The background of the slide is a vibrant collage of stylized hands in various colors (red, blue, green, orange, purple) and patterns (solid, dotted, striped). The hands are arranged in a way that suggests they are reaching upwards or coming together. A semi-transparent light blue rectangular box is overlaid on the top half of the image, containing the main title text.

Patient Public Involvement and Engagement (PPIE) in research (Health and Social care)

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Aims

**What is PPIE and
its place in
research?**

**Why is PPIE
important?**

**Challenges and
benefits**

**Applicability to
Public Health
programs/projects**

What is Patient Public Involvement and Engagement (PPIE) in research?



Roots of PPIE

- Dates back to 1950's when authority of medicine/health & social care were unquestioned
- Growing disillusionment over healthcare decisions made without considering the views and perspectives of the users
- People started questioning alternative care pathways for
 - specific disease conditions (DM)
 - shared experience (Domestic violence)
 - series of high-profile medical scandals (retention of deceased children's body parts for research without the knowledge or consent of parents)
 - unexpectedly high mortality rates for children undergoing heart surgery

Changing health service user response to established biomedical authority

A key influence on this movement was the work of **Paul Hunt**, a resident of Leonard Cheshire Homes who was an early campaigner for residents' rights (rights of disabled people) in the 1970s and 1980s.

Catalyst in development of service user led research (PPIE)

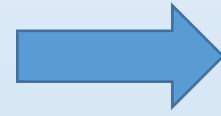


'Le Court'
Leonard Cheshire homes



What is Patient and Public Involvement and Engagement (PPIE) in research?

- A process of active partnership*



- Identify & prioritising research problems
- Designing
- Delivering research
- Dissemination

“Research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them”

*(NIHR INVOLVE <https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research>)

What is **Patient and Public** Involvement and Engagement in research?

- **Patient** : people obtaining health care services at present
- **Public** : patients or potential patients
carers
people who use health and social care services
people from organizations representing people who use services

‘distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services’

Participation

- Where people take part in a research study

Examples of participation:

- study participants of a clinical trial or other research study
- completing a questionnaire or participating in a focus group as part of a research study

Patient and Public **Involvement** and Engagement in research?

Members of the public are **actively involved** in research projects and in research organizations from the inception or planning stage



Involving older people in health & social care research



Examples of public involvement:

1. Involvement in **identifying research priorities**
2. **Offering advice** as members of a project advisory or steering group
3. Commenting on **research design**
4. **Commenting and developing patient information** leaflets or other research materials
5. Advising on **recruitment of patients** as participants and on ways of engaging with the public
6. **Undertaking interviews** with research participants
7. User and/or carer researchers **carrying out the research**
8. **As joint grant holders** or co-applicants of a research project

Approaches of involving public contributors

- Three broad models

1. Ideological democratic model : public contributors are empowered to help decide research priorities, questions, and methods, and carry out data collection, analysis, and dissemination

2. Outcome oriented model: public contributors actively work with researchers to improve the quality and relevance of researcher-led studies

3. Tokenism model: public contributors are only nominally engaged in order to meet external expectations or funding requirements

What is Patient and Public Involvement and **Engagement** in research?

- Activities and benefits of research shared with the public
- A two-way process, involving interaction and listening, with the goal of generating mutual benefit
- Information and knowledge about research is provided and disseminated




(NCCPE, 2018 <https://www.publicengagement.ac.uk/about-engagement/what-public-engagement>)

Engagement in research?

Examples :

1. Science festivals open to the public with debates and discussions on research
2. Open days at a research centre where members of the public are invited to find out about research
3. Raising awareness of research through media such as television programmes, newspapers and social media
4. Dissemination of the findings of a study to research participants, colleagues or members of the public

(NCCPE, 2018 <https://www.publicengagement.ac.uk/about-engagement/what-public-engagement>)

A diverse group of people, including men and women of various ethnicities, are gathered in a meeting or workshop. They are smiling and holding up colorful signs (yellow, blue, green) in a room with large windows and a brick wall. The image is overlaid with a large white diamond shape containing the text.

**Why is it important to
involve & engage public
in research?**



Importance of PPIE in research

1. **Accountability**
2. **Values and purpose**
3. **Trust**
4. **Relevance**
5. **Responsiveness**
6. **Ethical practice**

Importance of PPIE in research

1. Accountability

- Increasingly, institutions need to be **open and transparent** about what they are spending public money on – and why.
- The process of public engagement – **open two-way conversations** about what we do and why – helps to build understanding and appreciation of research organizations and help those organizations or universities to better fit their work to the expectations of wider society.

(NIHR INVOLVE <https://www.invo.org.uk/find-out-more/what-is-public-involvement-in-research>)

Importance of PPIE in research cont.

2. Values and purpose

- Helps the organizations to **'live' their values and purpose of wider social benefit**
- The values that drive public engagement – **commitment to wider social benefit**, to dialogue and to mutuality

Importance of PPIE in research cont.

3. Trust

- Research organizations/universities need to be part of the debate on the **social and ethical implications** of research
- Public engagement acknowledges that the **public have a genuine stake** in the work of research organizations/universities
- Gives **wisdom and sensitivities** that must be listened to and acknowledged
- Investing the time to **genuinely engage** with the public is a win-win situation in conducting research

Importance of PPIE in research cont.

4. Relevance

- Massive changes are seen in how knowledge is generated and consumed in the last 30 years
- Without public involvement and engagement, researchers' risk appearing out of touch and increasingly irrelevant.
- Dialogue and through, open-ended, curiosity-driven conversations and collaborations which respect the insights, experiences and expertise of the wider public enrich the focus, clarity and relevance of research and teaching.

Importance of PPIE in research cont.

5. Responsiveness

- Public institutions and businesses can **no longer offer their services on their own terms**
- Wider public, and policy makers are **increasingly making their voices**
- **Re-balancing of power** between institutions and citizens
- Public engagement helps research organizations/universities respond positively – by **building relationships** animated by dialogue, partnership and co-production, rather than simply by customer satisfaction

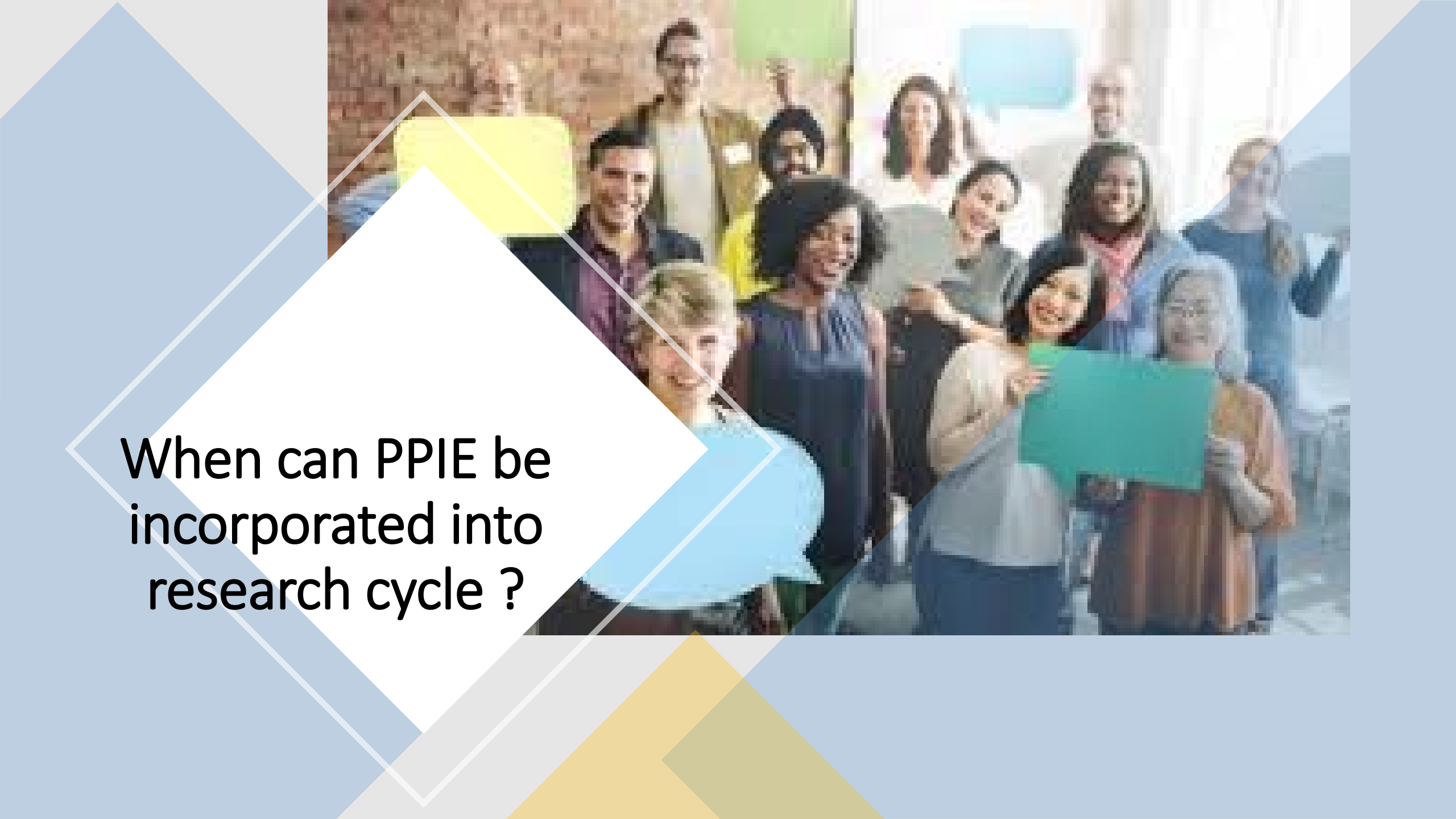
Importance of PPIE in research cont.

6. Ethical practice

Involving the public in research helps to ensure studies are ethically acceptable to the people taking part

- How?

- Makes research more relevant to patients' needs
- Helps define what is ethically acceptable
- Ensures information provided to participants is easy to understand
- Improves the process of informed consent
- Improves the experience of those taking part in the research
- Helps disseminate the findings of research to the public

A diverse group of people, including men and women of various ethnicities, are gathered in a meeting or workshop. They are smiling and holding up colorful signs (yellow, blue, green) in a room with large windows and a brick wall. The image is overlaid with a large white diamond shape containing the text.

**When can PPIE be
incorporated into
research cycle ?**

When can PPIE be incorporated into research cycle ?



For each stage of the research cycle, reflect why PPI in research and whether PPIE can inform and influence the aspects in different stages of a study

Is the research relevant to patient's lives?
Is the research a priority for patients?

Given potential risks, would people be willing to participate?

Is the research ethically acceptable to participants?

Is the process of obtaining informed consent ethically acceptable?

Is information for participants easy to understand and use?

Are the most relevant outcomes being assessed and measured in an acceptable way?

Are the research procedures appropriate?



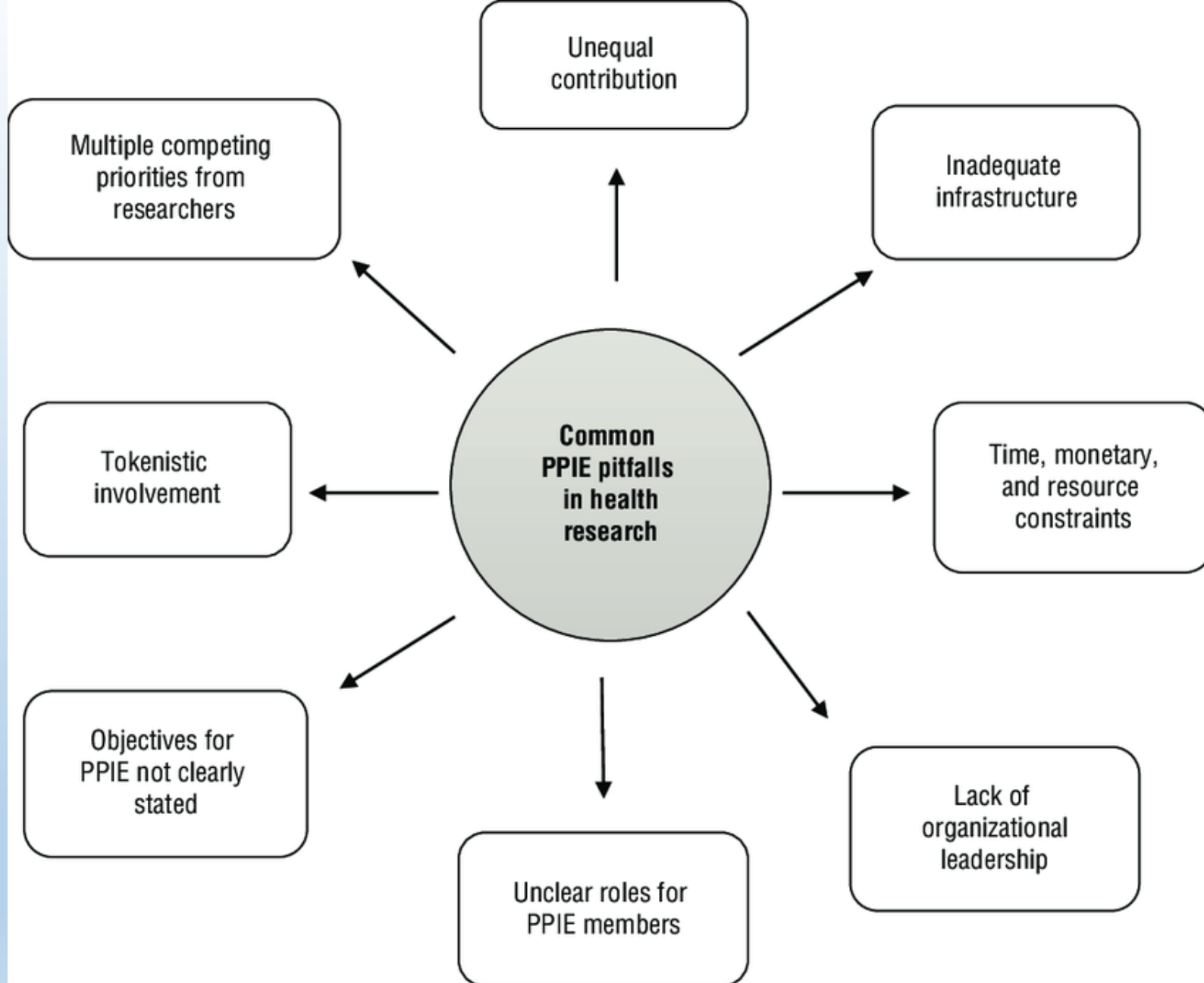
How will the study findings be shared with the participants and the wider public?

How will the study findings be interpreted?

Data collection: Has the safety and well-being of participants and researchers (including lay co-researchers) been considered?

How will the management of the study continue to consider the interests of participants?

Challenges



Impact of PPIE in research

- Quality and appropriateness of research is enhanced
- Likelihood of successful recruitment to studies increased
- Implementation of the findings is improved
- Create people centred research and empowers people by helping them to access, use, respond to, and create health research and innovation
- Public also get an opportunity to understand what research is and its processes when involved in research

Impact of PPI on research

“No matter how **complicated** the research, or how **brilliant** the researcher, patients and the public always offer **unique, invaluable insights**. Their advice when designing, implementing and evaluating research invariably makes studies more **effective**, more **credible** and often more **cost-effective**.”

Professor Dame Sally C. Davies
Chief Medical Officer, Department of Health

National organizations to advocate, promote and support PPIE in developed countries

- UK : INVOLVE (UK) of National Institute for Health Research (<https://www.invo.org.uk/>)
- USA: Patient-Centred Outcomes Research Institute (PCORI) (<https://www.pcori.org/>)
- Canada: Strategy for Patient-Oriented Research (<http://www.cihr-irsc.gc.ca/e/41204.html>)
- Western Australia: Consumer and Community Health Research Network (<https://www.involvingpeopleinresearch.org.au>)

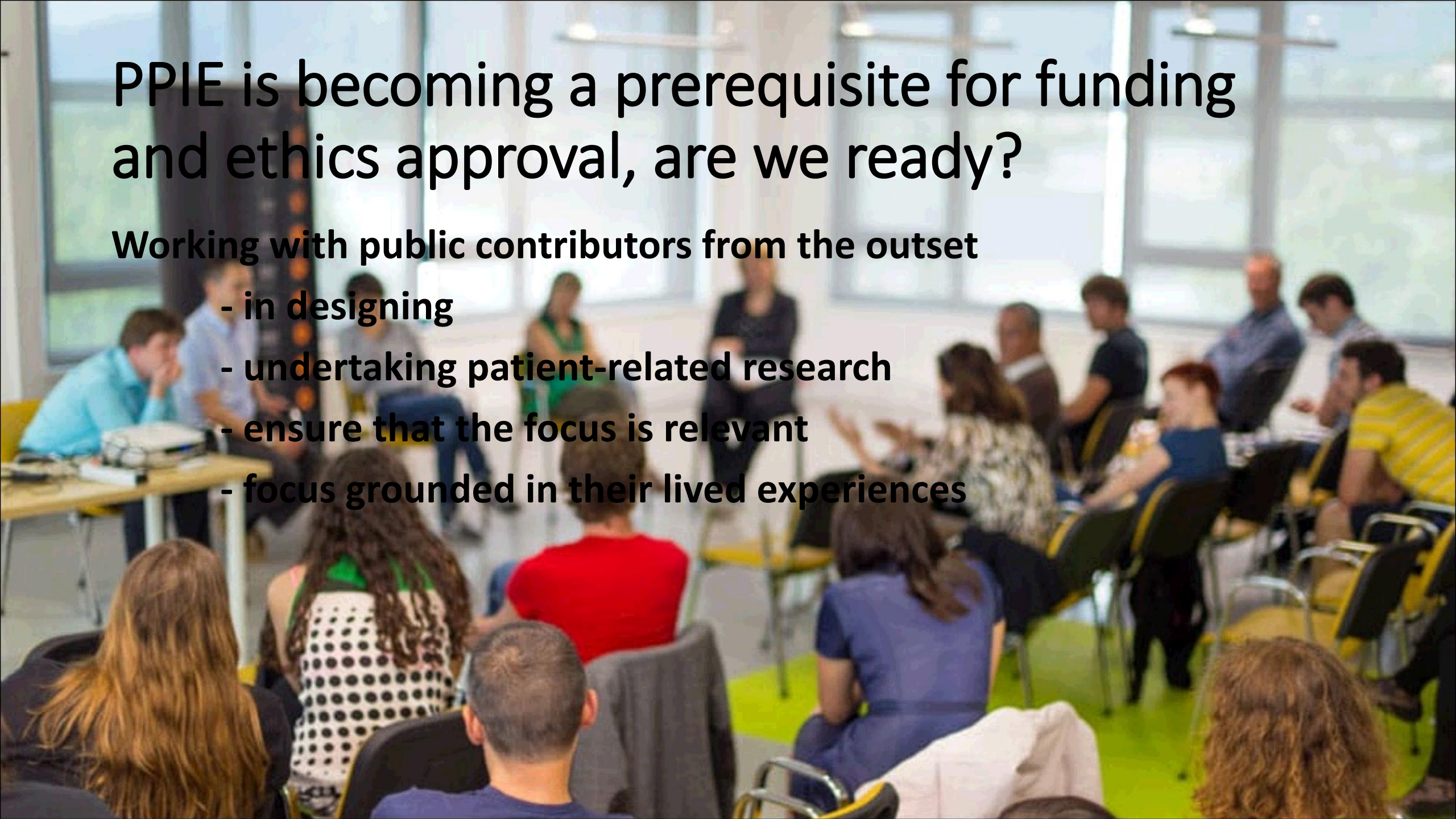
Medical Faculty, Keele University, UK

- Lay Informant Group
- Research User Group

PPIE is becoming a prerequisite for funding and ethics approval, are we ready?

Working with public contributors from the outset

- in designing
- undertaking patient-related research
- ensure that the focus is relevant
- focus grounded in their lived experiences




In the UK, ethics applications must include details on:

- PPIE done previously to shape the research design
- Plans to involve people during the study

“In which aspects of the research process have you actively involved, or will involve patients, service users and/or their carers or members of the public?”

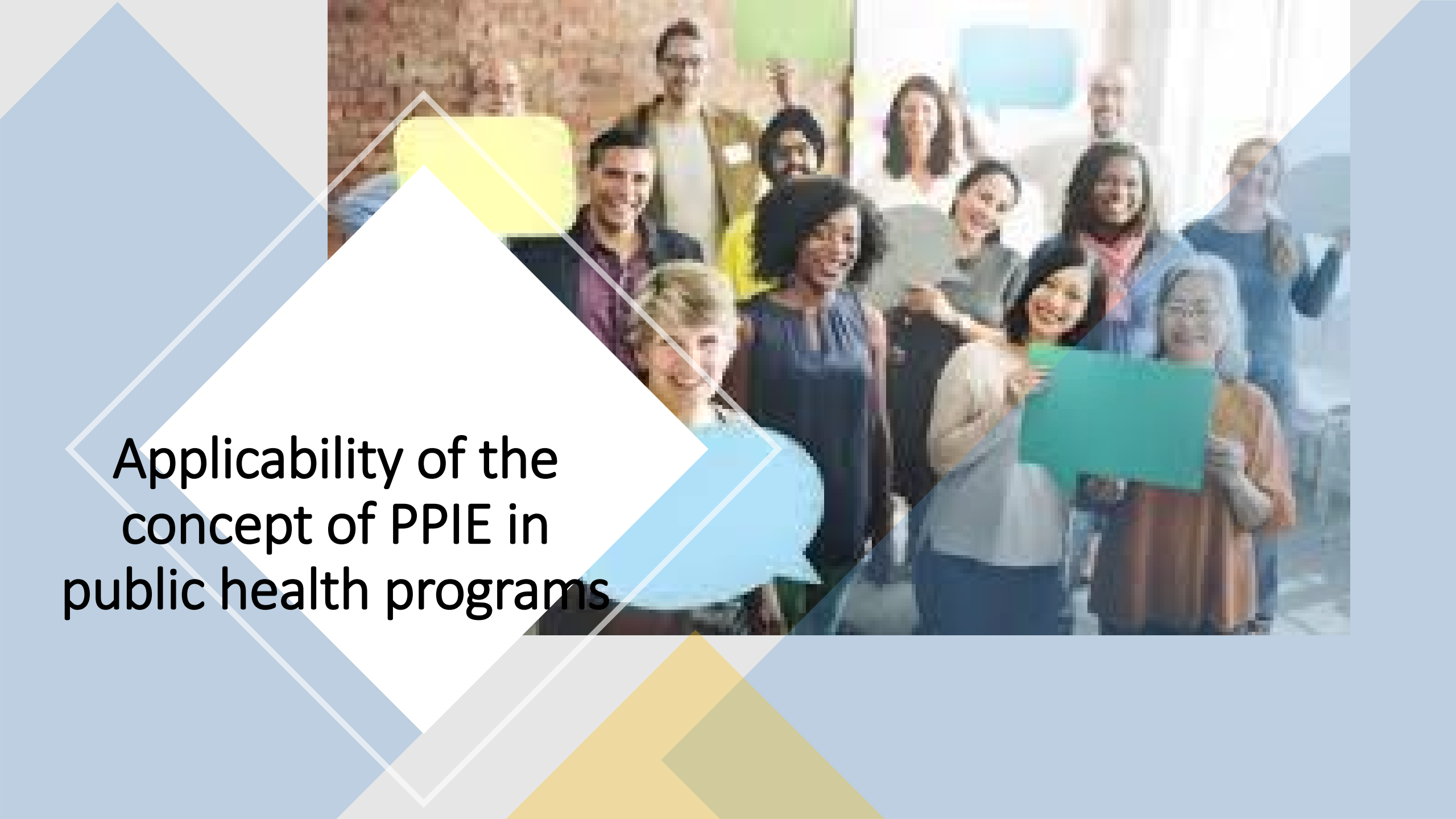
Reasons must be given for the absence of public involvement

A diverse group of people, including men and women of various ethnicities, are gathered in a meeting room. They are smiling and holding up colorful signs (yellow, blue, green) in a gesture of participation or agreement. The room has a brick wall and large windows in the background. The image is overlaid with a large white diamond shape containing the text.

How can we involve &
engage patients &
Public?

How can we involve & engage patients & public?

- Creating links with patients & public: in clinics, patient groups, charities, clinical research networks, individuals
- Planning & preparing patient and public involvement
- Costs
- How to get organized
- Glossary of terms and empowering the lay group
- Evaluate PPI

A diverse group of people, including men and women of various ethnicities, are gathered in a meeting room. They are smiling and holding up colorful signs (yellow, blue, green) in a celebratory or collaborative manner. The room has a brick wall and large windows in the background. The image is overlaid with a large white diamond shape containing the text.

Applicability of the concept of PPIE in public health programs

Applicability of the concept of PPIE in public health programs

Bottom up approach.....doing programs with public contributors

Helps community centred development, implementation and continuation of projects/programs

Ownership and sustainability

Increased impact on behaviour and life style changes

More cost effective

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