

Lived Experience involvement

In mental health-tech research



Bryony Doughty

MINDSET-XR INNOVATION SUPPORT PROGRAMME

MQ's role in the programme



Lived Experience involvement and engagement

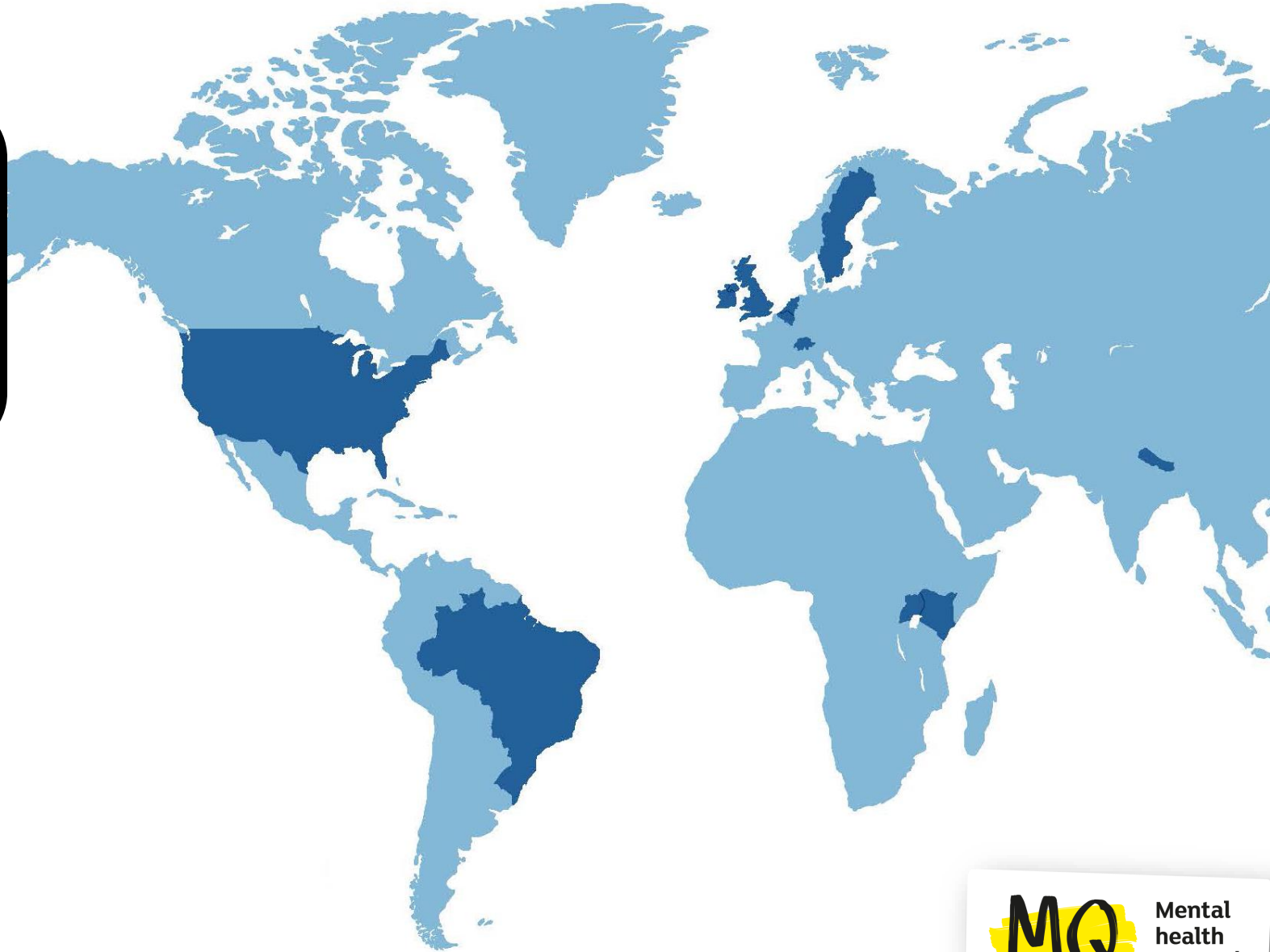
MQ's Global Impact

We have invested **£30 million**
To support ground-breaking
research through grants and
collaborations in **37 countries**

We do this

through:

- Delivering grant rounds
- Convening and consulting
- Partnering on research



4 Learning objectives



Clarify concepts on PPIE



Understanding the value of PPIE in MH tech research



Familiarising with the different activities in PPIE



Understand common challenges in PPIE and strategies to overcome them

Learning objective 1



Clarify concepts on PPIE

Commonly used terms



Lived Experience (LE)

People with Lived Experience

Lived Experience Experts

Experiential Advisors



Public and Patient Involvement and Engagement (PPIE)

Public and Patient Involvement (PPI)

Lived Experience involvement and engagement

Co-production with Lived Experience

What is PPIE

Patient and public involvement and Engagement (PPIE) refers to an active partnership between patients and the public and researchers in the research process, rather than the use of people as merely 'subjects' of research.

PPIE activities entail the recruitment, involvement and engagement of people with lived experience in research up to the stage of coproduction.

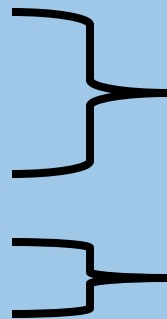
Coproduction is the approach in which researchers, practitioners and the public work together, share power and responsibility from the start to the end of the project, including the generation and dissemination of knowledge.

Who are the Patients and the

Public

- Patients
- Potential patients
- Carers
- People who use health and social care services

- User service groups
- Community organisations
- Lived Experience Experts



Link and representation of underserved and marginalised populations

Advocacy, communication and knowledge of research processes



Pipeline of Le

expertise

Research Participant

- Not PPIE -

LE Advisor

Lived Experience Expert

Public and Patient Involvement and Engagement (PPIE)

Empowered by their lived experience / expertise to advocate, advice and improve mental health practice and/or research

Person with Lived Experience of a condition

Advocacy, education, research

Coproduce mental health research

Increasing familiarisation with different research topics and designs.

Mature experience in research processes

Confidence in advocacy and communication

Influence mental health research processes

Translational skills to facilitate exchange between research and lived experience

Knows what the condition feels like



4 Learning objectives



Clarify concepts on PPIE



Understanding the value of PPIE in MH tech research



Familiarising with the different activities in PPIE



Understand common challenges in PPIE and strategies to overcome them

Learning objective 2



The value of PPIE in mental health tech research

Evolution of PPIE in MH research

Key Policies and Milestones in PPIE

- **1960s-1970s** Patient advocacy movements lead to recognition of the need for patient involvement in health decisions.
- **1990s** The UK Department of Health's "Research for Health" strategy emphasizes public involvement in health research.
- **1996** Establishment of Consumers in NHS Research (later renamed INVOLVE) to support public involvement at all research stages.
- **Early 2000s** PPIE institutionalized within UK; Research Governance Framework NIHR promotes PPIE as an ethical imperative of high-quality research.
- **2019** UK Standards for Public Involvement in Research developed to ensure consistent engagement.

Value of PPIE in MH Tech research

- The role of people with LE has evolved from passive subjects to active participants and collaborators, shaping the research agenda, design, and implementation.
- **Increase trust**
Commercial incentives added to a recent explosion of mental health tech products can generate mistrust and make difficult to filter those with a solid evidence-base.
- Sound coproduction with Lived Experience serves as a quality assurance mechanism for tech products.



Value of PPIE in MH Tech research

Diversity and inclusion in PPIE

- Helps to grow the network of partners.
- Increases the chances of buy in, investment, adoption and impact of MH technology.
- Increasing diversity is a continuous process and becomes easier for organisations, as their PPIE networks grow.
- Addresses mental health inequalities: Involve community organisations to reach underserved populations.



Value of PPIE in MH Tech research

- Makes products more relevant, through detailed knowledge of the issues that matter to them.
- Ensures that research is ethical and accessible.
- Translation of research into practical applications.
- Address digital and mental health inequalities
- Maximize investment of time and resources.
- Improves health and social services, treatments, and quality of care.



4 Learning objectives



Clarify concepts on PPIE



Understanding the value of PPIE in MH tech research



Familiarising with the different activities in PPIE



Understand common challenges in PPIE and strategies to overcome them

Learning objective 3



PPIE activities

LE involvement and engagement



Recruitment



Involvement



Engagement



Coproduction

LE involvement and engagement



Recruitment

Refers to **opportunities to involve people with Lived Experience in research.**

Recruitment can be conducted through digital and not digital channels depending on the population of interest, as well as on the resources and dissemination channels available to the organisations.

Examples:

- A. Social media
- B. Patient groups
- C. Lived Experience networks
- D. Mental Health advocacy groups

LE involvement and engagement



Involvement

Refers to the establishing an active partnership between patients and the public and researchers in the research process. It entails the establishment of formal governance mechanisms, as well as more informal practices to establish trust, rapport and openness.

Examples:

- A. Working with research funders to prioritise research.
- B. Offering advice as members of a project steering group or advisory board.
- C. Commenting on and developing research materials.
- D. Undertaking interviews with research participants.

LE involvement and engagement



Engagement

Refers to the different ways in which research can be shared with the public in a two-way process. Engagement encourages researchers to listen and interact with the general public, for example.'

Examples:

- A. Science festivals.
- B. Media coverage
- C. Social media
- D. Blogs, videos, interviews
- E. Dissemination through community workers and organisations

LE involvement and engagement



Coproduction

Researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge.

It shifts the power and focus on the strengths and expertise of people with lived experience who are involved as co-researchers.

Principles

- Sharing of power
- Including all perspectives and skills
- Respecting and valuing the knowledge of all those working together on the research
- Reciprocity
- Building and maintaining relationships

LE involvement and engagement



Coproduction

Features

- Establishing ground rules
- Continuous dialogue
- Joint ownership of key decisions
- A commitment to relationship building
- Opportunities for personal growth and development
- Flexibility
- Continuous reflection
- Valuing and evaluating the impact of co-producing research

Learning objective 4



Challenges and best practices in PPIE

LE involvement and engagement



Recruitment

Challenges

- Difficulties to reach and inform potential participants about the research being undertaken.
- Lack of relevant incentives for people to participate, considering their needs, priorities and interests.
- Difficulty to reach diversity of LE participants
- Identifying individuals with relevant lived experience

LE involvement and engagement



Recruitment

Best practices

- Think about innovative ways in which to recruit. Most charities have lived experience networks.
- Set appropriate incentives considering the basic, psychological and fulfilment needs of your group of interests. For example:
 - Providing monetary or other material compensation;
 - Promoting career development opportunities through links or mentorships with organisations.
 - Facilitating participation and covering transportation or internet costs;
 - Emphasising the potential impact of the research.

LE involvement and engagement



Recruitment

Best practices

- Consider the benefits guideline of [NIHR](#)
- Use both digital and not digital communication channels
- Incorporate standards of Equity, Diversity and Inclusion. There are organisations such as Equality Health who have a range of resources to help widen diversity and inclusion:
<https://equality.health/>
- Collaborate with community organizations, advocacy groups, and networks that work with individuals who have relevant lived experiences. These partnerships can help identify potential advisors and build trust.

LE involvement and engagement



Involvement

Challenges

- Ensuring meaningful participation. Advisors may feel their contributions are undervalued or not integrated.
- Disengagement and a lack of sustained involvement.
- Formal and impersonal research environments can make difficult to build rapport and trust.

LE involvement and engagement



Involvement

Best Practices

- Provide training in lay terms
- Use of glossaries
- Manage differences and expectations
- Allow opportunities for informal and unstructured exchanges with the research team
- Be transparent in communications and encourage feedback.

UNDERSTAND YOUR AIMS

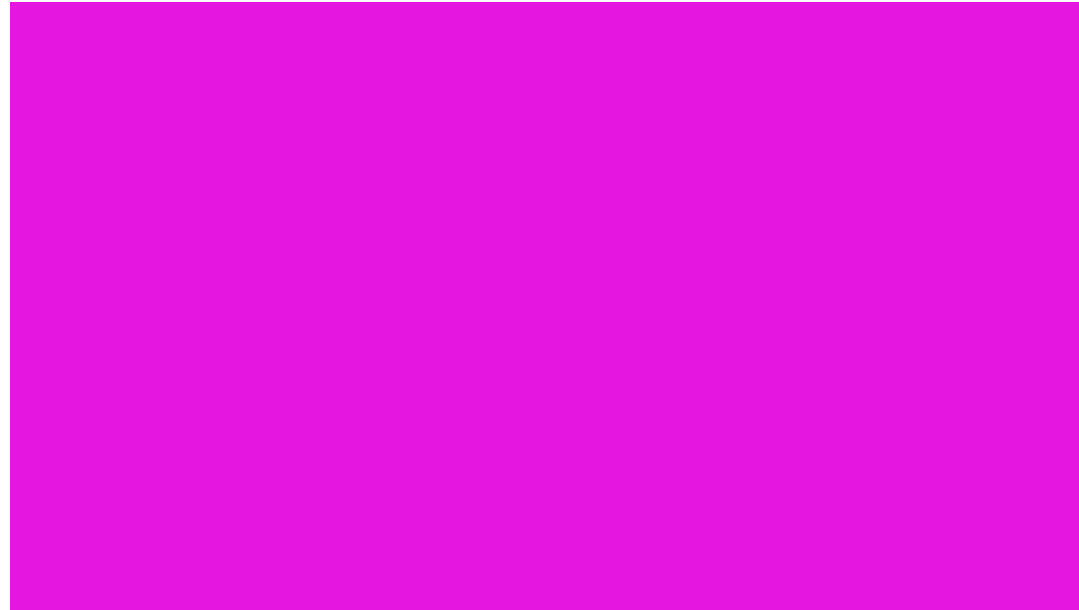
Ask yourself these questions:

1. What am I hoping to achieve? or What outcome am I looking for?
2. What issue or challenge in my research or research plans could the perspective of the public or experiential knowledge of patients help to overcome?
3. What difference or impact do I want this involvement to make?

LE involvement and engagement



Involvement



MindTech : [Watch & listen - Digital Youth](#)

LE involvement and engagement



Engagement

Challenges

- The admission of mental health difficulties to oneself and others, which can be highly stigmatising.
- Research in virtual and immersive technologies often involves technical concepts.
- Not everyone has access to the technology to experience virtual and immersive technologies firsthand.
- Traditional dissemination methods (e.g., academic papers, presentations) may not fully capture the immersive nature of the technology, leading to less impactful dissemination of the research findings.

LE involvement and engagement



Engagement

Best Practices

- Partner with community organisations and research charities such as Doctors/Health Centres, Recovery Communities, Shopping Centre billboards and Housing Associations.
- Provide opportunities for LE advisors to coauthor publications
- Provide opportunities for LE to act as advocates, speakers at conferences and events.
- Use simplified language and visual aids (e.g., infographics, videos) to explain complex concepts.
- Offer accessible demonstrations of the technology.

LE involvement and engagement



Engagement



MindTech: [What's Up With Everyone? \(whatsupwitheveryone.com\)](https://whatsupwitheveryone.com)

LE involvement and engagement



Coproduction

Challenges

- Building and maintaining trust and balance of power might be difficult in an environment that is usually researcher led.
- Jargon and technical language might hinder shared understanding.
- Different expectations about the role of LE advisors within the research project
- Tokenism (participation without meaningful influence)

LE involvement and engagement



Coproduction

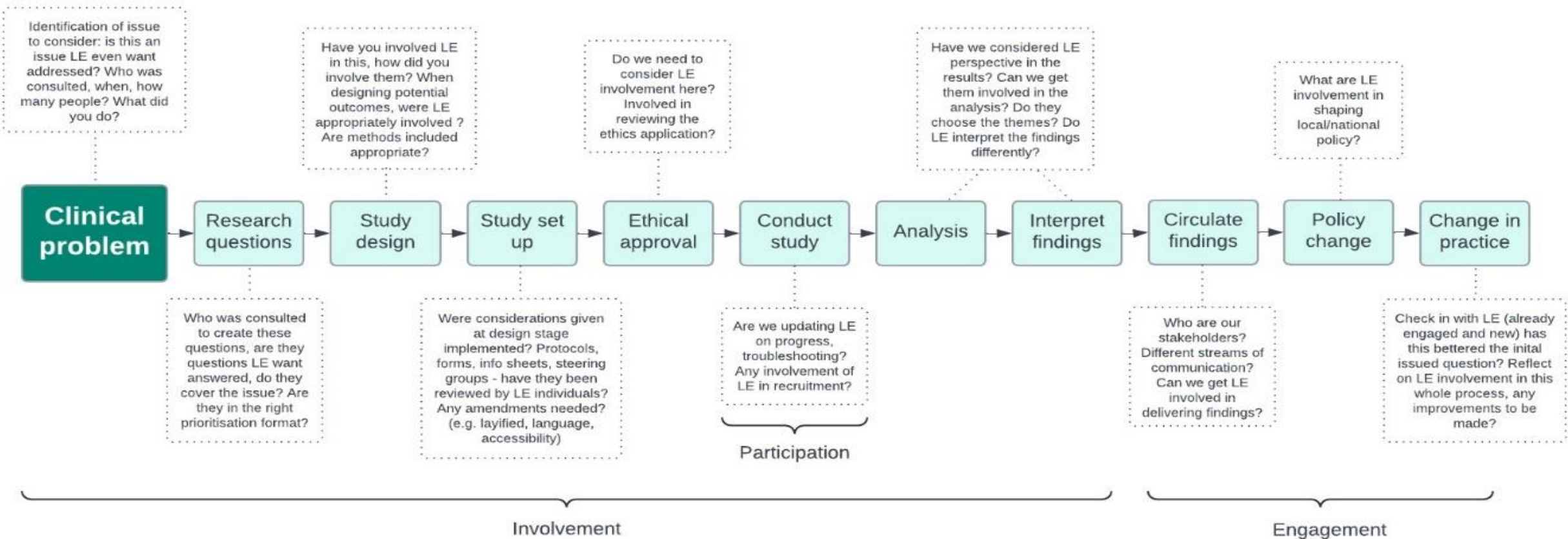
Best practices

- Creating a safe and inclusive environment for all
- Supporting different ways of partnering, taking time to understand how they feel best placed to contribute and what skills they already have
- Facilitate an initial dialogue to build shared understanding and expectations.
- Understand communication preferences among LE Advisors, including plenty of opportunities for meetings, debriefs.

LE involvement and engagement



Coproduction: start to finish



Learning summary



Summary

LE involvement and engagement

- Patient and Public involvement in research is now regarded as an integral part of any research project.
- PPIE entails an active partnership between patients, the public, and researchers in the research process, rather than using people merely as subjects.
- Researchers plan how to involve people, identify suitable population groups, and evaluate the impact of PPIE activities.

LE involvement and engagement

Importance of PPIE in Mental Health Tech Research

1. Relevance
2. Ethics and Accessibility
3. Practical Applications
4. Addressing Inequalities
5. Resource Maximization
6. Improved Services



LE involvement and engagement

Importance of PPIE in Mental Health Tech Research

● Skills Developed Through PPIE

- Research Understanding
- Advocacy and Communication
- Confidence and Influence



LE involvement and engagement

Activities in PPIE include



Recruitment



Involvement



Engagement



Coproduction

LE involvement and engagement

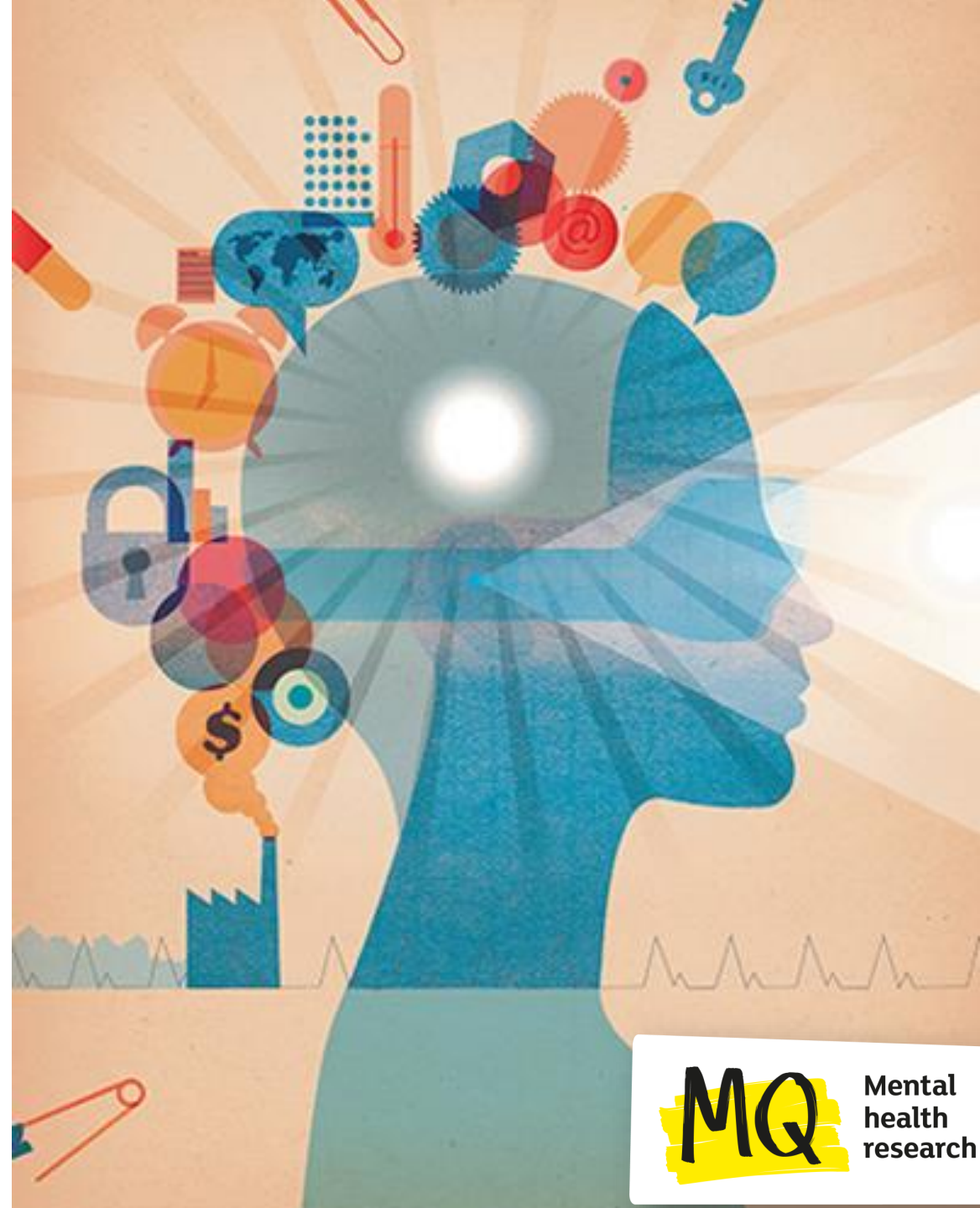
Existing barriers	How to overcome them
Digital inequalities	Adopt both digital and non-digital strategies for dissemination and engagement
Lack of relevant incentives	Set incentives in place which take into account the basic, psychological and fulfilment priorities from these populations, as seen by them
Tokenism	Increase decision-making power and influence of Lived Experience
Communication challenges	Increase translational efforts, allow bi-directional communication and avoid jargon
Stigma	Increase mental health awareness on the ground and empower others to challenge stigma

Common challenges and best practices in PPIE



Further Reading

- **Mindset-XR programme:**
<https://healthinnovationnetwork.com/resources/mindset-xr-patient-public-involvement/>
- **Other MQ content:** www.mqmentalhealth.org/the-importance-of-involving-patients-and-the-public-in-research
- **Digital Youth and Involvement:**
<https://digitalyouth.ac.uk/resources/watch-listen>



A background image showing a group of diverse people in a meeting. A woman in a pink blazer is standing and looking at a laptop. A man in a grey jacket is sitting at a desk with a laptop, looking at the screen. Another man in a blue jacket is sitting next to him, also looking at the laptop. A woman with curly hair is sitting in the foreground, looking down. The setting is a modern office with a wooden desk, a coffee cup, and a laptop. A blue semi-transparent banner is overlaid on the image, containing the text 'Test your knowledge'.

Test your knowledge