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*National Institute for  
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SCHOOL of  
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MEDICINE



## NIHR HPRU in Immunisation

### Public and Patient Involvement, Engagement and Participation Strategy

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### A. Background

This document outlines the Public & Patient Involvement, Engagement and Participation (PPIE) strategy for the HPRU in Immunisation.

In April 2014 the HPRU in Immunisation assigned a PPIE co-ordinator and in October 2014 the HPRU in Immunisation developed a PPIE plan. The feedback given by NIHR on the annual report 2014/15 (NIHR 2015) stated *“Public engagement approaches are in place as well as plans to increase research awareness. In future, however, we recommend that all activities are clearly aligned, monitored and reported in relation to the delivery of a PPIE strategy. There is no evidence of a strategy in place for PPIE and this should be prioritised for the coming months”*. In response to this feedback, the HPRU in Immunisation updated their PPIE plan (September 2015), assigned PPIE theme leads (November 2015) and organised a PPIE strategy development workshop (May 2016).

The objectives of the PPIE strategy development workshop were to identify and record past and current PPIE activities in the HPRU, to refine our PPIE strategy, and to initiate the creation of new PPIE action points for the HPRU as a whole, and for specific projects within each theme. Speakers included the HPRU directors, the PPIE coordinator and PPIE theme leads, the NIHR Senior Programme Manager in PPI and the PPIE chair of the HPRU in Emergency Preparedness and Response. The workshop was well attended and participants included members of the HPRU in Immunisation including our two lay advisory board members, and a member of the HPRU in Environmental Change and Health. Workshop

participants discussed past and current public engagement and participation activities, and debated on how best to refine the public engagement and public involvement strategic goals, and planned possible future activities. The PPIE strategy was refined further and discussed at the next HPRU management meeting (May 2016).

This document briefly explains the definitions of public and patient engagement, involvement and participation, in regards to the HPRU in Immunisation. It then goes on to describe the specific strategies of the HPRU in public and patient engagement, involvement and participation, the theme specific strategic objectives, the evaluation process, management process, dissemination plan and a timeline for the development of our PPIE strategy.

In designing and executing our patient and public involvement strategy we are following the guidelines laid out by INVOLVE (2012):

### **Public and Patient *Engagement***

“Where information and knowledge about research is provided and disseminated” (INVOLVE 2012).

*E.g. “Science festivals open to the public with debates and discussions on 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” (INVOLVE 2012)*

### **Public and Patient *Involvement***

“Where members of the public are actively involved in research projects and in research organisations” (INVOLVE 2012).

*E.g. “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” (INVOLVE 2012)*

### **Public and Patient *Participation***

“Where people take part in a research study” (INVOLVE 2012).

*E.g. “People being recruited to a clinical trial or other research study to take part in the research, ... completing a questionnaire or participating in a focus group as part of a research study” (INVOLVE 2012)*

## B. HPRU in Immunisation PPIE strategies

The HPRU in Immunisation has developed and refined their 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 their 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.

We define the term 'public' to include a number of different publics of public health, 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).

We have created an overarching narrative about the HPRU to be used in our communications with the public:

The HPRU in Immunisation provides publically funded and independent research on the English vaccination programme and supports national policy making

### Public and Patient *Engagement* Strategy

Our overarching Public and Patient Engagement Strategy for the HPRU in Immunisation is to raise awareness of our research at the HPRU and to share knowledge of research about vaccines.

The message we aspire to communicate, in addition to communicating about our research and our research findings, is the added value of the HPRU in Immunisation on the credibility and sustainability of the vaccination programme as a result of performing neutral and independent research on the impact, safety, optimal use and acceptability of vaccines.

We aim to engage the public, while representing the HPRU in Immunisation, at public events such as science festivals, public engagement events, and public lectures.

### Public and Patient *Involvement* Strategy

Our overarching Public and Patient Involvement Strategy for the HPRU in Immunisation is to improve the quality and relevance of research in immunisation by the HPRU.

We seek to enhance the input of the public and patients on studies conducted, their design and their output, by recruiting lay members into our advisory board, by getting public feedback on which studies to conduct, and feedback on study documents such as study information sheets and questionnaires. We also seek to have an engagement statement in each publication of the HPRU to encourage researchers to include this step in their design phase.

## Public and Patient *Participation* Strategy

Our overarching Public and Patient Involvement Strategy for the HPRU in Immunisation is to explore public perceptions and views of vaccines and immunisation programmes to help inform immunisation programmes in England.

We seek to explore public perceptions and views of vaccines and immunisation programmes by carrying out qualitative studies, interviewing relevant publics, such as parents and healthcare professionals, to identify factors influencing vaccination uptake and decision making.

### C. Theme specific strategic objectives

Each theme has created specific strategic objectives, that suite the structure and content of the individual theme, but also reflect the overarching strategies of the HPRU.

#### Strategic objectives for theme 1 – Electronic Health Record Research

**Engagement:** To expand our engagement activities with members of the public and patient groups to showcase the benefits of using anonymised health records for furthering understanding of the effectiveness & safety of vaccines, and to discuss public concerns about use of these data, via:

- public meetings and events
- online resources (e.g. 100 Ways of Using Data to Make Lives Better)
- social media (e.g. the #datasaveslives campaign)
- public outreach activities that encourages and supports the next generation of eHealth investigators (e.g. via school engagement programmes)

**Involvement:** To involve patients and members of the public (e.g. via the Patient Working Group of the Farr Institute, charities, the HPRU lay members) and other stakeholders such as GPs (via GP research networks) to:

- comment & advise on research questions / outcomes of importance for vaccine-related research using electronic health records (EHR)
- discuss and refine evolving findings and advise on dissemination

**Participation:** Objectives currently under discussion

Challenge: Theme 1's research comprises use of pre-collected, anonymised health data – individuals are not actively recruited into our studies.

## Strategic objectives for theme 2 - Modelling, Economics, Evidence-synthesis

**Engagement:** To communicate to the public that by applying the quantitative methods of modelling, cost-effectiveness and systematic reviews better immunisation decisions are made.

To help the public understand the implications of research in modelling, cost-effectiveness analysis and systematic reviews of vaccination in terms of policy making and daily life.

- public meetings and events
- online resources
- social media
- public outreach activities that encourages and supports the next generation of modellers and health economists.

**Involvement:** To conduct research using surveys and/or other methodologies in order to understand the values, behaviour and priorities of the public to inform modelling studies of vaccination.

**Participation:** To develop new research and participation activities which allow the public to discuss ways in which our values, behaviour and priorities can be reflected in the way decisions about immunisation are made.

For example: running a Discrete Choice Experiment among the general public which investigates the value of direct & indirect benefits in relation to side-effects.

## Strategic objectives for theme 3 – Vaccine Delivery and Confidence

**Engagement:** To use a variety of forums to raise awareness about our research, communicate findings and obtain feedback from members of the public.

e.g. Pint of Science, Science Festival, Immunisation Symposium, Vaccine Confidence Project Blog, Wellcome Trust Lunches

**Involvement:** To proactively involve members of the public (including stakeholders like health professionals) in the design and implementation of our research.

e.g. For new study aimed at exploring migrant's attitudes towards vaccination and their access to services, meet with key stakeholders (HCW and migrant groups) to discuss and influence research plans

**Participation:** To explore public perceptions and views of vaccines and immunisation programmes to help inform immunisation programmes in England.

e.g. People take part in a research study, via in-depth interviews, questionnaires, focus groups

## D. Evaluation

This PPIE strategy has been reviewed and approved by the PPIE management team and will be reviewed by all members of the HPRU.

Progress in delivering the PPIE strategies is discussed at our management meetings and the advisory board meetings. A summary of all PPIE activities, including staff training, 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 75 members of the public in total per year
- At least two research studies which include the public in the design phase per year
- At least two research studies which interview or survey members of the public per year

A few select projects will be evaluated to explore measures of success of PPIE and to measure intended and unintended outcomes.

## E. Management

The PPIE management team within the HPRU in Immunisation includes Anthony Scott (HPRU Director), Mary Ramsay (HPRU PHE Lead), Joe Haynes and Thembi Mhlanga (Project Managers), Pauline Paterson (PPIE co-ordinator), and Jemma Walker, Albert Jan van Hoek and Tracey Chantler (PPIE theme leads).

The PPIE coordinator is responsible for the overall PPIE within the HPRU in Immunisation. The PPIE theme leads are responsible for planning, monitoring and evaluating PPIE activities within their theme, in alignment with the overarching strategies of the HPRU.

## F. Dissemination

The PPIE strategy for the HPRU in Immunisation will be made 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.

## G. Timeline

April 2014	PPIE Coordinator assigned.
October 2014	PPIE plan drafted. Feedback invited by NIHR HPRU in 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. 2 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	PPIE strategy development workshop.
June-August 2016	PPIE strategy refined by PPIE management team and lay board members.
September 2016	PPIE strategy refined following feedback by members of HPRU and board members.
September 2016	PPIE theme specific strategic objectives refined in each theme.
January 2017	PPIE strategy made available on the HPRU in Immunisation website.

## H. References

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

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> Accessed April 2015.