

Patient & Public Involvement and Engagement (PPIE) strategy for the NIHR HPRU in Vaccines and Immunisation

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A. Background

The NIHR Health Protection Research Unit (HPRU) in Vaccines and Immunisation is a research partnership between Public Health England and the London School of Hygiene & Tropical Medicine (LSHTM), in collaboration with the University of Cambridge. The HPRU provides publicly funded and independent research to support national immunisation programme policy and delivery.

This document outlines the Patient & Public Involvement and Engagement (PPIE) strategy for the HPRU in Vaccines and Immunisation. We use the INVOLVE definitions for public involvement and engagement (2012) (see figure 1). INVOLVE is a programme funded by the NIHR, to support active public involvement in NHS, public health and social care research.

<h3>Involvement</h3> <p>Where members of the public are actively involved in research projects and in research organisations.</p> <p>Examples of public involvement are:</p> <ul style="list-style-type: none">■ as joint grant holders or co-applicants on a research project■ involvement in identifying research priorities■ as members of a project advisory or steering group■ commenting and developing patient information leaflets or other research materials■ undertaking interviews with research participants■ user and/or carer researchers carrying out the research.	<h3>Engagement</h3> <p>Where information and knowledge about research is provided and disseminated.</p> <p>Examples of engagement are:</p> <ul style="list-style-type: none">■ science festivals open to the public with debates and discussions on research■ open day at a research centre where members of the public are invited to find out about research■ raising awareness of research through media such as television programmes, newspapers and social media■ dissemination to research participants, colleagues or members of the public on the findings of a study.
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Figure 1: INVOLVE definitions of involvement and engagement (2012)

The HPRU in Vaccines and Immunisation have developed and refined our PPIE strategy in order to improve citizenship, accountability and transparency, to gain the perspective of members of the public based on their personal knowledge and experience, to improve the quality of our research by making the language and content of information provided more appropriate and accessible, to ensure methods proposed are sensitive to situations of potential research participants, and to help to ensure that research is relevant to the needs and interests of the public (See Appendix 1 for PPIE Strategy timeline).

We define the term 'public' to include a number of different publics, including invested publics (such as scientists, academics, healthcare professionals, managers, commissioners, policy makers and activists), recipient publics (those being vaccinated and their immediate family), and broader publics (such as the social networks of those being vaccinated, media, and organizations with an interest in public health). Not only do we strive to involve members of the public in terms of involvement and engagement, we also aspire to ensure that diverse members of the public are invited to take part in our research and activities. We aim to have a combination of public groups represented at our public

involvement workshops, especially following feedback from our December 2020 public involvement workshop where public and healthcare worker participants felt this was a positive aspect of our workshop.

B. Aims

Our aim for public involvement is to improve the quality and relevance of research in vaccines and immunisation by the HPRU.

We seek to enhance the input of the public and patients in HPRU research by involving them from an early stage in the research process, to identify research priorities and provide feedback on how research is conducted. This also includes providing insight into approaches used for participant recruitment, and commenting on and developing study documents, such as study information sheets and questionnaires. We involve the public through discussions at our public involvement workshops. For studies where public involvement has occurred, we seek to have a statement in each publication of the HPRU on how the public have been involved in the study, to highlight the value of PPI and encourage researchers to include PPI in their research. Our ambition is to embed PPI across all HPRU research, throughout the research process.

Our aim for public engagement is to raise awareness of our research at the HPRU and to share knowledge of research about vaccines.

To achieve this, the HPRU will engage with the public, while representing the HPRU, at public events such as an annual HPRU Open Science Day, science festivals, workshops with members of the public, social cafes, public lectures and by participating in media interviews. We will also maintain and frequently update our website and produce a regular newsletter, as well as produce user friendly and accessible dissemination resources, such as infographics. In our engagement activities we also aim to highlight the value of NHS patient data for research.

At the HPRU we are fully committed to the UK standards of involvement (NIHR 2019):

UK Standards of Involvement	How we aim to achieve these
<p><u>INCLUSIVE OPPORTUNITIES</u></p> <p>Offer public involvement opportunities that are accessible and that reach people and groups according to research needs.</p>	<ul style="list-style-type: none"> • We will advertise our workshops widely through a range of channels including through partnering with patient groups and community groups, such as HealthWatch. • For our workshops we will check which day of the week and what time of day is most convenient for members of the public to attend. • We will consider the physical accessibility of venues (e.g. wheelchair accessibility) and event accessibility (e.g. the availability of a hearing loop, providing large print versions of event documents etc.) • We will collect demographic data at our events so that we can evaluate and improve on reaching diverse members of the public. • At our public involvement workshops we have and will continue to ask participants how we can improve access to members of the public, ensuring diverse members of the public are aware of opportunities to participate.
<p><u>WORKING TOGETHER</u></p> <p>Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.</p>	<ul style="list-style-type: none"> • We seek to enhance the input of the public and patients on studies conducted, their design and their output, by holding public involvement workshops, and asking our public panel to feedback on which studies to conduct, and feedback on study documents, such as study information sheets and questionnaires, and aspire to the co-production of studies with members of the public. • We will evaluate our public involvement workshops through asking participants for their feedback on our workshops and getting their input on how we can improve future workshops. • The co-leads of PPIE are members of the HPRU PPIE network.

	<ul style="list-style-type: none"> • We will maintain ongoing discussions with PPIE leads from other HPRUs about possible collaborations. • At the start of our PPI workshops we will explain that we value all contributions and views and we remind participants to be mindful, considerate and respectful of everyone's views.
<p><u>SUPPORT AND LEARNING</u></p> <p>Offer and promote support and learning opportunities that build confidence and skills for public involvement in research.</p>	<ul style="list-style-type: none"> • PPIE training opportunities, as well as media and communications training opportunities, will be identified and signposted to members of the HPRU and our public panel. • The PPIE Co-coordinators regularly share PPIE resources with the PPIE theme leads. • The PPIE Co-coordinators regularly contact members of our public panel, support them and answer questions as they arise. • The PPIE team are developing HPRU specific guidance as a resource for our public panel. • The PPIE management team plan to submit abstracts and attend INVOLVE and STEM conferences. • All HPRU PhD students have been costed to undertake INVOLVE training and will be encouraged, expected and supported to undertake PPIE as part of their PhD training.
<p><u>GOVERNANCE</u></p> <p>Involve the public in research management, regulation, leadership and decision making.</p>	<ul style="list-style-type: none"> • At our first public involvement workshop in December 2020 we asked participants how they would like to be involved and we will adapt public panel involvement with them based on their and the project's needs. • We plan to ask our public panel to select two members every year to represent and give feedback from the public panels at the annual advisory board meeting. • Our public panel will be involved in governance of the PPIE strategies. • We will seek feedback on the management structure of the PPIE strategy at our public panel workshops, our management meetings and the advisory board meetings.
<p><u>COMMUNICATIONS</u></p>	<ul style="list-style-type: none"> • The HPRU has created an animated video to explain what the HPRU in Vaccines in Immunisation is, and, once finalised, will upload to our website.

<p>Use plain language for well-timed and relevant communications, as part of involvement plans and activities.</p>	<ul style="list-style-type: none"> • We seek feedback on lay summaries from our public panel. • We will maintain and regularly update our website and produce a regular newsletter, as well as produce user friendly and accessible dissemination resources, such as infographics.
<p><u>IMPACT</u></p> <p>Seek improvement by identifying and sharing the difference that public involvement makes to research</p>	<ul style="list-style-type: none"> • This PPIE strategy has been reviewed and approved by members of the HPRU and members of our public panel. Throughout the grant, the strategy will be reviewed and refined annually. • Progress in delivering the PPIE strategy is discussed at our bi-monthly management meetings and the annual advisory board meetings. • A few select projects will be evaluated to explore measures of success of PPIE and to measure intended and unintended outcomes. • We seek to enhance the input of the public and patients on studies conducted, their design and their output, by holding public involvement workshops, and asking our public panel to feedback on which studies to conduct, and feedback on study documents, such as study information sheets and questionnaires, and aspire to the co-production of studies with members of the public. • We seek feedback from members of the public and researchers from our workshops in a number of formats (verbally during the workshop, via email, and via an adaptable evaluation form for participants (see Appendix 2 for example)) and an adaptable evaluation form for researchers (see Appendix 3 for example). • We seek to have a statement in each publication of the HPRU where public involvement occurred, to increase awareness and encourage other researchers to include public involvement in their research. • We have the following documents which aid in monitoring and evaluating the HPRU's PPIE activities: <ul style="list-style-type: none"> ○ A log of PPIEP activities (available on a shared drive for HPRU members to access and update) (See Appendix 4 for template). ○ An adaptable evaluation form for PPI workshops for members of the public (See Appendix 2 for example).

- An adaptable evaluation form for PPI workshops for researchers (See Appendix 3 for example)
- A summary of all PPIE activities are also described in each annual report to the NIHR.
- The successful implementation of this PPIE plan will be measured by the following targets being met:
 - Public events attended by at least 100 members of the public in total / year
 - Research studies which include the public in the design phase per year (At least 3 / year)
 - Research studies which interview or survey members of the public (At least 3 / year)
 - Public involvement workshops (3 / year)
 - Immunisation HPRU newsletters (3 / year)
 - Open Science event (1 / year)
 - Studies involving co-development with the public (At least 2 / year)
 - Involvement in at least 10 media interviews / year
 - Development of HPRU specific guidance as a resource for our public panel
 - At least one element of PPIE in each of our 6 PhD student's research

C. Management

The PPIE management team within the HPRU in Vaccines and Immunisation includes Anthony Scott (HPRU Director), Mary Ramsay (HPRU PHE Lead), Lee White (Project Manager and Communications Manager), Pauline Paterson and Sadie Bell (PPIE Co-coordinators), and Helen McDonald & Jemma Walker, Nick Davies, and Tracey Chantler (PPIE theme leads). Sadie Bell is a core member and Pauline Paterson is a member of the HPRU PPI lead network. The PPIE management team link closely with the Communications Manager (Lee White) and the Knowledge Mobilisation Lead (Gayatri Amirthalingam).

The PPIE Co-coordinators are responsible for supporting and promoting PPIE within the HPRU in Vaccines and Immunisation. The PPIE theme leads are responsible for planning, monitoring and evaluating PPIE activities within their theme, in alignment with the overarching aims of the HPRU.

We will hold public involvement workshops regularly throughout the grant and invite our public panel to attend. At our first public involvement workshop in December 2020 we asked participants how they would like to be involved and we will adapt public panel involvement with them based on their and the project's needs. We plan to ask our public panel to select two members every year to represent and give feedback from the public panels at the annual advisory board meeting. Our public panel will be involved in governance of the PPIE strategies. We will seek feedback on the management structure of the PPIE strategy at our public panel workshops, our management meetings and the advisory board meetings.

D. Training

PPIE training opportunities, as well as media and communications training opportunities, will be identified and signposted to members of the HPRU and our public panel. The PPIE Co-coordinators regularly share PPIE resources with the PPIE theme leads. The HPRU has created an animated explainer video to explain what the HPRU in Vaccines in Immunisation is, and, once finalised, will upload to our website. The PPIE team are developing HPRU specific guidance as a resource for our public panel. The PPIE management team plan to submit abstracts and attend INVOLVE and STEM conferences. All HPRU PhD students have been costed to undertake INVOLVE training and will be encouraged, expected and supported to undertake PPIE as part of their PhD training.

E. Evaluation

This PPIE strategy has been reviewed and approved by members of the HPRU and members of our public panel. Throughout the grant, the strategy will be reviewed and refined annually. Progress in delivering the PPIE strategies is discussed at our management meetings and the advisory board meetings. A few select projects will be evaluated to explore measures of success of PPIE and to measure intended and unintended outcomes.

We have the following documents which aid in monitoring and evaluating the HPRU's PPIE activities:

- A log of PPIEP activities (available on a shared drive for HPRU members to access and update) (See Appendix 4 for template).
- An adaptable evaluation form for PPI workshops for members of the public (See Appendix 2 for example).
- An adaptable evaluation form for PPI workshops for researchers (See Appendix 3 for example)
- A summary of all PPIE activities are also described in each annual report to the NIHR.

The successful implementation of this PPIE plan will be measured by the following targets being met (see Appendix 5 for upcoming planned PPIE activities):

- Public events attended by at least 100 members of the public in total / year
- Research studies which include the public in the design phase per year (At least 3 / year)
- Research studies which interview or survey members of the public (At least 3 / year)
- Public involvement workshops (3 / year)
- Immunisation HPRU newsletters (3 / year)
- Open Science event (1 / year)
- Studies involving co-development with the public (At least 2 / year)
- Involvement in at least 10 media interviews / year
- Development of HPRU specific guidance as a resource for our public panel
- At least one element of PPIEP in each of our PhD student's research

F. Dissemination

The PPIE strategy for the HPRU in Vaccines and Immunisation is available on our HPRU website. Theme specific research studies will be published in peer-reviewed research journals and these will be published as open access (free and available to all online), when possible.

We will also work with our HPRU Knowledge Mobilisation lead when considering knowledge mobilisation with the public.

G. Key references

INVOLVE (2012) Briefing notes for researchers: public involvement in NHS, public health and social care research. INVOLVE, Eastleigh.

NIHR (2019) UK Standards for Public Involvement. <https://sites.google.com/nihr.ac.uk/pi-standards/standards>

NIHR (2015) Going the extra mile: Improving the nation's health and wellbeing through public involvement in research

NIHR (2015) Patient and Public Involvement and Engagement: NIHR Health Protection Research Units Annual Reports 2014/15 <http://www.nihr.ac.uk/get-involved/ccf-ppie-reports.htm>

NIHR. Patient and public involvement in health and social care research: A handbook for researchers.

Staniszewska S, Denegri S, Matthews R, et al. Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. *BMJ Open* 2018;8:e017124. doi:10.1136/bmjopen-2017-017124

Appendix 1. PPIE strategy timeline

March 2014	HPRU in Immunisation launched.
April 2014	PPIE Coordinator assigned.
October 2014	PPIE plan drafted. Feedback invited by NIHR HPRU in Vaccines and Immunisation members.
February 2015	PHE organised an event for their people's panel about the different HPRU's including information on how to get involved as a lay board member of our HPRU. Two lay board members were recruited.
September 2015	PPIE plan updated following feedback on annual report 2014/15 by NIHR.
November 2015	PPIE theme leads assigned.
May 2016	PPIEP strategy development workshop. The objectives of the PPIEP strategy development workshop in 2016 were to identify and record past and current PPIEP activities in the HPRU, to refine our PPIEP strategy, and to initiate the creation of new PPIEP action points for the HPRU as a whole, and for specific projects within each theme.
May 2016	The PPIEP strategy was discussed and refined further at an HPRU management meeting.
June-August 2016	The PPIEP strategy was further refined by the PPIEP management team and lay board members.
September 2016	The PPIEP strategy was further refined following feedback from members of the HPRU and its board members.
September 2016	The PPIEP theme specific strategic objectives were refined by each theme.
January 2017	The PPIEP strategy was made available on the HPRU in Vaccines and Immunisation website.
April 2020	The second grant of the HPRU in Vaccines and Immunisation started. Two PPIE co-coordinators were assigned.
Nov 2020 – Feb 2021	The PPIE strategy was further refined by the HPRU.
March 2021	Updated draft of PPIE strategy reviewed at workshop with members of the public. Updated version of PPIE strategy finalised.

Appendix 2. Evaluation form for members of the public for December 2020 PPI workshop



HPRU Shaping research in immunisation workshop – 7th December 2020

Thank you for attending this workshop organised by the NIHR Health Protection Research Unit (HPRU) in Immunisation. We hope you enjoyed it 😊

Please take a few moments to provide us with some feedback about this event. Your views are important to us and will help us to improve future events.

Thank you in advance,

Sadie Bell, Pauline Paterson, Lee White, Helen McDonald, Sandra Mounier-Jack & Tracey Chantler
From the HPRU in Immunisation

1. What did you enjoy and/or find useful about the workshop?

2. What could have been improved?

3. We are very keen to continue to involve members of the public to improve the quality and relevance of research in immunisation by the HPRU. What activities and events do you think it would good for us to organise in the future? E.g similar virtual workshops to today, face-to-face workshops, document feedback

4. Is there anything we could do to help you with your involvement with our research? For example, more information about our research (such as how electronic health records are anonymised, how we explore reasons for low vaccination coverage), more information about the UK vaccination programme, training in research ethics.



5a. Have you had previous experience with public and patient involvement?

Yes No

If yes:

5b. What experience have you had?

5c. In your previous experience, what worked well that we could apply with our future activities?

Thank you so much for your feedback.

Appendix 3. Evaluation form template for PPI workshops for researchers



|
Researcher Evaluation form for PPI Workshop
Shaping current and future COVID-19 related research in immunisation
7th December 2020

Researcher name:

1. What activity were you involved in at today's workshop?

2. How do you feel that your activity and the PPI workshop went?

3. What could have been improved?

4. What did you learn during today's workshop? (e.g. how to communicate findings to parents and engaging with them, and doing this virtually, how best to recruit members of the public into our study)

5. What PPI activities and events do you think it would good for us to organise in the future? (in terms of format, as well as any specific studies or areas e.g. design, dissemination)

6. Will anything in your research study change as a result of this workshop?
 Yes No
If yes, what will change?

Thank you for your evaluation.



Appendix 4. Template log of PPIEP activities

Date of activity	Activity	Activity name (if applicable)	Involvement? (actively involved in research studies and HPRU e.g. identify research priorities, feedback on participant recruitment, study documents)	Engagement? (provide and disseminate info about HPRU research and/or vaccine research e.g. annual science day, science festivals, media interviews)	Participation? (Explore public perceptions and views of vaccines and imms programme e.g. surveys, interviews, focus groups)	Activity lead(s) from HPRU	HPRU members involved	Collaborators involved (Add affiliation and HPRU if applicable)	How public recruited	Number of participants

Appendix 5. Upcoming planned PPIE activities

April 2021	Upload updated PPIE strategy to our website PPIE Theme Lead meeting HPRU in Immunisation newsletter
May 2021	Annual Science Day HPRU PPIE Network meeting
June 2021	Public Panel Workshop
August 2021	HPRU PPIE Network meeting HPRU in Immunisation newsletter
September 2021	PPIE Theme Lead meeting
October 2021	Public Panel Workshop