research priorities – patients experiences can lead to new ideas or can support the need for current research ideas. Research funding is limited and should address what matters most to patients.
- Study design – users can help to inform the design which can include the data collection methodologies.
- Identifying outcomes which are meaningful for patients – understanding patient experience and what is important to them can strengthen the outcomes of the study.
- Developing patient information and consent – users can ensure materials are clear and easy to understand
- Dissemination of findings

A lesser form of involvement is “consultation” which may include capturing the views of patients without including them in the design of the project.

You can consult with patients to ask their views on particular issues via:

- Questionnaires
- Social media

Some of the ways you can involve patients include:

- Utilising a patient forum/committee at an NHS Trust. Some trusts have committees who review research proposals and will provide their feedback on research proposals. Some of these groups are listed under “Links” at the end of this document.
- Holding focus groups with children, young people or their parents/carers
- Including a lay representative in the project’s steering group/project management group

This is by no means an extensive list and the most appropriate methods will be dependent upon the type of study, the research area, the type of patients involved, resources available and time frames. Not all patients will want to participate in the same way so try and provide a number of ways patients can be involved to be more inclusive.

What do I need to think about before I begin?

Before you decide to carry out PPI you need to know:

- Why do you want to involve patients in your research?
 - Is there anything specific you want to achieve from PPI?
 - How will the findings of the PPI be utilised?
 - How will the impact of PPI be fed back to those involved?
 - Do I have funding to reimburse expenses for those involved in the study?
- Further information and advice regarding this can be found on the INVOLVE website:
<https://www.invo.org.uk/good-practice-for-payment-and-recognition-things-to-consider/>
<https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

Tokenistic involvement with no real aims in order to “tick boxes” will have little impact on a project and will waste time and resource. Only commit to involving patients if you are clear about why you would like them to be involved. To be successful, patient and public involvement must be built-in to the project at the very start.

Where can I find support as a researcher/clinician who would like to involve patients?

CLDF's Research Hub was launched in October 2018 and aims to facilitate the involvement of those affected by childhood liver disease in research. CLDF can offer those carrying out research related to childhood liver disease help and support to ensure patients are fully engaged in the whole research process.

Through our Research Hub network and other communications channels we can:

- send out surveys/requests for written consultations to gather the views of those living with the condition as well as engaging network members in the process of your research and reviewing methods and documents
- arrange for you to consult and involve research hub members as well as others through our online forums and social media channels
- invite our research hub members to join focus groups to discuss your research
- provide support in regards to venue, refreshments and administration where appropriate and approved by the Information and Research Hub Manager and CEO.

Eligibility

- Applications will only be accepted for work based in the UK
- We would welcome applications that are in line with CLDF Research Strategy and priorities which can be found here: <https://childliverdisease.org/research/cldf-research-strategy/>
- We would especially welcome applications from researchers applying for CLDF research grant programmes.

How to apply

In order for CLDF to consider whether a study is appropriate to provide support for, please request an application form by emailing research-hub@childliverdisease.org. You must also submit a full study protocol, patient information sheet, consent form and ethical approval letter.

It can take up to a month to organise and carry out the process of involvement so we recommend that you submit the application form with as much notice as possible.

Please note there may be a cost associated with support provided by CLDF. This will be discussed with the Information and Research Hub Manager before final approval.

Patient information sheet

Researchers must provide a patient information leaflet to everyone they invite to take part in a research study, to ensure people can make an informed decision about this. This should include:

- why the research is being done, how long it will last, and what methods will be used
- the possible risks and benefits
- what taking part will practically involve, for example extra visits to a hospital or a researcher coming to interview someone at home
- what interventions are being tested, or what topics an interview will cover
- how the researchers will keep participants' information confidential
- what compensation is available to people if they are harmed as a result of taking part in the research
- who to contact for further information
- how the results will be shared with others

Report

CLDF will ask you for an update report after the involvement has taken place. The report will evidence the ways in which you engaged with the Research Hub and the impact on your research application. This will be shared with the members involved in your research as well as measuring the impact CLDF's Research Hub has made.

Where to get further information

For more information visit our website page <https://childliverdisease.org/research/research-hub> or contact Harpreet Brrang (Information and Research Hub Manager):

Email: research-hub@childliverdisease.org

Tel: 0121 212 6029

Post: Children's Liver Disease Foundation
36 Great Charles Street
Birmingham
B3 3JY

Useful Links

Health Research Authority and INVOLVE: <http://www.hra.nhs.uk/news/2016/05/23/new-hra-and-involve-briefing-and-guidance-on-public-involvement-and-ethical-review>

BCH Young person's advisory committee: <http://www.bch.nhs.uk/story/young-people/ypag/ypag>

NIHR Clinical Research Network: West Midlands – Young Person's Steering Group (YPSG): www.generationr.org.uk/birmingham

European Clinical Research Infrastructure Network: www.ecriin.org

INVOLVE:

Resource for researchers: <http://www.invo.org.uk/resource-centre/resource-for-researchers>

Exploring the impact of public involvement on the quality of research: examples:
http://www.invo.org.uk/wp-content/uploads/2014/11/INVOLVEExploringImpactQualityResearchExamples_updated-July-2014.pdf