

# 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 the UK Health Security Agency. 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 through 5 research themes:

1. Patient Research for Public Health
2. Diagnostics and Host Response
3. Pathogen and Vector Biology
4. Epidemiology and Risk Analysis
5. Knowledge Mobilisation

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 Unit's research to empower them to make informed decisions about their health. We aim to focus on informing and involving the public around our 5 research themes, although this should also expose and equip the public with the analysis skills to engage with public health more broadly.

The NIHR HPRU EZI follows the NIHR definition of involvement, engagement and participation (1):

- **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

## Aims

We have 2 overarching aims which we will focus our efforts to enable patient and public involvement, engagement and participation within the research of the Unit:

- 1) Embed patient and public involvement, engagement (PPIE), and participation within the culture of the NIHR HPRU EZI**

Our aim 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, and through building the capacity for PPIE activities in the Unit.

**2) Decrease the burden of emerging and zoonotic infections by increasing the relevance and impact of the work of the HPRU EZI**

Through integrating PPIE at all stages of research within the NIHR HPRU EZI, our research will incorporate the lived experiences and opinions of patients and the public. As a result, the Unit's research will become more impactful and relevant to the field of emerging and zoonotic infections. Increasingly relevant research will more meaningfully aid in the fight against emerging and zoonotic infections and improve public health. This change will be developed through the exploration of patient and public viewpoints to identify the most important factors relevant to these infections which will then be integrated within the Unit's researcher.

**The UK Standards for Public Involvement**

By supporting the research community and providing continuous learning and development opportunities for researchers at all career stages, important steps are taken in researchers' understanding of what PPIE entails, how to do it and the benefits it brings. Our aims will contribute to this long-term goal. These aims will be implemented through specific objectives framed around the [UK Standards for Public Involvement](#) to ensure our objectives meet national involvement standards.

These standards have been developed over several years through a UK-wide partnership (between Scotland, England, Wales, and Northern Ireland) and are designed to be a set of values in which researchers and institutions are encouraged to base their PPIE activities on. These standards are support and learning, communications, governance, impact, working together, and inclusive opportunities, which will be used as a framework to combat health inequality.

**Standard:** Support and learning

Definition: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.

**Objectives:**

1. Run recurring (virtual) PPIE induction training for all new starters within the Unit
2. Establish annual PPIE refresher training workshops for all PhD students and post-doctoral research associates (PDRA) within the Unit
3. Organise joint training days for researchers and public contributors within the NIHR HPRU EZI
4. Integrate use of alternative communication methods to guide trainings
5. Create an online PPIE guidance-repository with resources for researchers and public contributors, including additional training courses to supplement our own

**Long term goals:**

- Increase the capacity of researchers to understand and perform PPIE activities with minimal guidance while providing guidance for both researchers and public and patient contributors in PPIE

**Implementation:**

The PPI lead will hold short 'introduction to PPIE' training sessions, accessible to new members of the NIHR HPRU EZI and these will be repeated upon the intake of new starters and on request. Recurring annual PPIE 'refresher' training sessions will be implemented to remind members of the opportunities to involve contributors in their research. These refresher sessions will focus on more specific topics such as writing plain English summaries or using alternative methods of engagement and involvement such as art workshops or infographic design sessions, and will depend on the requests of researchers at the Unit and suggestions from the working group. In years 3 and 4 of our 5-year programme, the Unit will hold a PPIE training day, which will be attended by NIHR HPRU EZI researchers from all career stages and public contributors. These events are building on the successful event held during the first NIHR HPRU EZI. These trainings will be integrated in the Unit's training strategy and coordinated with the NIHR HPRU EZI training lead. The PPIE working group and/ or the cross HPRU PPI leads network will be consulted on training materials.

The NIHR HPRU EZI will create an online public involvement and engagement guidance-repository for all affiliated researchers and public contributors. The repository will be hosted on the Unit's website and compile existing guides supporting researchers and public contributors in their PPIE activities. We are keen to make the most of resources already developed by (NIHR) organisations and will only develop additional guidance where gaps in support are identified by the researchers' community or the PPIE working group. This will include additional training material for members of the Unit to access, if needed.

**Standard: Communication**

Definition: Use plain language for well-timed and relevant communications, as part of involvement plans and activities.

**Objectives:**

1. Enable researchers to attend PPIE conferences and share their learnings and successes at events through PPIE conference bursaries
2. PhD students and PDRAs will be delivered feedback on PPIE bursary proposals regarding the effectiveness and relevance of their planned PPIE activities
3. PPIE bursaries should be written in plain English
4. Visual and audio representations of the strategy will be made available on our website

**Long term goals:**

- Increase capacity of researchers to use appropriate communication techniques in their research and provide opportunities for researchers to communicate their research

**Implementation:**

To allow researchers to keep learning and sharing their great work, we will make bursaries available for researchers to attend public involvement or engagement conferences or events. These could i.e. be the annual conferences organised by the National Coordinating Centre for Public Engagement or BIG STEM Communicators Network or events by the NIHR Centre for Dissemination and Engagement. Alternatively, researchers can also apply for a bursary to present a scientific conference or event if they will be (re)presenting their PPIE work.

In addition, researchers will be able to apply for bursaries to support their own PPIE activities (described later). These bursaries will be required to be written in plain English as they will be reviewed by the working group, thereby allowing researchers to practice their skills in communicating their research to a lay audience. In addition, researchers will be provided with feedback from the working group and will therefore get advice from a lay audience on their PPIE ideas, implementation strategy, and communication of their research.

We are also looking at how we can diversify our communication through methods other than written documents. This allows individuals who either have a condition which limits their interpretation of written text, or who simply prefer communication through other methods such as visually, to access our materials. To this end, we will produce a visual and audio representation of this strategy which will be available on our website.

**Standard: Governance**

Definition: Involve the public in research management, regulation, leadership and decision making.

**Objectives:**

1. Training will be provided to public contributors involved in the Unit's governance
2. Include PPIE in the role descriptions of all research posts recruited for the NIHR HPRU EZI
3. Where feasible, have a public contributor member on interview panels
4. Establishment of a patient and public involvement and engagement working group
5. The PPIE working group has co developed a Terms of Reference which is reviewed annually by the group
6. Written, visual, and audio representations of the Terms of Reference will be available on our website after consulting with the working group
7. Researchers will be asked to present their work at working group meetings to receive feedback on how to incorporate PPIE activities into their work
8. Members of the working group will be invited to the HPRU EZI annual meeting
9. Set-up and support a rapid-response PPI group, which can provide input when infectious emergencies arise

**Long term goals:**

- Increase relevance by having input from public and patient contributors towards the structure and management of the HPRU

**Implementation:**

The NIHR HPRU EZI acknowledges that the inclusion of different voices of key stakeholder groups beyond academia is of the utmost importance to its research. A Patient and Public Involvement and Engagement working group has been established with the aim of providing strategic advice on PPIE activities of the Unit as a whole, rather than specific studies. Members of the group are a combination of public members (people with lived experience of a condition relevant to NIHR HPRU EZI) and academic members (one from each partner within the NIHR HPRU EZI). The public members were recruited via established connections that researchers have with relevant charities and individuals and where appropriate complemented with an open call for members. These members include: Jenny Camaradou (public), Rachael Pope (public), Rhys Inwards (public), Ben Cooper (academic), John Ellershaw (academic), Nadia Kontogianni (academic), and Shona Moore (academic).

This group will work with the PPIE lead to establish the Unit's Patient and Public Involvement, Engagement and Participation Strategy and support the PPIE lead in implementing and executing the strategy. The group defined their own terms of reference which will be reviewed when needed. We will provide additional training for public contributors who are members of the PPIE working group. This will include introduction sessions on the science the Unit plans to do and how the organisation is structured, so they can put their work into context. This training will be recorded and made available so members can re-watch it when needed. In addition, PhD students and PDRAs of the Unit will present their work during working group meetings. This will maintain integration of the working group with the research of the Unit whilst providing researchers the chance to observe the running of focus groups and receive feedback on how they can introduce PPIE activities into their research. Recommendations of the working group will be relayed at steering group meetings by the PPIE lead

to integrate their suggestions into the Unit's governance. Two members of the working group, on rotation, will be invited to attend the HPRU EZI annual meetings to meet the researchers of the Unit and learn about the work being carried out. Their time, travel, and additional requirements, will be reimbursed to ensure all members have full accessibility to attend.

In order to embrace the importance of involvement and engagement within the organisation, all new positions recruited with NIHR HPRU EZI funding, or via match funding, will include involvement and engagement skills as one of the desirable qualities on the role description. By formally including these qualities in the role description, the NIHR HPRU EZI sets an expectation with new researchers on its importance and it will become an element of assessment for potential recruits. We will also aim to have a public contributor on the interview panels organised for future positions at the Unit. This ensures that the recruitment process is transparent and there will be an expert in assessing the applicant's skills and passion for public involvement and engagement.

The COVID-19 pandemic has demonstrated the need for established relations with public contributors in order to facilitate rapid involvement during pandemics. The rapid response PPI group will consist of a mail list of people interested in supporting the work of the NIHR HPRU EZI and who are willing to work within tight timelines when infectious diseases outbreaks occur. The role description for this group will be widely advertised digitally and specific channels to reach diverse audiences will be used, such as networks of relevant charities, recruitment websites such as People in Research, and social media. The group will receive the NIHR HPRU EZI newsletter and, where feasible, will be invited to attend training events. Additionally, a small pot of funding will be available for researchers to make use of the rapid research response group, in order for them to be involved in the research application stage. This will enable researchers affiliated to the NIHR HPRU EZI to be included in the process despite limited time and resources available during infectious disease outbreaks.

**Standard:** Impact

Definition: Seek improvement by identifying and sharing the difference that public involvement makes to research.

**Objectives:**

1. The PPIE working group will review the PPIE strategy and other PPIE activities at the Unit
2. Progress of PPIE activities and the working group is discussed at each operational management team (OMT) meeting, of which the PPIE lead is present
3. PPI bursaries are provided to PhD students and PDRAs to include involvement within their NIHR HPRU EZI funded research projects
4. Bursary applications require evaluation of activity from public and patient contributors
5. Bursary applicants are required to submit an impact form after completion of their activity, of which excerpts will be showcased on our website
6. Researchers are encouraged to apply for PPIE seed-funding from university and external funders
7. The Unit's PPIE activities will be recorded in a shared internal Google docs spreadsheet and case studies will be disseminated in our newsletter, on our website, and via social media
8. A statement describing and evaluating involvement activities, based on the GRIPP2 form (2), will be included in each publication of the HPRU where public involvement occurred

**Long term goals:**

- Increase the relevance of HPRU EZI research and PPIE activities by establishing feedback mechanisms and dissemination of results from all research and PPIE activities

**Implementation:**

The PPIE working group will review PPIE activities in the Unit, including the PPIE strategy, PPIE training, and PPI bursaries to ensure a lay audience has input into their design and dissemination. Recommendations and experiences of the working group, as well as other PPIE activities, will be voiced at OMT meetings by the PPIE lead to ensure their thoughts are integrated into the Unit's work.

Bursaries of up to £1100 will be made available for researchers to include PPI throughout their study. To apply for the bursaries, researchers will submit a template in which they answer questions to outline and refine their PPI plans. All bursary applications will be reviewed by the PPIE working group before funding is made available. All applications are expected to be successful, though some might require adjustments based on feedback from the PPIE working group. Bursary applicants will be required to fill in an impact form after their activity has taken place to outline the successes and possible improvements for future PPI activities. Successful activities will then be published for others to learn from in the HPRU EZI newsletter and on our website.

Researchers will be encouraged to utilise internal and external engagement and funding opportunities through promotion via the quarterly NIHR HPRU EZI newsletter. The PPIE activities of the Unit will be recorded in a shared internal spreadsheet to enable all researchers to track their activities. This will also allow other researchers to observe, and be inspired by, other activities entered into the spreadsheet. Selected activities will be disseminated to researchers through our quarterly newsletter and will also be made available to the public through posting on our website and social media feeds.

**Standard:** Working together

Definition: Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

**Objectives:**

1. PPIE working group meetings are held online to allow access from any location
2. Collaborate with the knowledge mobilisation theme leads to share resources
3. Identify and connect with other organisations to share resources and increase dissemination to wider audiences
4. Where feasible, invite PPIE experts from external organisations to host seminars to both researchers and public and patient contributors at the Unit, e.g. during PPIE training events

**Long term goals:**

- Increase the diversity of the research and reach of the Unit's activities through encouraging the sharing of experiences, expectations, and resources between researchers, patients and the public while ensuring appropriate dissemination mechanisms

**Implementation:**

The PPIE working group meetings are currently held online, as this allows members who are based in different locations to participate. The frequency and timings of meetings are jointly decided by the PPIE lead, project manager, and working group members to ensure there is equal opportunity for all to attend. Where working group members are unable to attend the meeting, the PPIE lead will provide a follow-up call to share the material discussed at the meeting, seek any further suggestions or concerns from the member, and update them on the decisions of the group to allow for further feedback. As mentioned, the reflections of the PPIE working group on the Unit's PPIE activities will be shared at OMT meetings and will be used to improve our training materials.

We will work closely with the knowledge mobilisation theme leads as there are significant overlaps between PPIE and knowledge mobilisation and this collaboration will increase the awareness of PPIE within the Unit.

As PPIE is relevant to any research community, our ambition is to organise future PPIE activities jointly with other organisations within the NIHR infrastructure, such as other HPRUs, Clinical Research Networks, Biomedical Research Centres, Research Design Services or Applied Research Collaborations (ARC). We plan to reach out to the HPRU PPIE leads network as well as the ARC Oxford and Thames Valley and ARC North West Coast teams before broadening our collaborations overseas. This will allow us to share resources, discuss challenges in PPIE and how to overcome them, widen dissemination networks, and invite other experts in PPIE to provide seminar talks for our HPRU. In the future, we hope to organise collaborative PPIE events where researchers at the HPRU EZI and other institutes share their experiences in PPIE activities and showcase their research to the public.

**Standard: Inclusive opportunities**

Definition: Offer public involvement opportunities that are accessible and that reach people and groups according to research needs and outcomes.

**Objectives:**

1. Disseminate and raise awareness of specific guides available that support diversity on the PPIE guidance-repository on our website
1. Promote diversity awareness in PPIE training for PhD students and PDRAs
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. Advertise PPIE activities to diverse audiences through new collaborations
4. Encourage the use of additional tools (e.g. visual tools) to increase inclusivity in PPIE activities
5. Public and patient contributors are paid for their time in all instances

**Long term goals:**

- Develop and sustain a culture within NIHR HPRU EZI where diversity and inclusion are considered in study design, execution and dissemination

**Implementation:**

The PPIE guidance-repository on the NIHR HPRU EZI website includes a section dedicated to working with diverse audiences, utilising resources published by those groups such as those produced by the [www.ethnichealthresearch.org.uk](http://www.ethnichealthresearch.org.uk). This section also includes guides on how to plan meetings in order for those to be more accessible. Furthermore, researchers undergoing PPIE training will be given specific advice for promoting diversity and inclusion in their PPIE. Researchers will be informed to use the NIHR recommended reimbursement standards for all relevant PPIE activities.

From the third year onwards, the NIHR HPRU EZI will run an annual funding call for their affiliated researchers to develop PPIE and participation activities which are targeted at under-served audiences and communities to whom such events are often inaccessible. Learnings from these projects will be shared within the NIHR HPRU EZI and the wider involvement and engagement community through feedback reports on the activities, which again will be published as case studies on the HPRU website for reference and reflection for other researchers and the public.

To increase diversity and inclusion of our PPIE activities, we will encourage the use of multiple dissemination channels to further the reach of those advertisements (e.g. newsletters, our website, and social media). Furthermore, patient and public recruitment for any PPIE activities will be carried out through several recruitment networks, including related charities, People in Research, VOICE, GenerationR (young persons' support group), other relevant support groups, and social media. In addition to recruitment, we encourage the use of different methods of communication with patients and the public. This includes the use of visual methods (such as whiteboards or digital whiteboards), audio methods (such as recording of materials), and inclusive text methods (such as live close-captioning and the use of inclusive fonts). This will ensure those who prefer alternative methods of communication are included in our activities. Through increasing the diversity of those we interact with, the research performed at the Unit will be more relevant to wider audiences.

## Budget

The NIHR HPRU EZI has a PPIE budget of £10,000 per year, which is spread evenly across the four partners to manage. A proposed long-term budget to support the ambitions of this action plan:

|   | 2020-2021 | 2021-2022 | 2022-2023 | 2023-2024 | 2024-2025 |
|---|-----------|-----------|-----------|-----------|-----------|
| Training PPI members in governance            | £ 100     | £ 250     | £ 250     | £ 250     | £ 250     |
| Honorarium PPIE working group                 | £ 320     | £ 1280    | £ 1280    | £ 1280    | £ 1280    |
| Travel reimbursements PPI contributors        |           |           | £ 1,000   | £ 500     | £ 500     |
| Honorarium interview panel                    | £ 155     | £ 155     | £ 150     |           |           |
| PPIE conference bursaries                     |           |           | £ 450     | £ 450     | £ 300     |
| PPI bursaries (17x) for HPRU EZI PhD students |           |           | £ 11,100  | £ 7700    |           |
| PPIE funding call                             |           | £ 2400    | £ 3200    | £ 4800    | £ 4000    |
| PPIE training day                             |           |           | £ 1500    | £ 1500    |           |
| Bursaries to support PPI in rapid response    |           | £ 300     | £ 300     | £ 300     | £ 300     |
| PPI in developing HPRU EZI III application    |           |           |           |           | £ 1000    |
| PPIE dissemination event                      |           |           |           |           | £ 1500    |

The PPI bursaries are expected to be spent over several years. However, for practical reasons this budget reflects spending of the whole bursary in the year when they are expected to be allocated.

## Monitoring and evaluation

Throughout the involvement and engagement activities, we will make use of the ‘most significant change’ technique to evaluate specific PPIE activities. To monitor the progression of this strategy, each partner organisation will be encouraged to provide regular updates on their PPIE progress in advance of PPIE working group meetings. The working group will discuss each organisation’s update and will follow-up where required. The collected data will be used for annual reporting for the NIHR Central Commissioning Facility and for continued learning and reflection through dissemination of specific activities via our newsletter and on our website. The PPIE lead is the main point of contact and will collate feedback from public contributors involved in the work of the NIHR HPRU EZI.

To ensure that the strategy supports our aims to increase capacity, relevance, and diversity alongside the UK standards for public involvement, we will be recording several metrics:

- Shared PPIE activities Google docs spreadsheet
- Number of PPI bursary applicants
- Impact form for PPI bursary applicants, based on the GRIPP2 short form
- Number of PPIE conference bursary applicants
- The number of public contributors involved in interview panels
- The impact of public contributors on interview panels, captured via debriefs with contributors
- If the rapid research response group is required to act during a pandemic, a survey evaluation will be held amongst researchers and public contributors, once the pandemic has eased, to capture data on its effectiveness and impact

- Number of PPIE grants applied for outside the NIHR HPRU EZI and how many were successful will be tracked
- Number of publications with PPIE mentioned and number of lay co-authors
- The number of researchers and the types of engagement events they contribute to, including where possible further details of the audience who attended
- Collaborators and invited speakers summary sheet
- Summary of PPIE activities in the NIHR annual report

The above implementation plan will be evaluated based on the following objectives:

- PPIE training seminars (at least 1 / year)
- Working group meetings (at least 3 / year)
- Successful PPI bursary applications (17 over the next 3 years)
- HPRU EZI newsletters (4 / year)
- Research studies which involve patients and/or the public (at least 2 / year)
- Use of different communication methods (e.g. written text, graphics, audio) in PPIE activities (at least 2 / year)
- Updated HPRU EZI website to include working group membership details

The HPRU EZI also wants to improve diversity within its involvement and engagement work by raising awareness and providing the funding for researchers to trial reaching out to new audiences. To monitor the progress, there will be several data collected:

- Number of NIHR HPRU EZI diversity in PPIE grants applied to and funded
- Evaluation form of each diversity in PPIE grant, including open questions to understand the learnings of the project of engaging with specific under-served audiences
- Number of University/ external public engagement grants applied for and received based on work from a diversity in PPIE grant

## Glossary

**Capacity;** the skills and knowledge required to do something

**Engagement;** Where information and knowledge about research is provided and disseminated, for example science festivals, open days, media coverage

**Involvement;** involvement in research means research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them

**NIHR;** the National Institute for Health Research is the research branch of the NHS and funds health and social care research

**Outreach;** public engagement with schools and children is often labelled as outreach

**PhD student;** a Doctor of Philosophy student has often recently graduated from their Bachelor or Master, though it could be that someone does a PhD later in their career. In the context of the NIHR HPRU EZI, PhD students undertake 3 years of research projects where they learn and develop themselves as a researcher. After 3 years they are required to submit a thesis (large piece of written work), consisting of their research work and reflections in order to receive their doctorate

**PDRA;** Post-Doctoral Research Associates are researchers who have received their doctorate and finished their PhD. They are still in the earlier stage of their academic career and are often not the lead on a project

**Public contributor;** this is anyone who is involved in research. They could be patients, service users, survivors, carers and family members or someone with no relevant health condition but an interest in the research field

**UK Standards for Public Involvement;** these are standards which describe what good public involvement looks like and encourages approaches and behaviours that are the hallmark of good public involvement. These have been agreed by organisations across the four nations (Scotland, England, Wales, and Northern Ireland), including the NIHR

## References

1. Putting people first in research. [cited 2022 Feb 25]; Available from: [www.invo.org.uk](http://www.invo.org.uk)
2. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ [Internet]. 2017 Aug 2 [cited 2022 Feb 25];358:3453. Available from: <https://www.bmj.com/content/358/bmj.j3453>