

**Patient and Public Involvement and Engagement (PPIE) Plan 2020-2025**

1. ***Introduction***

This document outlines the Patient and Public Involvement and Engagement (PPIE) plan for the NIHR Health Protection Research Unit in Emergency Preparedness and Response (EPR HPRU).

The EPR HPRU is led by King’s College London (KCL) in partnership with Public Health England (PHE) and the University of East Anglia (UEA). This Unit brings together expertise in behavioural science and mental health, and outbreak investigation & response to produce multidisciplinary research to enhance PHE’s ability to minimise the public health impacts of emergencies. The EPR HPRU comprises multiple research projects across four priority work themes:

* **Theme 1 – Preparedness**
* **Theme 2 – Resilience**
* **Theme 3 – Response**
* **Theme 4 – Novel Technologies**

EPR HPRU PPIE policy is guided by the NIHR INVOLVE definition of public involvement in research as:

*“research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”* (<http://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/>).

and the NIHR INVOLVE definition of public engagement in research as:

*“Where information and knowledge about research is provided and disseminated”* (<https://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/>)

When defining ‘public’ we also draw on the NIHR INVOLVE definition of:

*“patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.”* (<http://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/>)

This plan therefore incorporates elements of lay-person public involvement and stakeholder group involvement (where these groups represent the public).

1. ***Purpose, aims and objectives***

The EPR HPRU is committed to incorporating PPIE in both the **strategic development of the Unit** and in **individual themes/research projects**. This will help us to meet our **aim of becoming an international centre of excellence for applied EPR research**.

To ensure that we can meet this aim, we are anchoring our PPIE plan around the UK Standards for Public Involvement, specifically:

|  |  |
| --- | --- |
| **“Inclusive Opportunities”** | “Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.” |
| **“Working Together”** | “Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.” |
| **“Support and Learning”** | “Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.” |
| **“Governance”** | “Involve the public in research management, regulation, leadership and decision making.” |
| **“Communications”** | “Use plain language for well-timed and relevant communications, as part of involvement plans and activities.” |
| **“Impact”** | “Seek improvement by identifying and sharing the difference that public involvement makes to research.” |

*(Reproduced verbatim from* [*https://sites.google.com/nihr.ac.uk/pi-standards/standards*](https://sites.google.com/nihr.ac.uk/pi-standards/standards)*)*

The purpose of this plan is to provide a framework to incorporate PPIE at a strategic level and to support the systematic development of PPIE across individual work themes and research projects. In order to ensure that public involvement is embedded at every level, it is important to align the aims of the PPIE strategy to those of the Unit. The table below reflects the broad aims of the EPR HPRU with accompanying aims for PPIE.

|  |  |  |
| --- | --- | --- |
| **PPIE strategy aims** | **EPR HPRU aims** | **Relevant UK Standards for Public Involvement** |
| Involve members of the public and relevant public stakeholder organisations in strategic level PPIE implementation. | Work with PHE, other government bodies and the wider community to identify and address knowledge gaps in the field of EPR | Inclusive Opportunities  Working Together  Governance |
| Ensure representation from seldom heard groups in order to ensure that procedures are appropriate for all. | Work with PHE to develop better procedures to protect the health of the public | Inclusive Opportunities  Working Together |
| Develop expertise in PPIE among Unit researchers, with an emphasis on conducting PPIE, accurate reporting of PPIE, and assessing impact. | Develop EPR research capacity within our team and across PHE | Support and Learning  Impact |
| Ensure PPIE is embedded within the work of individual themes and projects as appropriate. | Become an international centre of excellence for EPR research | Inclusive Opportunities  Working Together  Governance  Impact |

In the section that follows, we detail a programme of activities that will help to ensure that the aims identified in the above table are met.

1. ***Programme of activities***

This plan details the programme of activities that will be undertaken at a strategic and theme level. A detailed PPIE plan for individual work themes is being developed in conjunction with theme leads and will be made available on the EPR HPRU website. The central programme of activities outlined in this plan focus on:

* **Ensuring representation from seldom heard groups** through contacts within PHE’s COVID-19 inclusion health and health inequalities teams
* **Strategic level PPIE implementation** through the establishment of a PPIE steering group and representation on the advisory board
* **Theme level PPIE implementation** through discussions with the PPIE lead, membership on the PPIE steering group, and participation in the public involvement workshops
* **Enhancing Involvement and Engagement** through the public involvement workshops and a developing programme of engagement events/ methods.
* **Public Involvement Training, Mentoring and Support** through mentoring and support provided by the PPIE lead
* **PPIE Quality Assurance** with a specific emphasis on feedback, monitoring, and transparency

More detail on each of these elements is presented below.

*3.1 Ensuring representation from seldom heard groups*

Representation from underserved groups remains a substantial issue for PPIE. Given the potentially variable effects of Public Health emergencies on different sociodemographic and ethnic groups, it is critically important that steps are taken to maximise involvement from across society.

The EPR HPRU has partnered with colleagues within PHE’s COVID-19 health inequalities and inclusion health teams to identify relevant stakeholder and gatekeeper organisations to ensure broad representation both within the PPIE steering group (referred to in 3.2) and at PPIE workshops, involvement, and engagement events. This relationship has already yielded successful involvement from underserved groups in COVID-19 guidance review activities undertaken during Y1 of the Unit.

The EPR HPRU will also leverage existing relationships with other HPRUs (the PPIE lead for the EPR HPRU is also co-PPIE lead for the Modelling and Health Economics HPRU and sits on the HPRU PPI Lead Network Planning Group) to ensure diversity in public involvement.

When combined with involvement from members of the PHE People’s Panel (a public involvement network run by PHE’s Public Involvement Officer), this will ensure a mixture of: a) representation from across different sociodemographic groups; and, b) individuals with different levels of experience with public involvement, within the activities of the Unit.

*3.2 Strategic-Level PPIE Implementation - PPIE Steering Group*

In order to ensure that PPIE is firmly embedded in the Unit at a strategic level, we are establishing a PPIE steering group that will oversee PPIE activities and report directly to the Management Group. This group will **meet six-monthly** and will be responsible for reviewing the PPIE plans developed by individual themes, as well as taking a high-level overview of current and planned projects in order to make suggestions as to how public involvement could be incorporated into the workplan. This will encourage consistency across work themes and allow best practice to be shared across the Unit. More detail concerning the membership of the PPIE steering group is included in Section 6.

In addition to this PPIE steering group, the EPR HPRU has a member of the public sitting as a permanent member of the Unit advisory group.

*3.3 Theme-Level PPIE Implementation*

In order to ensure that PPIE is embedded throughout the work of the HPRU, each theme (in conjunction with the PPIE lead) is responsible for planning, updating, and reporting on the PPIE conducted within projects. Initial engagements have been held between the PPIE lead and theme leads to discuss: a) PPIE work conducted to date during Y1; b) proposed PPIE work across the existing forward business plan (e.g., primarily covering Y2); and, c) specific needs within themes/projects where PPIE may be less straightforward. Planned PPIE activities across Y2 for each theme will be presented on the EPR HPRU website. These plans, alongside the forward business plan, will be reviewed by the PPIE steering group at **six-monthly intervals**.

* 1. *Enhancing Involvement and Engagement - PPIE Workshops*

Alongside integrating public involvement in both theme and strategic level planning (through the PPIE steering group), we also recognise the importance of providing regular opportunities for researchers to engage and involve members of the public in their research at various stages of the research lifecycle. To facilitate this, **we are planning a programme of full-day PPIE workshops at** **six-monthly intervals** (staggered with steering group meetings in order to ensure PPIE events every three months) throughout the lifetime of the Unit. These workshops will draw together theme researchers, the PPIE steering group, and other lay members drawn from groups detailed in 3.1 (advertised through appropriate stakeholder and gatekeeper organisations).

Theme researchers will be asked to submit research projects for which they would like public involvement support and will present these to the lay representatives in attendance for input and advice. This will provide the opportunity for both initial feedback during the session, but also for more sustained work between individual lay members and theme researchers for specific projects.

These workshops will also provide the opportunity for theme researchers to present research at a more advanced stage in order to gain insight re: potential non-academic routes of dissemination and engagement.

Further engagement activities are detailed in the following sub-sections:

*3.3.1 Publication policy*

The purpose of our Unit is to carry out research and make it public so that others may benefit. To this end, all peer-reviewed journal articles that we publish are Open Access – i.e. they are free to the public at the point of publication. Copies of our publications are made available on our website (<http://epr.hpru.nihr.ac.uk/publications>) for ease of access.

*3.3.2 Website*

The Unit website (<http://epr.hpru.nihr.ac.uk/>) is a central repository for information about research activities, events, publications and opportunities for the public to engage with and participate in our research. The website is regularly updated and includes a live Twitter feed, a section for upcoming events and a news section that highlights new publications/events and provides recordings/podcasts of previous events when available.

*3.3.3 Social media*

Our Twitter account (@EPR\_HPRU) shares news about our research and opportunities to be involved in our research. Other individual researchers also regularly tweet about their work (e.g. our director @WesselyS).

*3.3.4 Media engagement*

We engage with traditional broadcast and print media both proactively and reactively in order to reach wider public audiences. Our proactive media engagement includes the use of press releases to promote new publications and to launch new studies. For example, a recent article produced by the Resilience theme of the EPR HPRU focused on the [mental health of staff working in intensive care during COVID-19](https://pubmed.ncbi.nlm.nih.gov/33434920/) and received widespread media coverage, including: an article on the BBC News website, the Today programme, and commonly read newspapers such as The Sun. This work was also presented to the All Party Parliamentary Group on Coronavirus and was included in the PHE Mental Health and Wellbeing surveillance report.

*3.3.5 Events and other face-to-face engagement*

EPR HPRU staff regularly engage in public-facing talks about our research. A programme of face-to-face engagement will be established when possible given the ongoing constraints of the COVID-19 pandemic.

*3.4 Public Involvement Training, Mentoring and Support*

It is important to ensure that researchers within the EPR HPRU feel sufficiently well trained and supported to be able to incorporate PPIE within their project and theme-level work. To support each Theme Lead in developing PPIE plans and to standardise quality control monitoring across themes, the PPIE Lead (with input from the PPIE steering group) will be able to provide guidance in the form of briefing notes and templates for plans, terms of office, role description templates and feedback forms.

As a baseline, all research staff are invited to complete the [Public Involvement in Research MOOC](https://www.imperial.ac.uk/patient-experience-research-centre/ppi/ppi-training/) delivered by the Patient Experience Research Centre at Imperial College, London, and Module 1 (“Knowledge of the NIHR and Patient and Public Involvement (PPI)”) of the [Public reviewing with the National Institute for Health Research](https://www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/#top) course.

Furthermore, the PPIE lead will signpost researchers to relevant academic literature to support the delivery of ‘gold standard’ PPIE within the Unit (for example, [the GRIPP2 reporting checklists](https://www.bmj.com/content/358/bmj.j3453), and the [Public Involvement Impact Assessment Framework](http://piiaf.org.uk/)).

Lastly, the PPIE steering group will also consult with theme leads to understand training needs, and will work to: facilitate training for researchers in how to involve the public in research, identify external PPIE training opportunities, and ensure all staff across the Unit are aware of these opportunities. The PPIE lead also sits on the HPRU PPI Lead Network Planning Group and is contributing to the training offer as part of this engagement.

*3.5 PPIE Quality Assurance*

The EPR HPRU is committed to ensuring quality in PPIE activities through:

* Provision of training for researchers in how to involve the public in research (see section 3.4)
* Specifying what is expected from public contributors at the start of all PPIE activities
* Providing/monitoring feedback on whether these expectations have been met
* Providing a space for members of the public to contribute with confidence
* Evaluating PPIE activities against pre-specified indicators of success
* Sharing lessons learned/good practice from theme level PPIE activities across the Unit
* Annually updating PPIE plans in the light of researcher and public feedback on PPIE activities
* Making PPIE plans and activities publicly accessible on the HPRU website

This plan will be reviewed annually and evaluated against the criteria shown in the table below. If indicators of success are not met, the PPIE steering group will conduct a review to establish whether activities need to be undertaken differently or whether a different approach is required, and the plan will be updated accordingly.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **PPIE Activity** | **Review Activity** | **Review date** | **Indicator of success** | **Completion** |
| 2021 PPIE Plan development | Review and input by members of the public  Review of PPIE plan by EPR HPRU management group | March 2021 | Successful input into, and iteration of, the plan | Completed |
| Ensuring representation from seldom head groups | Review of recruitment to PPIE activities (in particular the steering group and workshops) | PPIE steering group meetings | Successful involvement of representatives from a range of socio-demographic backgrounds within the work of the HPRU | Ongoing |
| Strategic & theme level PPIE implementation | Review of work of the PPIE steering group  Review of theme level plans for compatibility with overall PPIE strategy | PPIE steering group meetings | The PPIE steering group review indicates that PPIE activities to date (both at strategic and theme level) have either supported or changed research plans | Ongoing |
| PPIE training, mentoring and support | Review of process of developing theme level plans  Review of PPIE training needs  Signposting to, and provision of, support and training for PPIE  Review of theme level PPIE activities \*based on public and researcher feedback forms\*) | PPIE steering group meetings | Theme leads were sufficiently well supported to contribute to the PPIE plans for their research projects by the end of each year of the HPRU  Researcher feedback on training events indicates that they were useful  Public feedback on PPIE activities (including the workshops) indicates that (1) PPIE aims were clearly explained, (2) they were given sufficient opportunity to express their views, (3) they found the involvement interesting, and (4) they would be willing to be involved in future research activities  Researcher feedback on PPIE activities indicates that these were useful and have supported or changes research plans | Ongoing |
| Feedback and monitoring | Annual review of all PPIE plans (Theme Leads)  Review of provision of feedback to public contributors (Theme Leads)  Review of lessons learned | Theme leads annual PPIE review  PPIE steering group meetings | Theme leads complete annual PPIE review and incorporate participant and researcher feedback into updated theme level PPIE plans  There is evidence from theme level reviews that feedback has been provided to public contributors following PPIE activities  The PPIE steering group share learning points from theme level PPIE updates across the Unit | Ongoing |
| Transparency | Review of website content | May 2021 (and yearly thereafter) | Theme level PPIE plan is uploaded by the end of May 2021 | Ongoing |

\*See Appendix A and Appendix B for sample feedback forms for public and researchers.

1. ***Resources***

£30,200 of central management funds have been set aside to support PPIE activities across the lifetime of the project, the breakdown of which is detailed in the below table:

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **2020-2021** | **2021-2022** | **2022-2023** | **2023-2024** | **2024-2025** | **TOTAL** |
| **Funding Amount** | £7,000 | £5,800 | £6,800 | £5,800 | £4,800 | **£30,200** |

This funding includes provision for both HPRU staff (e.g., public involvement training costs, costs associated with organising meetings and workshops with members of the public, etc.) and for members of the public (e.g., travel costs, subsistence costs, and reimbursement for engagement activities, including: workshop attendance, focus group attendance, and document review).

Payment for public involvement will be made in accordance with PHE’s “Policy for Payment for public involvement in PHE’s work: guidance for staff v4.00” which itself was based on INVOLVE guidance. Specifically, payment is based on the duration of involvement required according to the below two tables (reproduced verbatim from the aforementioned document):

|  |  |
| --- | --- |
| **Duration of involvement activity** | **Rate** |
| “For involvement in a task or activity requiring little or no preparation and which equates to approximately one hour of activity or less e.g. taking part in a tele-conference to provide comments” | “£25” |
| “For involvement in a task or activity requiring little or no preparation and which equates to approximately half a day of activity e.g. attending a focus group” | “£50” |
| “For involvement in a task or activity which equates to approximately half a day’s activity where preparation is required e.g. attending a committee or working group meeting inclusive of reading papers” | “£75” |
| “For involvement in all day activities where the rate covers both preparation for and attendance at meetings and any follow up activities after a meeting” | “£150” |

|  |  |
| --- | --- |
| **Length of document** | **Rate** |
| “Short document – less than 50 pages” | “£25” |
| “Medium size document – 50-200 pages” | “£50” |
| “Lage document – over 200 pages” | “£75” |

1. ***Leadership and lines of reporting***

A PPIE steering group has been formed to provide leadership and steer in strategy development and support for PPIE activities across our four priority work themes. Current leadership of the steering group is as follows:

Dr Dale Weston – PPIE Lead (PHE)

Prof James Rubin - Assistant Director of the Unit (KCL)

Prof Richard Amlôt – Assistant Director of the Unit (PHE)

In addition, each theme has nominated a contact individual who will be responsible for keeping the theme PPIE strategies updated throughout the year, with regular contact and interaction with the PPIE lead. These individuals will form the membership of the PPIE steering group.

|  |  |
| --- | --- |
| **Theme** | **Named Individual** |
| Preparedness | Holly Carter |
| Response | Fiona Mowbray |
| Resilience | Dale Weston |
| Novel Technologies | Julii Brainard |

3-5 lay individuals are being recruited to the membership of this steering group in order to ensure representation and co-production at the strategic level.

In addition to this PPIE steering group, the EPR HPRU has a member of the public sitting as a permanent member of the advisory group.

1. ***Partners and Collaborators***

Alongside the PPIE steering group presented within the previous section, there are a series of partners and collaborators with whom aspects of this strategy will be delivered.

As detailed in 3.1, pre-existing relationships between the PPIE lead and: the **PHE People’s Panel**; and **representatives from PHE’s COVID-19 health inequalities and inclusion health teams** will be leveraged to ensure successful delivery of PPIE within the Unit.

Furthermore, the PPIE Lead is also co-PPIE lead for the **Modelling and Health Economics HPRU** and sits as a member of the **HPRU PPI Lead Network Planning Group**. The **HPRU PPI Lead Network** represents an excellent resource for sharing and discussing best practice within PPIE across the Units.

1. ***Monitoring and Reviewing PPIE activities: Emphasis on impact***

All PPIE activities will be annually evaluated against pre-specified indicators of success. Indicators of success for this plan are described in section 3.5 above. Indicators of success for PPIE activities associated with specific research projects will be identified in the theme level PPIE plan.

The PPIE steering group will be responsible for evaluating and updating this plan. Theme leads will be responsible for evaluating and updating their contributions to the theme level plan.

1. ***Management and Governance of PPIE activities***

Progress in delivering the PPIE strategy will be fed directly into the management and governance processes of the Unit through PPIE steering group reports to the Management Group. PPIE is a standing item for all Management Group meetings. A summary of all PPIE activities and reviews will also be incorporated in the annual report to the NIHR.

**APPENDIX A: PARTICIPANT FEEDBACK FOR WORKSHOP ACTIVITIES**



**Example PPIE participant feedback form**

|  |  |  |
| --- | --- | --- |
|  | Yes | No |
| Were the aims of this consultation exercise clearly explained? |  |  |
| Were you given sufficient opportunity to express your views? |  |  |
| Did you find this workshop interesting? |  |  |
| Would you be willing to engage in this type of consultation exercise in the future? |  |  |
| Would you be interested in further involvement with this particular project? |  |  |
| Would you like feedback on the actions we have taken as part of this consultation? |  |  |
| Would you like to hear about the findings of this research? |  |  |

|  |
| --- |
| If you indicated that you would like to receive further information or take part in future activities, please provide your name and contact details |

|  |
| --- |
| Please use this box to let us know if you have any further comments or questions about this workshop |

**APPENDIX B: SAMPLE RESEARCHER FEEDBACK FORM**



**Example PPIE researcher feedback form**

|  |  |  |
| --- | --- | --- |
|  | Yes | No |
| Do you feel that the aims of this consultation exercise were met? |  |  |
| Do you think this consultation exercise was useful? |  |  |
| Has the consultation exercise changed your research plans? |  |  |
| Is there anything you would do differently next time? |  |  |

|  |
| --- |
| Please make a note of any immediate thoughts about why this exercise was useful / what you learned |

|  |
| --- |
| Please make a note of how this exercise may change your research plans / why plans may not change |

|  |
| --- |
| Please make a note of any immediate thoughts about what could be done differently/better next time |

Please summarise the PPIE participant feedback below:

|  |  |  |
| --- | --- | --- |
|  | No of Ps who said Yes | No of Ps who said No |
| Were the aims of this consultation exercise clearly explained? |  |  |
| Were you given sufficient opportunity to express your views? |  |  |
| Did you find this workshop interesting? |  |  |
| Would you be willing to engage in this type of consultation exercise in the future? |  |  |
| Would you be interested in further involvement with this particular project? |  |  |
| Would you like feedback on the actions we have taken as part of this consultation? |  |  |
| Would you like to hear about the findings of this research? |  |  |

Please make a note of any additional comments/suggestions provided by participants that may influence the way that you run PPIE sessions in the future