

Introducing Patient and Public Involvement (PPI) and how to apply it with your research

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Before we begin

- Go to `Mentimeter.com` and put the code `xxxxxx`
- This is a VERY brief introduction of the concept of PPI
 - Usually, people need AT LEAST 10-20 hours (and much more) training about PPI.
 - Being realistic about your expectations from this one-hour session
- We will share how we have done it- before understanding the concept - and what are the key lessons for the future

What is PPI?

- “Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them” (NIHR, 2023)
 - The term PPI is mainly used in the UK and in medical research
- There are some interlinked terms e.g.,
 - PPIE (Patient and Public Involvement and Engagement)
 - CEI (Community Engagement and Involvement) – mainly used in health system research

Definition of CEI

- *"An **active involvement** of the **community** throughout the research process, **using participatory approaches** and **working in partnership with all key stakeholders**. CEI includes a range of activities which involve **interactions between researchers, community members and stakeholders**, aimed at **improving the relevance, value** and conduct of health research."*

Who are 'stakeholders' in research?

- People who have an interest in, or influence over, what research is done and how it is done
e.g.,
 - Policymakers
 - Academia
 - Healthcare professionals
 - Third sectors/NGOs
 - Community/religious leaders
 - Patients (experts by experience)
 - Family carers

What about 'the public'?

- A broader group of people, which the stakeholders are part of, who may have a general interest in research and its role in society.
- These terms will have different meanings for different research projects.
 - The 'community' to be engaged with for research involving **alcohol users** will be very different from the community engaged with in research exploring different **treatments for childhood malaria**.

Do we need to include every stakeholder?

- It depends
- You need to understand **all the groups of people who are, or could be, affected** by the research in the community.
- Think carefully about which groups you are **prioritising**.
- Consider which people are included or excluded, and **why**.
- You may want to 'map' important stakeholders early, to prioritise and plan the research

Why is PPI important/needed?

- Provide ways to encourage critical reflection that can challenge researcher views.
- Enable researchers to identify existing community and stakeholder groups.
 - work with them to help address wealth and power dynamics between researchers and communities
 - to build local capacity
- Promote sustainable relationships between researchers and community stakeholders that go beyond the life of a single research project.
- Nurture trust between communities and researchers, contributing to sustainability
- Break down communication barriers

Inclusion of the views of those most affected by the research

- Listening
- Learning
- Responding with stakeholders
- Providing feedback and actions

Ethical needs


- Researchers are more aware of the health priorities of all those affected by the research.
 - To assess whether the research is **useful** and **relevant** locally.
- Ensuring that **appropriate methods of engagement** and informed consent in research are used.
- Improving individuals' understanding of research so they can make informed choices about whether they want to participate in research or not.
- Community views can be included in the development of institutional policies.
- PPI has the potential to strengthen the protection of research participants, including reducing their risk of stigmatisation.

PPI supports the study implementation

- Enhance participant recruitment and retention into studies.
- Any rumours and misconceptions circulating in the community, can be detected, discussed and acted upon where necessary.
- PPI can help with ways to share important research findings with stakeholders.
- PPI can strengthen community relationships and promote a supportive environment, where other research studies can be implemented.

IAP2 Spectrum of Public Participation

IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION 

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

Do I need to do a PPI? Sound like a pain

- Up to you - I am not your father. I am not assessing your annual research performance
- However, major funders have increasingly **required patient and public engagement and involvement.**
- **Some funders will desk reject your applications immediately if you have no PPI element:**
 - The Wellcome Trust
 - National Institute for Health and Care Research (NIHR)
 - National Institutes of Health (NIH)
 - The Medical Research Council UK

“How have you involved patients, participants, patient advocacy groups or communities in developing your proposal? What ongoing involvement will they have in the research? (200 words)”

Wellcome Discovery Award application form 6/23

Questions?

Challenges when undertaking PPI

- Power dynamics
- Managing multiple voices

Addressing these challenges might require:



A skilled and experienced facilitator to ensure that less powerful voices are heard

A careful approach to ensure diverse stakeholders are represented

Ensuring the recording of all views before moving forward to discuss a consensus

Different expectations and priorities

Addressing these challenges might require:



Ensuring very clear communication about the purpose, risks and benefits of the research both at the beginning and throughout the research life cycle.



Being clear and honest about what the research can and cannot deliver.



Research/engagement fatigue



Addressing these challenges might require:



Listening to community preferences about how they want to be engaged.



Clearly defining the goals of each CEI activity at the outset, so that their impact or influence can be explored. Make sure the goals are revisited regularly in case circumstances change.



Clearly defining the purpose and expectations of all participants at each meeting or activity.

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Conducting PPI in different contexts



Addressing these challenges might require:



Listening to community preferences about how they want to be engaged.



Hearing from the community on how they view stigma and possible ways it could be addressed.



Clearly defining limits of what CEI can and cannot achieve.



Clearly defining the purpose of each meeting or activity.

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Key ingredients for a successful PPI

- A commitment to the social value of health research
- Creativity to design appropriate ways of engaging communities
- People who have an understanding of local structures and systems
- People who have an understanding of the local culture
- Trained and experienced professionals
- Funding

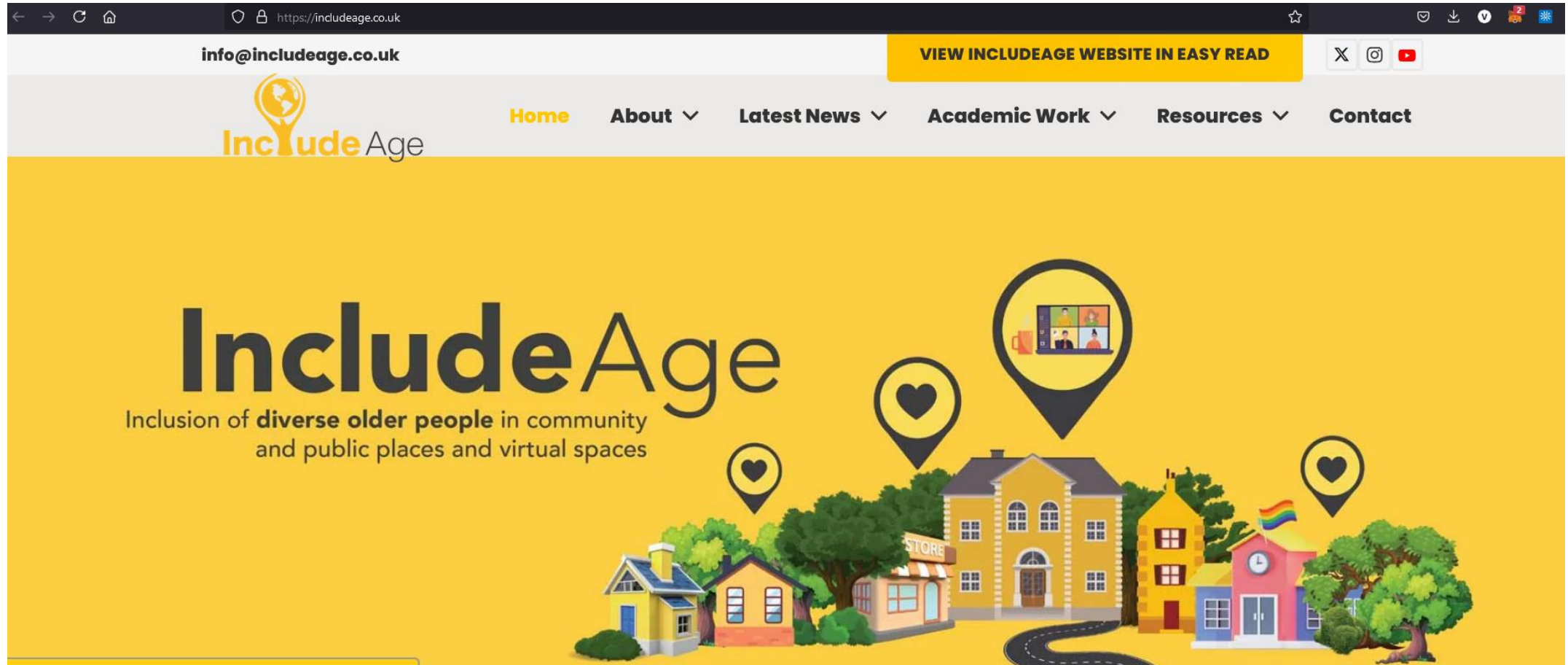
Examples of PPI-embedded projects

<https://link.springer.com/book/10.1007/978-3-031-27223-3>

- A co-produced academic book written together between academic, people with dementia, family carers



£2m ESRC-funded project



- *Closing Assessment and Referral Equity in Metastatic Breast Cancer in Thailand (CARE-T)*

Published on 24.12.2024 in **Vol 10 (2024)**

📌 Preprints (earlier versions) of this paper are available at <https://preprints.jmir.org/preprint/55300>, first published December 08, 2023.



Evaluating Online Cannabis Health Information for Thai Breast Cancer Survivors Using the Quality Evaluation Scoring Tool (QUEST): Mixed Method Study

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Conclusions

- PPI is one way to enhance the quality and relevance of your research with stakeholders
- It improves communication skills between different stakeholders and empower those who are less heard
- PPI has its benefits and challenges- prepare accordingly
- Funders has increasingly required PPI as a part of application

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An Introduction and Practical Guide to Community Engagement and Involvement in Global Health Research

NIHR | National Institute for Health and Care Research



About this course

This is a free online course on community engagement and involvement (CEI) in global health research.

The aim of this course is to develop learners' understanding and knowledge of CEI, supporting their ability to plan and design ethical and impactful CEI in health research. For the purposes of this course, we use the term CEI to mean:

"An active involvement of the community throughout the research process, using participatory approaches and working in partnership with all key stakeholders. CEI includes a range of activities which involve interactions between researchers, community members and stakeholders, aimed at improving the relevance, value and conduct of health research."

In progressing through the modules, learners will gain a better understanding and appreciation of the terms used for CEI, the broad range of CEI aims and approaches, and the overall value of CEI. CEI is an essential and rewarding component of research, and, as the course authors, we hope that you enjoy learning about it.



Collaboration

This course was produced by the National Institute for Health and Care Research (NIHR) in collaboration with Mesh Community Engagement Network.

Questions?

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Appendix

For practical guideline, see

- https://usher.ed.ac.uk/sites/default/files/atoms/files/respire_stakeholder_engagement_guide_v3.pdf

**Stakeholder Engagement
in Global Health Research**

A RESOURCE GUIDE



This table gives example answers to the questions on slide 12 'Thinking through your approach'

Who do I engage and involve?	Which stakeholders are interested in your research or who are key to its success?	Are there existing groups who advise on research or who already work in with this health topic or community?	What expertise, knowledge or skills do you need in your team?	Who are your potential research participants and which groups in the community are most likely to be affected by research outcomes?
Example answers	<p>Hospital-based research Ministry of Health officers Hospital/clinic lead Key clinicians</p> <p>Community-based research Local leaders e.g. mayor/chief Education officer NGO/CBO leads</p>	<p>Hospital-based research Patient groups Local Hospital research committee Nurses/clinician groups</p> <p>Local health management groups/committees</p> <p>Community-based research Community Advisory Boards NGOs and CBOs Community Advocacy Groups</p>	<p>CEI professionals Lived-experience or service-user representatives Education advisers Monitoring & evaluation experts Filmmaker or participatory arts practitioner Professional facilitator</p>	<p>People who live in the local area Women's groups Religious leaders Community leaders Hospital staff Patients or those living with a condition Carers or parents Those at risk of illness or health condition Young people Ethnic minority groups</p>

How do I reach communities, patients or public?	How (through what mechanisms) are people already coming together?	Who are they working with already? (these organisations can be added to your stakeholder list)	When are they coming together? (in leisure time at weekends, as part of their job, at school or at medical appointments)	Where are they connecting or gathering already? (a venue that the community feel comfortable with already is preferable)
Example answers	Community Advisory Board Village Council Patient Support Groups Cinema screenings Online forums Medical appointments	NGO or Health Charity Youth Group Church or religious group Advocacy or Activist Organisations	If you organise new meeting or workshop, ensure it is on a suitable day and time. Or ask to join an existing meeting	Online on a social media group Church Village hall shopping centre local market School health clinic Theatre festivals or fayres



Remember that these are not the only answers to these questions, you can be creative in thinking of new approaches and ideally work with the community so they can lead on the best methods of engagement

References

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