

# **PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT POLICY**

## Introduction

Patient and public involvement and engagement (PPIE) is crucial in research as it enhances the quality of research, fortifies any conclusions drawn from research outcomes and ensures that different perspectives are considered, all while keeping those who the research affects in mind.

Throughout this document, the use of the term "coeliac disease" refers to coeliac disease, dermatitis herpetiformis (DH) and all other gluten related autoimmune conditions, including but not limited to gluten ataxia and peripheral neuropathy. "Patient" and "public" refer to people with relevance to the research such as service users, patients, potential patients, carers and other community members. Throughout they may be used interchangeably.

This policy sets out Coeliac UK's expectations regarding patient and public involvement and engagement in research and provides guidance on implementation. The policy is based on best practice from reputable organisations, including the National Institute for Health and Care Research (NIHR). It has been created to ensure consistency and transparency.

### Vision

The research we carry out as an organisation and the research that we fund or support in other ways, is relevant to those it is aimed at benefiting.

### What is Patient and Public Involvement and Engagement (PPIE)?

PPIE means involving and engaging patients and the public in research. It allows those affected by research to have a voice and ensures research is done *with* or *by* patients/the public, rather than *about*, *for* or *to* them as participants only.

Involvement is when patients and the public have an active role in every stage of the research process from the planning, managing, designing, conducting, disseminating and measuring the impact of research. Involvement is important as it means that stakeholders and those affected are considered throughout the research process.

Meaningful Involvement:

1. Involves the *right* people
2. Involves *enough* people
3. Involves those people enough
4. Describes and measures the impact

Engagement is when information is actively shared in a two-way process between the public and researchers. Engagement is important as it encourages researchers to listen to and interact with relevant stakeholders during the research process.

### Why is PPIE so important?

PPIE is important because it ensures research is aimed at benefitting the target group, therefore certifying research relevance. It enriches research in a way that cannot be achieved by any other means and increases research impact.

PPIE should be implemented at frequent, relevant intervals throughout any form of research. This ensures that involvement affects all aspects of the research and means it is not tokenistic.

### **UK Standards for PPIE**

The UK Standards for Public Involvement in research were published in 2019<sup>[1]</sup> by The UK Public Standards Development Partnership consisting of the NIHR, The Public Health Agency, Health and Care Research Wales and the Chief Scientist Scotland, with the intention of improving the quality and consistency of public involvement in health care research. There are six standards which provide guidance to help researchers to implement PPIE, these are:

- Inclusive opportunities
- Communications
- Working together
- Governance
- Impact
- Support and learning

These six standards underpin Coeliac UK's PPIE objectives.

### **Coeliac UK's PPIE Objectives**

1. Govern how PPIE is implemented in research relating to coeliac disease and the gluten free diet and support researchers to implement PPIE effectively, ensuring that a diverse range of perspectives and stakeholders are involved. Advise researchers and the public on how to make sure PPIE is effective and highlight the purpose and benefits for research outcomes.
2. Support patients and the public to be involved with and engaged in research regardless of their background, endeavouring to make it accessible to all, according to research needs.
3. Foster relationships and effective two way communication between researchers, key stakeholders, patients and the public

### **Coeliac UK will implement PPIE in its research, relating to the six standards**

Inclusive opportunities, we will:

- actively work to ensure that we are publicising opportunities to the relevant wider audience.
- provide a variety of opportunities when possible.
- actively identify barriers that may inhibit participation and seek to overcome these.

Impact, we will:

- listen to the impact that research has had on relevant individuals and groups.
- strive to disseminate research impact to all relevant parties.

Support and Learning, we will

- provide expert insight relating to the research subject, for the coeliac community and best practice in terms of PPIE.
- provide training and support to the public so they can assist with effective PPIE.
- educate researchers on how to support the public when they are involved in research.

Communications, we will:

- maintain contact with patients and the public throughout the course of the research project.
- Be clear about the expectations of the members of the public when they are being involved and engaging with research.

Working together, we will:

- Form links with relevant partners and organisations when beneficial to the research.
- Listen to the feedback of patients and the public and implementing their ideas.

Governance, we will:

- Adhere to the PPIE policy and process for onboarding and supporting patients and the public with their involvement and engagement in research.
- Abide by best practice and look to relevant organisations for guidance whenever necessary.
- Consider ways to break down barriers to participation and ways to encourage equality, diversity and inclusion in research.

### **Benefits of PPIE for patients and the public**

- Ensures that research is focused and remains relevant to those it impacts.
- May learn new things about the subject or how to better manage their condition and health.
- Feel seen, heard and cared about.
- Develop a greater understanding of ongoing research.
- Reassured as to how funds are used.
- Provides hope.

### **Coeliac UK will support researchers to implement PPIE, aligned to the six standards**

Inclusive opportunities, we will:

- Encourage researchers to identify and overcome barriers that may inhibit individuals or groups from being able to be involved with research.
- Encourage researchers to provide a variety of opportunities for involvement.

Impact, we will:

- Support research that is targeted to have an impact on our community and relevant stakeholders.
- Encourage researchers to disseminate research outcomes to all relevant parties.

Support and Learning, we will:

- Provide expert insight relating to the research subject for the coeliac community.
- Provide training and support to the public so they can assist with effective PPIE.
- Educate researchers on how to support the public when they are involved in research.

Communications, we will:

- Maintain a rapport with the researchers and public and ensure that communication is consistent and clear.
- Encourage researchers to communicate findings in a variety of ways for appropriate engagement with relevant parties.

Working together, we will:

- Help to recruit, onboard and then support members of the public throughout the process.
- Support researchers to make sure PPIE is effective.

Governance, we will:

- Advise best practice for implementing PPIE.
- Consider the standards for PPIE and due diligence when planning for PPIE.

### **Benefits of PPIE for the researcher**

- Ensures that research is relevant and appropriate.
- Ensures that research remains ethical.
- Enhances research quality as they may gain additional information, understanding or perspectives.
- Ensures research has a patient focus which may motivate the research team and remind them of the importance of their work.
- Raises awareness of the research topic.
- Facilitates participant recruitment and retention.
- Improves communication and relations between research communities and the public.
- Gives the public a clear idea of where funds are used which can in turn generate more funding/donations.
- Strengthens funding applications.

### **Who to recruit**

When involving and engaging patients and members of the public in research it is important to be clear about the reason for the involvement and consider how their experiences, knowledge and thoughts will enhance research outcomes. The individuals involved will be wholly dependent on the research process and the anticipated outcomes, but a diverse range of relevant perspectives should be included. It is important to try to

recruit a wide variety of impacted individuals and consider affected groups that might not be so obvious.

## **Equality Diversity and Inclusion (EDI) in PPIE**

Equality means that everyone is given equal access, meaning that barriers are removed. Diversity means representation of an entire community and a broad range of groups and individuals. Inclusion means that different groups are welcomed and treated equally. All of these are important as they ensure that PPIE will reflect the wider coeliac community.

Every person **eligible** to participate in a particular research project, based on the research **inclusion and exclusion** criteria, should have an equal opportunity and not be excluded due to gender, age, ethnicity, disability, geographical location, sexual orientation or partner status, religion or belief, socioeconomical or education status.

## **Barriers and Accessibility**

Research involvement and engagement opportunities should be inclusive and accessible to all individuals and groups relevant to the research.

Barriers that may stop people from being involved must be considered and removed where possible.

**Time** - researchers should attempt to be flexible and fit around the commitments of the patients and the public, such as jobs, childcare or caring responsibilities, responsibilities and hobbies.

**Location** - researchers should be prepared to assist with any travel that may be necessary for those involved with the research, including reimbursement of reasonable pre-authorised expenses.

**Technology** - although society as a whole is becoming increasingly technologically literate, not everyone has the same access and knowledge of technology so researchers may need to facilitate access to equipment or training to members of the public and patients, depending on the requirements of the work, or make reasonable adjustments.

**Costs** - the value of the person's time and any expenses they incur must be costed within research. Please see further information about payment for PPIE participation, below.

## **How to Involve**

Planning, management, design, conducting and measuring the impact of research.

- Defining/posing the research question
- Defining the aims and objectives
- Planning/designing the implementation
- Developing documents for the public
- Monitoring progress
- Assessing results
- Communicating the research to others

## How to Engage

- Research open days
- Tours of facilities
- Research seminars/talks/information sessions
- Q and A sessions or forums
- Blogs or information sites
- Podcasts
- Information packs
- Interactive displays or websites
- Outreach programs
- Pop-ups in the community

## Examples of PPIE in a project

- Providing feedback on resources such as webpages, leaflets, posters, surveys
- Attending workshops or conferences to talk about lived experience/answer questions
- Sit on a project steering group or attend project meetings and provide input
- Attending interviews, focus groups, or discussions
- Identifying evidence gaps, helping with grant applications, study design, collecting and then sharing data
- Speaking about research at local events or groups
- Providing personal thoughts about projects competing for funding
- Discussing personal experiences
- Giving feedback about a particular trial design

## Risks to PPIE and how to mitigate these

Implementing effective PPIE takes time and can make a research project more costly overall. This can be managed by ensuring meticulous planning activity is conducted at the very start of the research process, to ensure that sufficient time and funds are allocated to cover the costs and scheduling requirements of implementing PPIE.

Participation on an involvement and engagement level also requires a commitment from the patient or member of the public. Researchers can encourage and retain contribution by appreciating the time and effort each individual provides and working around their needs as much as possible. Additionally, expenses should be offered to those recruited to ensure that financial constraints are not a barrier that may inhibit some individuals from engaging and getting involved.

Broad representation can be difficult to achieve when involving patients and the public in research, but it is important as it ensures that findings are translatable to the wider affected population. The best way to avoid sampling bias and achieve representation is to conduct random sampling. This is not always possible, depending on the nature of the research. When possible, researchers should look to recruit from the wider affected population by communicating as broadly as possible to a large proportion of the population.

Patient organisations are integral in facilitating links between the public and the research community and are therefore vital to implementing PPIE, in the best interests of both patients and researchers.

Coeliac UK is the only charity in the UK dedicated to supporting people with coeliac disease, gluten related autoimmune conditions and those who care for them, representing a population of around 1 million individuals. With a history of more than 50 years and an ongoing membership of around 65 thousand, the charity has been a strong collective voice for the coeliac community and has become an established, respected contributor to research on both a national and international scale, in the view of both patients and researchers. Coeliac UK has the knowledge and resources to ensure that integral PPIE is implemented appropriately in research.

Participants in research need to have the capacity (time, availability, transport etc.) and facilitated access to contribute to research and so researchers must consider ways to support those within the target group by breaking down any potential barriers.

### **Funding for PPIE participants**

To reduce the chance of potential PPIE participants from being inhibited from taking part, due to a loss of income and the cost of taking part, PPIE participants must be costed for their time and any expenses.

The NIHR advises £25 per hour as a reasonable amount for a PPIE participant. Expenses should also be provided on top of this, such as reasonable travel costs and anything that the participant has to fund to facilitate their involvement in research, above and beyond what they already budget within their typical functioning (e.g. they may already have a laptop and pay for WiFi for personal use so the research team does not have to cover this, but if the participant is required to travel, the research team should cover these costs).

Please note the £25 per hour payment relates to PPIE participants and does not apply to individuals who have been recruited as research study participants (i.e. those patients who have research done *on* or *to* them) nor does it apply to people recruited to clinical trials. Support for such research is costed differently on a case by case basis. Patients should be made aware of any funding/expenses for that research before they consent to participate.

The PPIE participation payment is also not payable to volunteers who choose to give their time freely in a very different role/capacity. When choosing to get involved in research you should read all the information available and contact relevant parties or individuals for further information, if you are not clear on anything.

### **Coeliac UK Grant Applications and PPIE**

Within the Coeliac UK research grant application there is a section on PPIE and a requirement to include:

- Detail how patients and the public will be involved and engaged throughout the course of the research project.
- List any costs that that will be put towards PPIE.
- Explain how PPIE members will be recruited.
- Describe the PPIE infrastructure (management and coordination).
- Demonstrate how they will ensure that EDI has been considered when planning for PPIE.
- Plans to disseminate research impact to the PPIE participants and the wider relevant community after the research is complete.



- Note potential barriers and how these might be overcome.
- Be clear about who is being involved and why and how the involvement should enhance the research.

If you would like assistance with implementing PPIE in your research, please contact us via email at [research@coeliac.org.uk](mailto:research@coeliac.org.uk).

## **References**

1. <https://sites.google.com/nih.ac.uk/pi-standards/the-project/early-development>

## APPENDIX

### **Roles, responsibilities and expectations**

The research team must be very explicit in their expectations of PPIE members from the beginning and clearly define role and responsibilities. Some additional expectations, specific to the project and role itself must be provided by the research team as well as the contributions required that support funding for PPIE participants.

### **Patients/members of the public:**

- Make sure that you are fully aware of the role, the expectations of you and that you have read all associated documents and asked any necessary questions BEFORE signing an agreement to be involved.
- Be truthful about the reasons you are eligible to take part (e.g. diagnosed with coeliac disease, carer, parent of child with coeliac disease).
- Attend agreed meetings/workshops/sessions.
- Advise of any changes to your circumstances that may affect your involvement.
- Inform the researcher/Coeliac UK if you are unhappy or have any concerns.
- Respect confidentiality and adhere to any non disclosure agreements in place.
- Respond within the agreed deadlines.
- Let the researchers know if you are no longer interested in being involved.

You must meet the minimum contribution requirements and terms of the specific project to receive any agreed PPIE participant funding. This should be made very clear to you before you agree to be involved. If you are unable to meet these requirements at any stage of the project, it is important that you let your point of contact, or the principal investigator (lead project researcher) know so that any possible or reasonable adjustments can be considered.

You do not have to accept any PPIE participant funding and instead may choose to allow the research team to keep the funding for future research or accept the funding and donate it to Coeliac UK's Research Fund. If you choose to not accept any PPIE participant funding you should consider and specify where you would like the funding allocated.

### **Issues with Technology**

If notified in advance, researchers may be able to facilitate access to equipment that is necessary for the project, if you do not currently have access to what is required. Please note that this is not always the case. Researchers should provide training or reasonable adjustments where necessary to ensure everyone can use the required technology.

### **Virtual Calls, Workshops, Meetings, etc**

Cameras must be switched on unless stated otherwise or pre-agreed with the meeting organiser. If you struggle to connect for more than 10 minutes, please do not continue to attempt to connect. Instead, notify the research team and they will arrange an opportunity to catch up another time so you may contribute as planned.

If there is a genuine reason that you cannot have your camera on during a call, please contact the research team in advance as they understand that certain people may have

personal circumstances that mean they are not comfortable with being on camera. They will still expect you to contribute to the discussion verbally or via the chat function.

You must contribute appropriately to every meeting as planned and agreed, unless your circumstances change, in which case you must let your main contact know. Involvement in meetings can take a variety of forms, including speaking in the meeting, writing in the chat during the meeting or contacting the research team after the meeting via email or telephone to offer your personal contribution.

## **Researchers will**

- Be clear about the research project in terms of commitment/time.
- Compensate you for the commitment and cover agreed reasonable expenses (varies depending on project).
- Be clear about the required contribution to receive any PPIE participant funding. The contribution will vary depending on the project and the role itself.
- Let you know of any changes to the project and any changes to your roles and responsibilities as soon as possible.
- Provide enough notice for you to be able to attend meetings etc.
- Keep you updated on the progress of the project itself.
- Provide any relevant training to help you carry out your role.
- Work within GDPR regulations.
- Withdraw or exclude your input at your request, should you change your mind.
- Be clear as to who your point of contact should be for any questions about your involvement and provide the details of any possible alternative, additional contacts.
- Answer any questions or communications from you in a timely manner.
- Dedicate time to talking to you and provide reassurance or further training when necessary.
- Be flexible around your other commitments when it is possible to do so.