

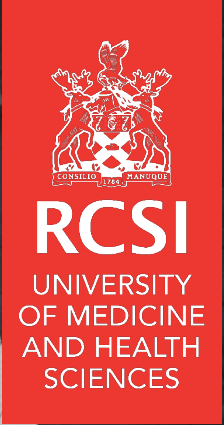
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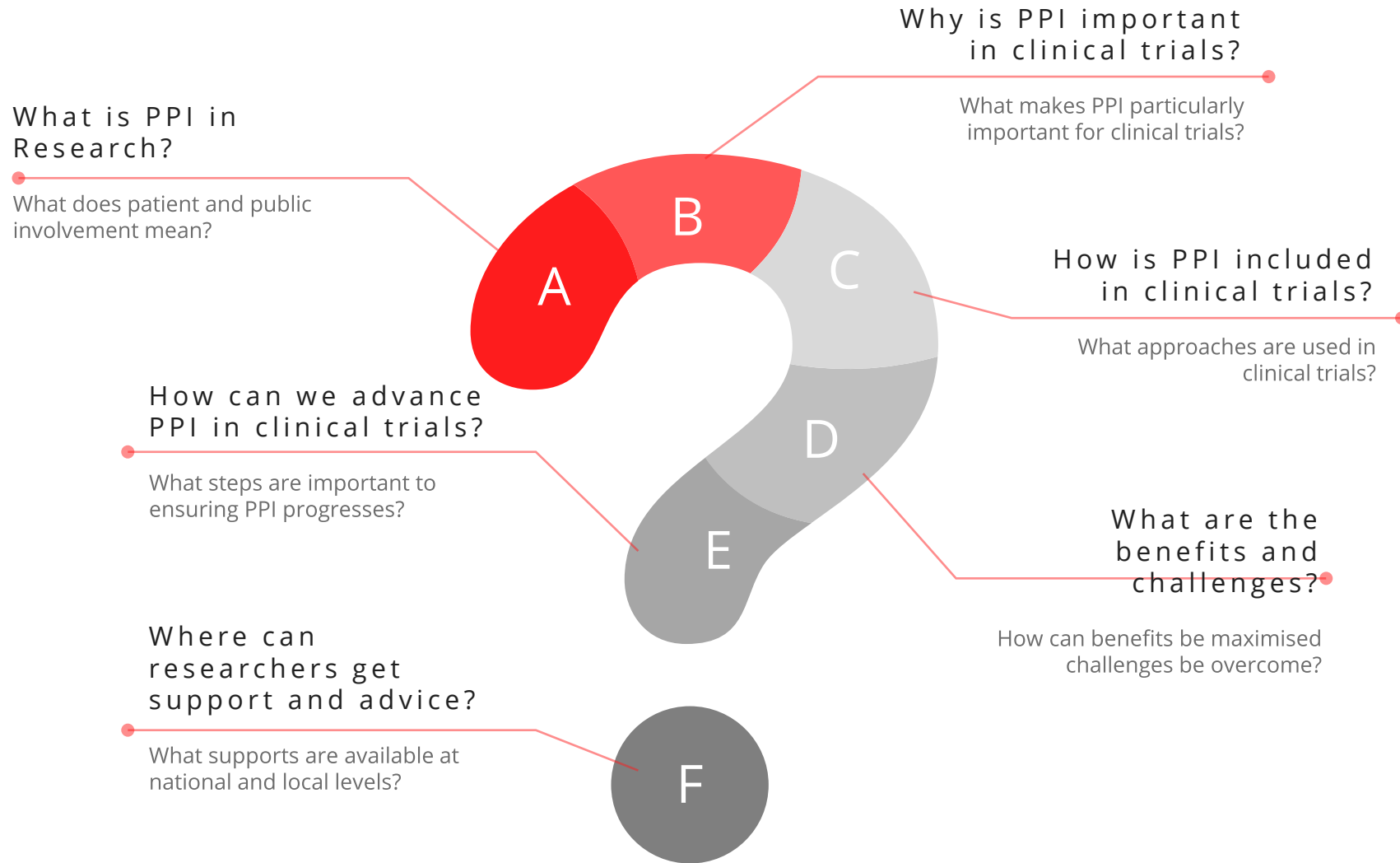
Embedding Public and Patient Involvement (PPI) in Research

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WHAT IS PPI?



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What is Public and Patient Involvement in Research?

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PPI

Public involvement in research is research carried out 'with' or 'by' patients or public rather than 'to', 'about' or 'for' them.

It is an active partnership between patients, carers and members of the public with researchers that influences and shapes research.

(NIHR, UK)



PARTICIPATION



ENGAGEMENT



INVOLVEMENT

People giving their data to researchers in a research study, as 'research subjects' or 'research participants'

Type of research activity
Genetic material; Blood samples; Questionnaires; Interviews; Focus Groups; Surveys.

Researchers communicating about their research with people

Presentations; Seminars; Conferences
Stakeholder engagement
Outreach programmes; Educational activities

Researchers collaborating with patients/public across the research cycle

Research need; gap; questions
Funding and ethics applications
Advisory Panels;
Research plans; materials; dissemination;
Translation into clinical devices/products/services/policy



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IDENTIFYING AND PRIORITISING

Members of the public can help inform priorities for research.



DESIGN

Clarifying research questions, methodology, recruitment strategy development etc.



ANALYSING/ INTERPRETING

Interpreting data with/as part of the research team



UNDERTAKING/ MANAGEMENT

Collecting data, carrying out interviews, participation on steering groups etc.



DISSEMINATION/ IMPLEMENTATION

Sharing findings, writing up findings for publication, advising where to publish/showcase advocacy etc.



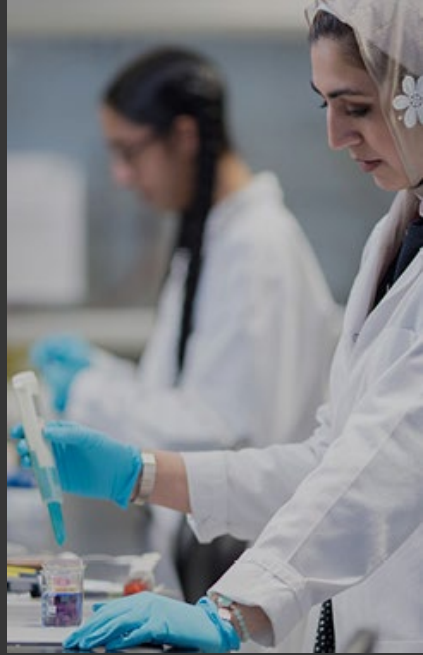
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PPI & CLINICAL TRIALS

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Why is PPI Important in Clinical Trials?





PPI & Clinical Trials

Clinical trials play a critical role in determining safety and effectiveness of new treatments, but have historically been conducted with limited input from patients.

This has meant that trials may have failed to address needs and priorities of patients, failed to recruit to target/had high dropout rates, or communicated findings in ways that are difficult to understand.

PPI aims to address these by involving patients to improve relevance, quality, and acceptability and ensure results are communicated clearly.



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PPI IN CLINICAL TRIALS

How is PPI Included in Clinical Trials?

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PPI in Clinical Trials

PPI may take many forms, depending on the stage of a trial and the priorities and needs of patients.

Other factors including team training, experience, resources, and the condition itself will also impact the approaches to PPI that may be used.

These are only a few examples.



DESIGN

PPI Contributors can co-design the clinical trial protocol to ensure the trial is relevant to their needs and priorities.



GOVERNANCE

PPI Contributors can be involved as members of governance structures such as trial steering committees.



STUDY PROCEDURES

PPI Contributors can inform the consent process and study materials and improve patient experiences.



DISSEMINATION

PPI Contributors can co-author publications, lay summaries etc. and guide dissemination of findings to wider audiences.



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BENEFITS & CHALLENGES

What are the benefits and challenges?

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BENEFITS

Benefits of PPI in Clinical Trials



Improved Relevance and Quality

If trials are designed to address needs and priorities of patients they are more likely to generate results that are meaningful to patients and the wider community.



Improved Recruitment and Retention

Involving contributors in the design and conduct of trials builds trust, and improves the chances of recruiting and retaining trial participants as practicalities and preferences can be considered in the design.



Improved Communication

PPI contributors can ensure results are communicated broadly and in a way that reflects the needs and preferences of patients and the wider public. This can help improve outcomes and increase the impact of the research.



Additional form of Expertise

PPI contributors provide insights based on their expertise that would otherwise not be accessible to the research team, They may also provide guidance about solving problems and managing issues arising.

CHALLENGES

Challenges of PPI in Clinical Trials



Recruiting and Retaining PPI Contributors

Researchers can sometimes find it difficult to identify and recruit PPI contributors.

Using formal and informal channels including social media can be useful. Patient organisations and charities can help. The PPI Ignite Network PPI Opportunities Noticeboard may be useful too.



Training and Resources

Lack of training can lead to different expectations, communication challenges, and friction/conflict. All team members including researchers and PPI contributors should undertake training. Financial resources and time should be planned into grant applications and funding for payments and other reward/recognition systems should be considered.



Establishing Impact

Researchers have often struggled to establish the impact of their PPI activities, leading to lack of clarity about how PPI shaped the research. Tools such as the CUBE framework and others can be used to establish and report impact.



Poor Reporting

Poor reporting has led to challenges building on the work of others. This can be reduced by following specific reporting guidelines e.g. GRIPP2 and publishing PPI separately where relevant..



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ADVANCING PPI

How can PPI in Clinical Trials be further developed?





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GROWTH

How is PPI growing in Ireland?

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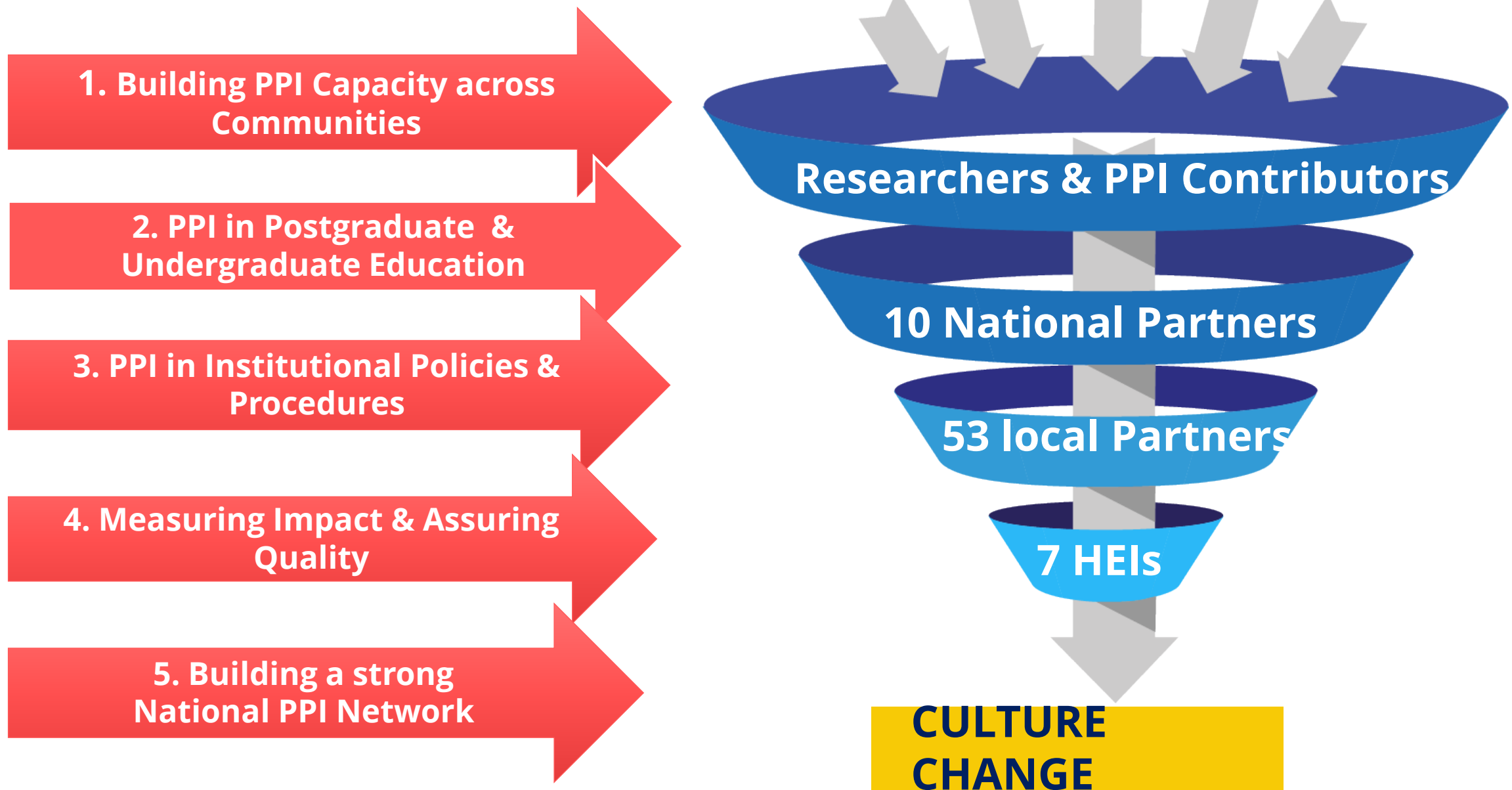
Contact us:
hello@ppinetwork.ie

Promoting excellence & inspiring innovation

The PPI Ignite Network promotes excellence and inspires innovation in public and patient involvement (PPI) in health and social care research in Ireland.

[About Us](#)[Sign up to our newsletter](#)

The Bigger Picture – the HRB National PPI Ignite Network 2021-2025: 5 Work Packages, 70 Lead/National/Local Partners



Case Studies

[Home](#) > [Case Studies](#)



PPI IGNITE NETWORK

Case Studies

We focus on continually improving the quality of involvement, fostering the development of equitable partnerships with patients, carers and the public.

Here we share Case Studies from across the Network, examples of different PPI approaches, across a broad range of research topics and methods. The Case Studies focus on the PPI component of the research and we hope these case studies inspire reflection and debate that will help to deepen our understanding of involvement.



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Thank you

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