

# Patient and Public Involvement, Engagement and Participation Strategy NIHR HPRU EZI

## Background

In April 2020 the [National Institute for Health Research Health Protection Research Unit in Emerging and Zoonotic Infections \(NIHR HPRU EZI\)](#) renewed its contract for another 5 years. The NIHR HPRU EZI is a partnership between the University of Liverpool, Liverpool School of Tropical Medicine, University of Oxford and Public Health England. We aim to support and strengthen Public Health England in its role of protecting England from emerging and zoonotic infections, whilst increasing research capacity in this field.

The NIHR HPRU EZI believes that patient and public involvement, engagement and participation have incremental benefits for our research. They are necessary to ensure our research is relevant, informed, impactful and accountable.

Any member of the public is susceptible to emerging and zoonotic infections. An outbreak of these infections can lead to emergency situations where flexibility and a rapid research response are essential. To ensure these are appropriate, it is essential that public involvement and engagement are embedded within the Unit, so appropriate involvement can be taken within restricted timelines. With such a high relevance to public health, it is important to engage the wider public in the Units research to empower them to make informed decisions about their health.

The NIHR HPRU EZI follows the NIHR definition of involvement, engagement and participation:

- **Involvement** – where members of the public are actively involved in research projects and in research organisations
- **Engagement** – where information and knowledge about research is provided and disseminated
- **Participation** – where people take part in a research study

## Vision

Our vision is to create a culture shift in which meaningful patient and public involvement, engagement (PPIE) and participation are embedded within the culture of the NIHR HPRU EZI. This will be achieved by including them at the start and throughout the research programme and our governance structure, staying true to our values of reciprocity, transparency and inclusivity.

## Aims

We aim to achieve this vision through 3 strategic areas where we will focus efforts to enable patient and public involvement, engagement and participation with its research:

- 1) Build **capacity** among researchers and public contributors to enable meaningful patient and public involvement and engagement within NIHR HPRU EZI
- 2) Strengthen public **relevance** of the research undertaken via involvement and engagement
- 3) Improve **diversity** of the audiences the NIHR HPRU EZI engages with

The aims are linked to the UK Standards for Public Involvement. The aim around capacity will focus on the standards “support and learning” and “communication”, relevance is linked to the standards “governance” and “impact” and diversity relates to the standards “working together” and “inclusive opportunities”.

## Objectives

To meet the aims, we have set the following specific objectives. Further details on how these will be executed can be found in the implementation plan.

Central to the execution of the objectives are the values reciprocity, transparency and inclusivity. This includes reimbursing public contributors for their time in line with NIHR guidance, being transparent about the opportunities and difference public contributors can make, sharing feedback on public contributor's input and making appropriate adjustments to ensure activities are accessible to those who want to be involved or engaged with research.

### Aim 1: Building capacity

When we talk about building capacity, we put an emphasis on continuous learning and development. It is about ensuring that both researchers and public contributors involved in NIHR HPRU EZI projects have the skills, knowledge and support in place to conduct involvement and engagement. It also entails informing researchers about the various ways that involvement and engagement can have an impact on their work and the benefits it can bring. The capacity building programme will be executed in collaboration with the NIHR HPRU EZI training lead.

With our involvement, engagement and participation strategy, we commit to support researchers to not only become leaders in their academic field, but also champions for involvement and engagement in their work. We also commit, especially due to the more fundamental nature of many research projects, to give support to public contributors and provide training where relevant to make their contributions meaningful.

#### **Short term (within the first year)**

1. Establish a recurring (virtual) PPIE induction trainings for all new starters within the Unit
2. Create an online PPIE guidance-repository with resources for researchers and public contributors
3. Enable researchers to attend PPIE conferences and share their learnings and successes at events

#### **Medium term (within 2-3 years)**

4. Organise joint training days for researchers and public contributors within the NIHR HPRU EZI

#### **Long term (within 5 years)**

5. Build towards a culture change within the NIHR HPRU EZI where PPIE activities are embedded throughout the research process

### Aim 2: Strengthen public relevance

By acknowledging the benefits involvement and engagement can bring to research, the NIHR HPRU EZI will build on its achievements in public engagement of the first 5 year funding round and strengthen involvement in its research. To truly strengthen the relevance of research, involvement should be included from the start of the research process. There is also a need to be open about the research conducted by the Unit and have conversations about the work with a wider audience, current and new relationships with charities will be crucial for this. We also commit to strong involvement in our governance structure to ensure that the research and direction include a public perspective.

***Short term (within the first year)***

1. Set-up a structure to facilitate involvement in the Unit's governance and recruit for all roles involved
2. Provide training to public contributors involved in the Unit's governance
3. Include PPIE in the role descriptions of all research posts recruited for the NIHR HPRU EZI
4. Where feasible, have a public contributor member on interview panels
5. Provide PPI bursaries for PhD students and Post-Doctoral Research Associates (PDRAs) to include involvement within their NIHR HPRU EZI funded research project

***Medium term (within 2-3 years)***

6. Set-up and support a rapid-response PPI group, which can provide input when infectious emergencies arise
7. Encourage researchers to plan, develop, participate and evaluate public engagement events with relevant audiences
8. Encourage and support researchers within NIHR HPRU EZI to apply for PPIE seed-funding within their university and from external funders

***Long term (within 5 years)***

9. Use ongoing learning from NIHR HPRU EZI II to support stronger involvement in the design of NIHR HPRU EZI III

**Aim 3: Improve diversity**

Though emerging and zoonotic infectious diseases can affect everyone, health inequalities can lead to certain groups in society being disproportionately affected. The Unit commits to actively raise awareness, facilitate opportunities to diversify the public input we gain and act upon the importance of diversity in research participation, engagement and involvement.

***Short term (within the first year)***

1. Disseminate and raise awareness of specific guides available that support diversity

***Medium term (within 2-3 years)***

2. Set-up a recurring funding call for the NIHR HPRU EZI to conduct involvement/ engagement activities with audiences that are often excluded or unheard
3. Organise activities to raise awareness of the importance of diversity in research involvement, engagement and participation

***Long term (within 5 years)***

4. Develop and sustain a culture within NIHR HPRU EZI where diversity of the public in research participation, engagement and involvement is one of the elements taken into account in study design, execution and dissemination

This strategy is meant to be a living document and has been created by the NIHR HPRU EZI Patient and Public Involvement and Engagement working group, which exists of both academic and public members. The strategy will be reviewed by the working group as and when needed. This strategy provides a framework to establish a culture shift within the Unit that embraces involvement and engagement at the early stages of research development and throughout the whole cycle.