



**National Institute for
Health Research**

**Patient and Public Involvement and Engagement:
NIHR Health Protection Research Units Annual Reports 2016/17**

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Background

All recipients of National Institute for Health Research (NIHR) Health Protection Research Units (HPRU) funding provide the NIHR with an annual report detailing the activity and progress made in the previous financial year. Annual reports provide valuable information that allows the NIHR to review performance, enable decision making on future funding requirements, answer Parliamentary Questions, prepare briefings for Ministers, respond to other requests for information, and share information amongst the [NIHR Coordinating Centres](#).

There is a patient and public involvement and engagement (PPI/E) section in the annual report that requests the following information, in no more than one page:

Please summarise your progress to date in implementing the NIHR HPRU's strategies for both patient and public involvement and public engagement, reporting on the following areas:

- Progress made in the delivery of your aims and objectives as detailed in your involvement and engagement strategies. What activities and outcomes are you delivering? What partnerships and collaborations are you involved in? What resources are you deploying? How is monitoring and reviewing of progress linked into the reporting and governance structures of the HPRU?
- Any significant changes or revisions to your involvement and engagement strategies.
- Examples of the impact that your involvement and engagement activities are having. This could be in individual research projects and / or across research areas and / or in the governance and management structures of the HPRU itself. Please highlight any significant successes or challenges.

Please report on your involvement and engagement strategies separately. Please also describe how you make patients and the public aware of the research being undertaken within your Unit, and signpost them towards appropriate information about participating in research.

Each year, the NIHR makes the PPI/E sections of annual reports publicly available. All the reports in this series, both current and previous, can be downloaded from the NIHR website: www.nihr.ac.uk/ccf-ppie-reports.

Health Protection Research Units (HPRUs)

Healthcare Protection Research Units (HPRUs) are research partnerships between universities and Public Health England (PHE) and act as centres of excellence in multidisciplinary health protection research in England. PHE was established in April 2013 and incorporates the responsibilities of the Health Protection Agency. The role of the 13 HPRUs is to support PHE in delivering its objectives and functions for the protection of the public's health. For more information about HPRUs: [click here](#).

Purpose of this report

This report briefly summarises the PPI/E activities undertaken by HPRUs during 2016/17 in delivery of their PPI/E strategies. Following the submission of annual reports, all the PPI/E sections were compiled in a draft document that was shared with the HPRUs. This provided an opportunity to review and edit content; to add any necessary information about context, to explain abbreviations and acronyms and provide contact and website details.

The main aim of making this information publicly available is to support and promote the sharing of knowledge, learning and good practice across the NIHR and beyond. In addition, this report, along with others in the same series, begins to address Recommendation 9 of the [Going the Extra Mile](#) Report which followed a strategic review of public involvement in the NIHR:

Recommendation 9 – Coordination: All NIHR Coordinating Centres and infrastructure organisations should have a strategy, framework or plan that covers the promotion and advancement of public involvement, participation and engagement in research. Leadership, accountability and funding for this agenda within organisations must be clear and transparent. Progress should be reported annually, made publicly available and an overview included in the NIHR’s annual report.

[‘Going the extra mile’](#): Improving the nation’s health and wellbeing through public involvement in research’ (2015)

We believe this working document will be of interest and practical use to a number of different audiences including: all those who have responsibility for developing and delivering PPI/E strategies across the NIHR, the public, patients, service users and carers, researchers, research funders, all NHS organisations, Public Health England, industry and third sector organisations.

Further information and feedback

If you would like to know more about any of the specific PPI/E activities of the HPRUs please contact them directly.

The [NIHR Central Commissioning Facility](#) has produced this report and we welcome feedback from anyone who reads it. For example, it would be helpful to us to know who reads this report, whether readers find it informative and useful, or not and what we can do to improve it. To give your feedback, please email ccfpfi@nihr.ac.uk using the subject header ‘HPRU PPI feedback.’

**Blood Borne and Sexually Transmitted Infections HPRU
Annual Report 2016/17:
Patient and Public Involvement and Engagement (PPIE)**

Website	http://bbsti.hpru.nihr.ac.uk/
PPIE web pages	
PPIE Strategy	
Contact Name	
Contact Email	
Contact Phone	

As requested we report below on our **involvement and engagement strategies separately**. However, our approach is integrated and presented here as background.

This HPRU consists of three Themes, delivered over the five year period by a largely stable community of postdoctoral researchers supported by senior staff and enhanced by a range of doctoral projects in a range of dispersed locations. For this reason, as described in previous reports, we have taken a **capacity building approach** with a view to embedding PPI/E in our culture and working practices as a cross-cutting Theme from the bottom upwards. We previously reported that we had commissioned externally a report on our PPI/E readiness and plans; our establishment of a group of early career researcher **PPI/E champions** charged with developing competence in their locations and Themes; assistance to other researchers in early PPI plans; and allocation of resources for PPI/E. This group held regular meetings supported by Professor Jackie Cassell and Ms Natalie Edelman (former NIHR RDS adviser, and now NIHR doctoral fellow) as PPI/E lead and PPI/E expert adviser respectively. Here we report progress in year 3 and plans for the final phase of the HPRU.

Every Theme and Steering Group agenda includes PPI/E, and providing visibility to this priority at every level across the HPRU. The Early Career Researcher led PPI/E group assesses funding applications using the following framework: (i) clarity on the “end-users” of the study who need to be involved and/or engaged; (ii) clarity, feasibility and appropriateness of PPI/E; (iii) linkage to a PPI/E champion within the HPRU; (iv) plans for accessing the end-users of the study, whether organisations or individuals; (v) plans for consulting and/or collaborating with the end-users of the study (modes of communication, e.g, online, presentations to groups, individual consultation, recruitment to study team), and (vi) the expected impact of the PPI/E work and *how this will be evaluated*. Funding is released on the recommendation of the group who may suggest revision.

INVOLVEMENT STRATEGY AND ACTIVITIES

To date we have particularly focussed on embedding **early public involvement** as the most important element of capacity building for PPI/E and in our prioritisation of training and funding. In a highly sensitive area this underpins the approaches we take to **public engagement** to minimise the risk of poorly communicated and stigmatising messages at a later stage. A good example of this is a doctoral project by Josina Calliste relating to sexual health outcomes in young BC women (Theme A). This is a group labelled as “hard to reach” for reasons related to STI stigma and negative sexual stereotypes of Black people. Due to the sensitivity of sexual health research with both young people and Black communities it is essential that the research does not reproduce and reinforce existing stigmas and stereotypes. Therefore it was important to have consultation/involvement/community

engagement at the outset of this study; that the researchers build a supportive framework for engagement, which supports later dissemination whatever the findings of the research, as well improve accountability to the researched communities. In the first year of her doctorate, Josina developed a strategic plan for PPI building a network of public advisers in South London through community contacts, to advise on a number of areas in the research, ranging from the design of recruitment materials, interview and focus group topic guides and research questions. The PPI group will support analysis by reviewing early interpretations and developing concepts and theories, and support the approach to and implementation of engagement dissemination activities.

Patient and public involvement in STI and hepatitis. We also know from early experience recruitment to PPI for STI and hepatitis is challenging, because these are stigmatised diseases, often single episode and the groups at greatest risk are often marginal voices in society. While HIV advocacy is very well developed for some key population groups, as a chronic condition it presents very different challenges for PPI. Natalie Edelman, expert PPI/E adviser and NIHR doctoral student, has undertaken work with women seeking sexual health services in GP practices and community settings in Brighton and Hove. Natalie Edelman is developing a clinical prediction rule (CPR) using psychosocial items. The PPI aspects of this work have included: early stage consultation with women attending Brighton Women's Centre on CPR delivery; co-production of lay summaries of the systematic review and Natsal-3 analysis; opportunistic PPI on survey design with women attending a Brighton GP surgery; further PPI consultation on survey design with young women attending Newhaven Youth Forum. Currently she is working with under-graduate student volunteers in Brighton University's Sexual Health service to develop a leaflet presenting survey results, which will be distributed to participating GPs. She has been awarded a place in the British Science Festival in September 2017, at which women will be able to try out the CPR in paper-and-pen and tablet formats. Natalie has reported on her experience in specific **challenges in recruitment to STI related PPI** as training for the PPI/E champions and also presented this work at the NIHR trainees conference (awarded a prize). Together with an NIHR RDS colleague, she has recently published a manuscript on the evaluation of PPI which informs the work of our PPI/E champions(1)

In Theme B, Rosenberg and colleagues and colleagues have conducted interviews with patients to explore their views on monitoring disease progression and delivery of care to patients with chronic hepatitis B. As a consequence we have developed a new service that will enable patients to attend the hospital (UCLH) for blood tests and to collect prescriptions without having to await consultations with medical staff. Management plans and information will be disseminated through telephone consultations at the patients' convenience.

Antenatal care for pregnant women with HBV infection has also been redesigned with input from patient representatives to ensure that women are seen by both a hepatitis specialist and a midwife in single visits during their antenatal care. This service has been re-designed with the goals of improving antenatal and post-natal hepatitis care for mother and baby, to improve vaccination delivery and to disseminate knowledge and testing for BBV within families.

Dr Lorraine McDonagh has undertaken interviews with young people which have explored potential content of digitally enhanced interventions to improve testing for chlamydia and other STIs/HIV. These will be used together with the results of a systematic review of barriers and facilitators to chlamydia testing in primary care settings, to inform the selection and specification of interventions to appropriately increase chlamydia testing. (Theme B).

Our Early Career Researcher PPI/E group has worked to draft a manuscript presenting the public involvement challenges experienced in this field for the reasons described above. An abstract has been submitted for the 2017 NIHR INVOLVE conference, with a view to gaining feedback. We then plan to develop a workshop for the 2018 INVOLVE conference, which will seek to develop consensus on good practice in this field.

ENGAGEMENT STRATEGY AND ACTIVITIES

At a **HPRU PPI/E Challenge Workshop** we are running in the summer of 2017, we will be articulating a fuller public engagement strategy for the final phase of the HPRU, changing gear from our initial emphasis on capacity development in involvement. This is now our priority as the pace of outputs and intervention development increases, to secure and develop their impact on public health and ensure appropriate and effective communication. At the workshop we will explore the impact of stigma and marginalised communities on the choice of approaches to **public engagement**, with advice from experts in PPI and in media communications.

With a view to building capacity for patient and public engagement, Professor Caroline Sabin's Methodological and Statistical Issues in Clinical HIV Research, five-day course, Royal Free, July 2016) provided two complimentary places for the HIV community – this helps to build capacity within the community so that people then feel able to participate as PPI members on study research teams/steering committees etc. As a result of this, Professor Caroline Sabin has employed one community member (in a paid role) to prepare a community report for the final dissemination meeting of a large EU-funded collaborative study.

Public participation:

Please also describe how you make patients and the public aware of the research being undertaken within your Unit, and signpost them towards appropriate information about participating in research.

Lay summaries of all projects are published on our website. A variety of different approaches are taken to signposting participants to our research depending on what is appropriate and acceptable in the various settings. This ranges from personal invitation, leaflets and posters in clinic settings to recruitment through community groups and services (e.g. to reach participants of particular age, ethnicity or sexual orientation).

Chemical and Radiation Threats and Hazards HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.ncl.ac.uk/hpru/
PPIE web pages	http://www.ncl.ac.uk/hpru/engagement/
PPIE Strategy	http://www.ncl.ac.uk/media/wwwnclacuk/hpru/files/patient-and-public-involvement-strategy.pdf
Contact Name	Dr Pamela Denham
Contact Email	pamela.denham@hotmail.co.uk
Contact Phone	0191 208 7195

A Steering Committee was set up in 2014/15 to oversee and guide PPIE activity across the 4 Newcastle Themes and the 2 KCL Themes Newcastle are working on. It is chaired by a lay person with experience of PPI and includes the project director and coordinator, PHE, researchers and a lay representative from each theme. Training on PPI had been offered to researchers, lay members recruited for each theme and a pre-meeting held to discuss PPI strategy. This report covers the Newcastle Themes.

Theme 1 - Health effects of medical radiation exposure

Theme 2 - The skin and barrier function in radiation and chemical exposures

Theme 3 - Chemical exposures and the development of primary biliary cirrhosis

Theme 4 - Chemical exposure and neurological and psychiatric disorders.

Lay representatives are involved in each theme and contribute to the development of the work by attending team meetings, commenting on proposals, offering contacts, suggesting how to reach out to a wider public, commenting on guidelines.

In our 2016 report we said that in 2016/17 we planned to investigate ways for Themes to reach out to a wide audience through social media; tapping into schools' events; and producing training guidance on presentations. At each meeting the Committee would take a deep dive into PPIE activities in one of the themes, including contributions from the lay representatives.

We have also been working with the Newcastle University Faculty Engagement Team about developing an interactive web site and, with their help, provided information to themes about training opportunities.

In 2016/17 the Committee met 3 times. We have taken deep dives into 3 of the themes and will cover the theme 3 at our next meeting in July 2017. In the discussion of theme 2, the committee explored their experience of using social media and took advice from Newcastle University press office on the use of various forms of media and on how to get the most out on-line live sessions.

The committee noted contrasts in that theme 2 and theme 4 are concerned with investigating and publicising dangers whereas theme 1 is aiming to explain the balance of risks in using radiation in treatment and is concerned to avoid raising alarm unnecessarily.

It also recognised the lack of trust in experts and a tendency for people to search on line for information that fit personal views.

Under Theme 1, a large amount of work has been devoted to improving PPI, including a 'deep dive' into the Theme at the PPI Steering committee meeting in November 2016, completion of external training for a nominated PHE staff member on use of PPI in research; a much more detailed PPI plan including trialling the use of artistic media in collaboration with the Institute for Creative Arts at the next engagement event; and initial discussions and planning have taken place for a cross-HPRU joint public and patient workshop on biomarkers in public health research.

In theme 4, development of the research project was informed by talking to patients presenting to hospital with toxicity from drugs of misuse. PPI representatives are embedded in the theme and are invited to attend all research meetings where they are contributing to interpretation of data, providing input on dissemination and helping to plan further research. A pesticide questionnaire included a section to collect information on public concerns about chemicals. Thematic analysis of responses determined that the most prevalent concern was

'chemical exposure we cannot control', with inhaled and industrial/agricultural chemicals prominent.

Future plans

We are aiming to improve our on-line presence by taking advantage of the development of the Voice North (VN) website managed by the University's Faculty Engagement team. Originally established to involve older members of the public to get involved in research projects, the website is being expanded to reach a wider and more diverse audience and a launch is planned for the summer. VN need new material and HPRU need a higher profile and to reach out to a wider audience. The new platform will offer a range of options including establishing a special interest group to comment on and be involved with HPRU activities, publicising results (e.g. links to publications with lay summaries), posing questions for debate e.g. those raised in discussion in the steering committee's deep dives. Blogs and polls can be used to encourage people to look at the group and results. We recognise the new platform could offers lots of opportunities but also that it would depend on people contributing material, keeping the information up to date and responding to comments and queries. A strong moderator will be needed and material expressed in terms suited to the lay audience since the information on the current HPRU web site is aimed at a more academic audience.

Mid Term Event

The original proposal envisaged holding a major PPIE event at the midpoint of the project but the EAG agreed that it should be postponed until 2017/18. We hope to have 3 strands of activity at the event - presentations; round table "meet the scientists" sessions; and live online sessions to reach out to a wider audience.

The event is likely to include

- 2 Theme presentations in the morning
- Round table/meet the scientists discussions in the afternoon
- Live feed interaction with question and answers from theme leads throughout the day.

Schools could be involved through the on-line option with theme leads involved in the on-line items.

Public engagement:

Specific engagement activities by theme 1 have included presentation of (and elicitation of views on) the project and general radiation risks at several public events, including the Harwell Campus Science in Your Future event for female GCSE level students and, in addition, development of resources for the public which are planned for inclusion on PHE's website.

Data from Identification of Novel Psycho-active Substances (IONA) is provided to PHE and the Advisory Council on the misuse of drugs (ACMD) and can be used to update public access websites providing information about drugs of misuse such as 'Talk to Frank'. The IONA study and preliminary data were presented at an Inside Government event ('Tackling Legal Highs') in January 2016.

Public participation:

Theme 1: A particular issue is how to consult about the research without raising undue concern, especially to avoid young people refusing treatment because they believed it was

too big a risk. Until results are available this is a sensitive topic. How to seek public views on consent – in a positive way e.g. “would you want a sample analysed”?

Canvassing opinions, e.g. a presentation at a Harwell Campus STEM event, the HPRU Matters event and the opinion of their work experience colleagues, suggested that people found it difficult to understand the balance of risks and benefits of treatment and placed a high level of trust in clinicians

The External Advisory Group had suggested that at least 1 representative has training in engagement organised by SAHSU (Small Area Health Statistics Unit) and the scope for joint trials of questionnaires be considered. A team member will take up the training offer in November. The Theme lead will feedback details from SAHSU, collaboration across the HPRUs and using focus groups to trial public/patient data collection and dissemination.

The theme has contacts with other researchers in medical radiation, and consideration is being given to how to involve social sciences and The European Alliance for Medical Radiation Protection Research (EURAMED) Groups.

The lay member is liaising with the University’s Institute for Creative Arts Practice which aims to build bridges between medical research and the arts e.g. to use visualisation to take fear away from the word radiation. The aim would be to seek views at the mid-term PPI/E event on how to express radiation in an arts form and then to agree a brief for a joint project with the Institute. Another lay member is being recruited to the Theme.

Theme 2: In the discussion, the PPI/E committee asked about their experience of social media and took advice from the university’s press office on how to get the most out on-line live sessions.

The Theme lead explained that it was essential have something of substance to talk about and to be confident and well-prepared. His recent press experience to talk about skin health, ageing and sun screen was of great public interest and stimulated a good response - particularly a Reddit session in which he answered questions from the public in real time. The public became very engaged, asking some great questions. Press Office had reported that the session was the ‘hottest’ of the day and had attracted nearly 500 comments. As well as informing the public some useful international links had been made. We noted that Reddit may not be appropriate to all HPRU themes. This topic is one that the public can become engaged in and spark a lot of interest and debate. Other Themes need to give thought to what might be appropriate issues for putting to the public by Reddit, Twitter etc.

Theme 4: Research was discussed at a PPI/E event in November 2015 and helpful feedback was obtained for recruitment of skin sample donors, recruitment for pesticide questionnaire completion.

The deep dive event in 2016 covered 4 aspects of the research

- Identification of Novel Psycho-active Substances (IONA)
- Novel Psycho- active Substances Stem Cell Assay and Derivation of Human Stem Cells
- Public concerns about chemical exposures and their suggestions for public science communication
- Can Cytochrome Oxidase be used for Detecting Carbon Monoxide Exposure?

The committee identified potential Issues to include in the midterm event

- Carbon Monoxide Exposure

- Presentation on novel substances and make sure younger adults in the audience, if not in person, on-line.
- Stem Cells - Potential for “Meet the Scientist” Demonstration
- Where do people get information and do they trust it?
- Question to pose in round table session– What springs to mind when I say Risk from Chemicals?”

Advice on chemical poisoning was provided for the BBC drama ‘Casualty’. The IONA study and the issue of ‘legal highs’ has been widely discussed by HPRU staff in the media, including radio (BBC Radio 1 Newsbeat, BBC Newcastle), TV (BBC Panorama, BBC North East and Cumbria) and print (Newcastle Chronicle).

Emergency Preparedness and Response at King’s College London HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://epr.hpru.nihr.ac.uk/
PPIE web pages	http://epr.hpru.nihr.ac.uk/about/public-and-patient-involvement
PPIE Strategy	http://epr.hpru.nihr.ac.uk/about/public-and-patient-involvement
Contact Name	Dr Julia Pearce
Contact Email	Julia.pearce@kcl.ac.uk
Contact Phone	020 7848 7282

Patient and public involvement:

There have been no significant changes to the Emergency Preparedness and Response at King’s College London Health Protection Research Unit (EPR HPRU) patient and public involvement (PPI) plan since the Annual Report 2015/16. PPI progress and achievements this year include:

- All theme level plans were reviewed in April 2017 by the PPI subgroup and feedback provided to theme leads. Updated theme level PPI plans have been uploaded to the EPR HPRU website (<http://epr.hpru.nihr.ac.uk/about/public-and-patient-involvement>).
- Having identified challenges associated with conducting PPI for disease modelling research in 2015-16, the EPR HPRU PPI lead (Julia Pearce) met with the HPRU in Modelling Methodology PPI lead (Maria Piggini) to discuss mutual learning opportunities and potential cross-theme activities. We are currently discussing a plan to set up a cross-HPRU PPI panel to review proposals for upcoming research projects to provide feedback on how best to incorporate PPI in new projects that involve complex technical modelling procedures.
- A number of successful PPI activities have taken place this year, including a workshop that was co-organised with Age UK to obtain feedback from older adults on the research design of a Theme 2 PhD study on communicating risk during an influenza pandemic to target population groups; input of patient representatives for table-top exercises in Theme 7; obtaining feedback from research participants at the end of an experiment in Theme 1 as to the appropriateness of the information and consent processes, to inform future work.
- Another notable example of the successful incorporation of PPI into an individual research project involved the co-development of research objectives for a Theme 4 project on emotional resilience among forced migrants. This work employed a structured iterative process based on input from the refugee community in Norwich in the research design process. The PPI representatives from this project are currently co-authoring a

journal article with Theme 4 researchers on good practice in incorporating PPI in research design for submission to *Research Involvement and Engagement*.

- Additional workshops and activities have been scheduled for 2017/18 to ensure that PPI continues to be incorporated at key decision points in individual research projects. For example, in May 2017 a panel of members of the public will conduct a review of research protocols for a new Theme 5-related PhD study on the risks of chemical contamination and steps that can be taken to reduce these risks.

Public engagement:

There have been no significant changes to the Emergency Preparedness and Response at King's College London Health Protection Research Unit (EPR HPRU) patient and public engagement (PPE) plan since the Annual Report 2015/16. PPE progress and achievements this year include:

- Ongoing promotion of events and research outputs on our website (<http://epr.hpru.nihr.ac.uk/>) and via our twitter account (@EPR_HPRU).
- Ongoing publication policy of producing open access peer-reviewed journal articles to maximise accessibility of our research findings. This policy is published on our website (<http://epr.hpru.nihr.ac.uk/node/117>). Our up-to-date publications list can be viewed at <http://epr.hpru.nihr.ac.uk/publications>.
- Ongoing publicity of our work through press releases and media engagement. For example:
 - Rubin (Theme 1) discussed the National Flooding Cohort study in a piece for CNN on the mental health effects of climate change.
 - Smith (Theme 1) discussed her work on factors affecting parental uptake of the childhood flu vaccine in The Times and Independent.
 - Wessely and Rogers (Themes 1 & 2) provided multiple television, radio, and newspaper interviews about public responses to terrorist attacks in response to the attack on Westminster Bridge in London on 22nd March 2017.
 - Hunter (Theme 4) discussed his work on the fight against Zika virus in the Independent, Mirror, the Atlantic and Daily Mail, amongst other place.
- Ongoing engagement in a range of public-facing talks, including:
 - A presentation on 'Thinking Fast and Slow' by Theme 3 on 30 March 2017 at The Cut Science Café in Halesworth, Suffolk <http://newcut.org/sciencecafe/history>).
 - Talks by Rubin to school children in one of the flood-risk areas that contributed to the National Flooding Cohort study about the findings.
 - Podcasts (e.g. Rogers' on risk and terror - <https://www.mixcloud.com/warstudies/podcast-risk-and-terror/>; Webster on the nocebo effect - <http://www.sarbjoal.com/2017/02/28/what-do-we-know-about-the-nocebo-effect-and-how-it-works/>).

Public participation:

Please also describe how you make patients and the public aware of the research being undertaken within your Unit, and signpost them towards appropriate information about participating in research.

In addition to the engagement activities described above, we advertise for participants for our studies via local networks (e.g. locally held mailing lists), through paid-for advertising in our local areas (e.g. Gumtree adverts), via social media, and on our website

(<http://epr.hpru.nihr.ac.uk/volunteer>). Our website also hosts a database allowing people to register their interest in future studies on a 'no obligation' basis. We then send interested people information sheets about new research as they become available.

Emerging and Zoonotic Infections HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.hpruezi.nihr.ac.uk/
PPIE web pages	http://www.hpruezi.nihr.ac.uk/public-involvement/
PPIE Strategy	http://www.hpruezi.nihr.ac.uk/public-involvement/ppi-ppe-strategy/
Contact Name	Victoria Grimbley
Contact Email	grimbleyv@liverpool.ac.uk
Contact Phone	0151 795 8317

Each theme maintains a record of PPI or PPE activities undertaken. Updates are sent to the HPRU's PPI/PE lead on a quarterly basis. This information is disseminated more widely via the HPRU Emerging and Zoonotic Infections newsletter, the HPRU website and twitter account in order to build on each activity and achieve the highest possible impact. Every quarter at the HPRU's Steering Committee, attended by the HPRU Director, PHE Lead, two lay members and the Theme Leaders, PPI/PE activities are monitored and reviewed. These meetings help to facilitate additional development of good practice and ensure that activities are appropriately monitored and involvement evaluated. Beyond this, the HPRU Scientific Advisory Board, which includes the two lay members, review the Unit's overall direction and progress.

There have been no significant changes to the Health Protection Research Unit Emerging and Zoonotic Infections (HPRU EZI) patient and public involvement and engagement (PPIE) strategy since the Annual Report 2015/16. Progress and achievements this year include:

Patient and public involvement:

- The HPRU continues to meet its objective of 'public involvement in decision making at a strategic level' as our two **lay representatives**, GB-T and LC, have attended a number of HPRU meetings and events in the past year, including the annual Scientific Advisory Board (SAB) meeting in December 2016, SAB Teleconferences held every four months, and Public Involvement Panel meetings.
- Our **Public Involvement Panel (PIP)** continues to thrive as a diverse, active and engaged panel of patients and other research users. The panel was established jointly by the HPRU and the University of Liverpool's Institute of Infection and Global Health in 2015. The HPRU has supported the PIP financially by funding some travel expenses and meeting support costs. The PIP held three meetings in 2016-17, including a PIP training day with a morning session for panel members on 'academia for the public' and an afternoon public involvement workshop for HPRU researchers and PhD students. HPRU researcher, Mark Ellul spoke about how as a researcher it was invaluable to receive feedback on his research from the PIP which helped get his research funded by the NIHR. Panel member Ben Wills-Eve addressed issues on NIHR grant applications and what the NIHR looks for in terms of PPI. On 10 November 2016, Dr Tom Whitfield, a HPRU researcher, presented a project for input from the panel. HPRU members are well-represented on the panel, which includes Professor Tom Solomon, Dr Fiona McGill, and lay representative LC. <https://www.liverpool.ac.uk/infection-and-global-health/public->

[engagement/pip / http://www.hpruezi.nihr.ac.uk/about-us/news-and-events/public-involvement-panel-training-day/](http://www.hpruezi.nihr.ac.uk/about-us/news-and-events/public-involvement-panel-training-day/) / https://twitter.com/igh_pip.

- PhD student Liz McGinley has since April 2015 held various meetings with volunteers on the Tick Activity Project <https://www.liverpool.ac.uk/infection-and-global-health/research/zoonotic-infections/tick-activity-project/>

Public engagement:

- Our website <http://hpruezi.nihr.ac.uk/> and Twitter account [@HPRUezi](https://twitter.com/HPRUezi) are updated more regularly with information on our research, and our public engagement programme has expanded over the past 12 months <http://www.hpruezi.nihr.ac.uk/public-involvement/>. The HPRU Project Officer has joined various public engagement groups across The University of Liverpool, including: the Faculty of Health and Life Science's Public Engagement Working Group; and the University's Public Engagement Forum. By joining these groups the HPRU is better placed to disseminate initiatives and encourage HPRU researchers to get involved in public engagement activities, such as the following:

Objective - Public Events programme

- In May Dr Clarissa Oeser engaged with around 100 farm workers on Hepatitis E and zoonoses at the British Pig and Poultry Fair in Coventry. Later in September, Clarissa engaged with factory producers of the Cranswick Sausage on Hepatitis E.
- HPRU researcher Aislinn Currie-Jordan presented work on Vector Biology as part of the Liverpool School of Tropical Medicine Mosquito Diaries Exhibition at the Royal Society Summer Science Festival held in London, 4-7 July <https://royalsociety.org/science-events-and-lectures/2016/summer-science-exhibition/exhibits/mosquito-diaries/>
- The HPRU EZI and Gastrointestinal Infections jointly funded the North West Zoonoses Group (NWZG Annual Conference on Emerging Themes in Zoonoses held on 6 July 2016 at the University of Liverpool. HPRU EZI PhD student Stephanie Begemann discussed her research on AMR, food and animals. A wide range of stakeholders attended the conference, from both the public and private sectors.
- On 17 September John Tulloch attended the Lyme Disease Action Group Annual Patient Conference and networked with researchers and patients with a view to present the following year.
- On 27 September, Dr Cyril Caminade spoke about 'Did El Nino 2015-16 fuel the South-American Zika outbreak?' at The Wellcome Trust headquarters in London.
- The HPRU published a tick awareness leaflet aimed specifically at Key Stage 1 and 2 children in October 2016. The leaflet contains key messages on how to prevent tick bites and gives advice on safe tick removal aimed at engaging with children through the use of age-appropriate language and captivating illustrations. The leaflet will be shared with schools and displayed during specific times of the year when ticks are active, to remind children to be tick aware <http://www.hpruezi.nihr.ac.uk/about-us/news-and-events/tick-awareness-leaflet/>
- Our Mosquito Diaries exhibit featured at the World Museum, Liverpool (25th June). Approximately 200 visitors; the Royal Society, London (5th-7th July 2016). Approximately 14,500 visitors; Manchester Science festival, Museum of Science and Industry (25th October 2016), and at the Family Science Fair, Ness Gardens. As part of British Science Week. 11th March 17. Approximately 500 visitors.
- The HPRU provided funding to educate food vendors in low-income settings in Nairobi, Africa. A training session was given to over 30 vendors in order to improve food safety practices in the area.
- We held two further evening events in our series of 'Infectious Science in the Pub' events on 12 December 2016 at The Vines public house in Liverpool, and on 6 March 2017 at the Everyman Bistro in Liverpool. This free-of-charge event, attended by around 70 members of the public, featured six fast-paced scientific TEDx-style talks from HPRU

researchers on topics such as big data, Zika virus, climate change and poliovirus. The objective of the event is to encourage people from all ages and backgrounds to take an interest in emerging and zoonotic infections, and the event provides an opportunity for HPRU researchers to develop their public engagement skills

<http://www.hpruezi.nihr.ac.uk/1507.aspx> and <http://www.hpruezi.nihr.ac.uk/1514.aspx>

- Our Annual Conference 'Zika and Other Emerging Infections', held at the Liverpool Medical Institution in Liverpool on 13 December 2016, was open to the public, and provided an opportunity for some of our researchers to present their work. Keynote talks were given by Dr Patricia Sequeira, Laboratório de Flavivírus, Instituto Oswaldo Cruz, Brazil on *'The FioCruz response to the Zika outbreak'* and Dr Alain Kohl, MRC Programme Leader, MRC-University of Glasgow Centre for Virus Research on *'Zika virus interactions with host cells'*. <http://www.hpruezi.nihr.ac.uk/about-us/news-and-events/hpru-ezi-annual-conference-awards/>
- The HPRU had an 'Infections of the Brain' stall at the 'Meet the Scientists' event held at the World Museum in Liverpool this year. On 21 January 2017 we ran fun workshops for children during the 'Brainiacs' event. Over 2,000 children with their families came to learn about infections on the brain, how to prevent them and how to cure them. Children (and adults) had the unique opportunity to dress as a scientist or physician and try to destroy infections inside jelly brains. Visitors also had the opportunity to see what the brain looks like in sections and learn about the importance of recognising brain infections. <http://www.hpruezi.nihr.ac.uk/media/11933/nihr-hpru-in-emerging-and-zoonotic-infections-newsletter-spring-2017.pdf>
- On 11 March 2017, during British Science Week, we had a 'Mosquito Madness' exhibit at the Ness Botanic Gardens Family Science Fair. This exhibit highlighted the PhD student Aislinn Currie-Jordan's work on improving our understanding of UK mosquito species through hands-on activities and demonstrations <http://www.hpruezi.nihr.ac.uk/1521.aspx>

Objective – School's programme

- In September the HPRU engaged with primary school children in science via social media (with BlueEllie and Dr Scott) and role play. We provided child friendly scientific equipment to create a permanent scientist role play area in their classroom. Through engagement with this science lab the children make child lead YouTube videos hosted by #whywedoresearch and their twitter account to inspire other schools <https://twitter.com/WQP1Adventure>
- During British National Science and Engineering Week 2017, we organized two workshops for 12-14-year-old students coming from a school in a less privileged area. At the workshops, students had the unique opportunity to become scientists for a day and learn about infections in humans and animals and global health. Students extracted DNA from strawberries and bananas, observed through the microscope mosquitoes from the same species that transmit many infectious diseases. They also observed through the microscope their own cells from their cheeks and prepared some cool science badges and some beautiful colourful mosquitoes with "pipe cleaners".

Objective – Media

- We have had much media exposure over the past year, including appearances on radio and television by our researchers on BBC News, France Culture, and NTN24, and mentions in news articles in The Guardian, the Mirror, Wired, Washington Post, amongst others, particularly in relation to Zika virus and the Ebola outbreak in West Africa. For example, Professor Matthew Baylis appeared on BBC World News on 22 December 2016 to discuss the Zika outbreak <http://www.bbc.co.uk/programmes/p04m5v5v>
- Three HPRU EZI newsletters have been published with a deeper focus on public involvement and engagement activities - <http://www.hpruezi.nihr.ac.uk/about-us/newsletters/>.

- The University of Liverpool's Faculty of Health and Life Sciences Public Engagement team have selected HPRU PhD student Raquel Medialdea Carrera as a case study for her excellent experience of public engagement work. Activities include taking part in Meet the Scientists, running science workshops in Sierra Leone and organising Infectious Science in the Pub which saw researchers give inspiring and fascinating talks about their work to the public over a pint!
https://www.liverpool.ac.uk/media/livacuk/facultyofhealthandlifesciences/casestudies/Case_studies,Raquel,Carrera.pdf
- Professor Tom Solomon has been involved in the development of a module for a MOOC. The 'In the footsteps of Zika... approaching the unknown' MOOC is available online, for free (for a year) and has been translated into four languages (English, French, Portuguese and Spanish). The module addresses what is known and unknown about the neurological adverse effects of the Zika virus in French Polynesia and in Brazil. Professor Solomon's lecture on 'Neurological Complications of Flaviviruses focusing on the effects of Zika in adults' closes the module. www.hpruezi.nihr.ac.uk/1418.aspx

Resources:

- In December PhD students John Tulloch and Liz McGinley set up a Lyme and Tick-Borne Disease Working Group to bring together all researchers across HPRUs, PHE and the Royal Liverpool University Hospital to collaborate in research and funding in this area.
- The HPRU EZI and Gastrointestinal Infections jointly funded a bespoke training day on 'Presenting about Science'. This day was aimed at PhD students and HPRU researchers and run by James Piercy, from Science Made Simple. James holds the LAMDA gold medal in public speaking, is a trainer for FameLab International and recently won the Royal Society Radio prize. The training focused on enhancing public engagement skills in order to present to and engage effectively with different audiences.
- The HPRU has this year provided funding for the following projects: One Health Big Data stall at the Edinburgh International Science Festival; an Ebola Survivors' Workshop in Sierra Leone; and an 'Infectious Science in the Pub' event in Rio de Janeiro on the Zika virus.

Public participation:

Our website includes a Public Involvement and Engagement page, for making patients and the public aware of the research in our Unit and inviting them to get involved <http://www.hpruezi.nihr.ac.uk/public-involvement/>. The members of our Public Involvement Panel have copies of our leaflet with information on our research, for distributing to interested parties. We bring HPRU promotional material including banners and leaflets to patient and public involvement and engagement events to promote the HPRU.

Environmental Change and Health HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.hpru-ech.nihr.ac.uk/
PPIE web pages	http://www.hpru-ech.nihr.ac.uk/public-engagement-2/
PPIE Strategy	http://www.hpru-ech.nihr.ac.uk/files/2017/01/HPRU_ECH_PPI_strategy_v4.pdf
Contact Name	
Contact Email	
Contact Phone	

Our public involvement and engagement strategy has been finalised and is available on the HPRU website. A training session on PPI/PPE was held at the Second Annual Meeting (November 2016), led by Kath Maguire (University of Exeter). A poster on our public involvement work was presented at the PHE Research and Applied Epidemiology Conference in March in 2016 (Warwick).

Public Engagement.

A website for the HPRU includes accessible summaries of our research. Areas of interest to general public include health implications of flooding, heatwaves, urbanisation, infectious disease, green space (natural environment), and climate change. Because the needs and levels of understanding of a non-expert audience will be different from those of our academic audience, we will also include lay summaries on the web site with the assistance of experts on communication based at the LSHTM and PHE.

PHE runs a public blog series, Public Health Matters, which covers topics on the theme of climate change effects on health. The Met Office has produced a video on the HPRU which is available on [YouTube](#) (3).

Theme 1.

PHE and the Met Office publish a blog on Climate Change and Public Health (4):. LSHTM staff were involved in the exhibition in the LSHTM foyer in Jan-Feb 2016 on "HEALTHY CITIES & SUSTAINABLE LIVING". HPRU is linked to the cabinet on climate risks to urban areas and housing. A piece on the HPRU project in the Met Office magazine, Barometer. The Met Office has several permanent web pages on weather, climate and health topics (for instance on pollen, heat and cold). The Met Office also supports the health sector through joint communications and media activities (for example, with Public Health England), and seasonal campaigns (e.g. Get Ready for Winter (5)) are used to promote health issues. A range of channels are used including web, traditional media and social media.

Theme 2.

PHE staff organised a workshop on air pollution with Kings College Environmental Research Group and the HPRU in Health impacts of Environmental Hazard [HPRU HIEH], which was followed by discussion with community group leaders, councillors, and stakeholders.

PHE runs a public blog series, "Public Health Matters", which covers topics on the theme of climate change effects on health.

HPRU supported research by PHE on the health impact from air pollution episodes was the focus of several pieces in the media (*The Times, Daily Mail, Evening Standard, RT, Greenpeace Energydesk*), and a Parliamentary Question.

Theme 3.

See involvement activities below re HEPE. Public engagement through HEPE includes using local media such as newspapers and radio and communicating the commitment to public engagement.

Exeter University (LF) organized the Big Data Workshop in June 2014 which included businesses (SMEs, PHE, Met Office, NGOs, community individuals, and local government). The UoE model of public engagement (6) identifies four key elements: flexible approach to engagement, active engagement with public concerns, a strong public voice, and an ability to respond to public feedback.

Public involvement

Public involvement activities are focussed on specific projects within each theme.

Theme 1. Flooding and health

Public workshops designed to promote co-production of research outcomes took place in 2015 and 2016 for the project relating to flooding, resilience and health, led by the University of Exeter. Participants were invited to take part from across multiple organizations important to flood response and recovery, including the National Flood Forum which represents individuals that have been flooded.

Theme 2. Housing, household energy and health.

UCL has continuous public involvement on housing research through its Housing, Energy, and Wellbeing (HEW) project and the 'Total Performance of Low Carbon Buildings in China and the UK' (TOP) project. The HEW workshops have included representatives from non-government organizations and community groups. Group model building workshops include people from the public and community representatives, and participants who engage in their community and church. The HEW-WISE web-enabled simulation environment accessible to everyone on the HEW website

The HEW project has also held interviews with interested people from the public to inform the research. Public involvement is achieved through participatory system dynamics. The system dynamics modelling process includes continuous engagement with public [and stakeholders] through in-depth interviews to elicit qualitative understandings of the links between elements of the researched system and workshops in which a joint systemic understanding and a broad set of policy evaluation criteria are developed. This participatory approach is used to avoid unintended consequences arising either across sectors, in implementation or after delay because it enables stakeholder emancipation and the generation of solutions that represent synergies between the participants' sectors and goals.

Theme 3 Natural environment, green space and health

Since 2013 the **Health and Environment Public Engagement (HEPE)** group [2] has been increasingly acting as a resource for researchers in the European Centre for the Environment and Human Health, including those currently working on Natural environment, green space and health. HEPE are involved in both in planning and evaluating the Centre's research. HEPE is modelled on the NIHR Collaboration for Leadership in Applied Health Research and Care South West Peninsula (PenCLAHRC) Public Involvement Group ([PenPig](#) [9]). It is led by Dr Garside (UoE) with support from Dr Kath Maguire (PenCLAHRC funded research fellow in public involvement and engagement) and researchers working with the HPRU.

An initial engagement workshop organised in partnership with local community organisations explored media stories about the environment and health, to attract interest in joining HEPE. Those involved were engaged in deciding the purpose and scope of HEPE, defining roles and beginning the process of two-way communication. As well as regular quarterly meetings HEPE members attend project specific workshops, review documents electronically and support teaching. Staff and students are encouraged to interact with the group to develop their research. A member of HEPE (Dr Green) has participated as an active Member of the HPRU External Advisory Board (see below).

HEPE Quarterly Meetings – Discussions about the HPRU		
Date	Researchers involved	Content
April 2015	Professor Fleming, Dr Mat White, Dr Ben Wheeler, Dr Tim Taylor Dr Ian Alcock Dr Ruth Garside Dr Kath Maguire	<ul style="list-style-type: none"> • Explained the purpose and research goals of the HPRU • Asked the group to consider how they would like to be involved • HEPE agreed to support External Advisory Board • To discuss question prioritisation and review documents
July 2015	Professor Fleming, Dr Ruth Garside Dr Kath Maguire	<ul style="list-style-type: none"> • Updated group on progress • Agreed to consultation event in the autumn • HEPE to suggest potential additional invitees
October 2015	Dr Ruth Garside Dr Kath Maguire	<ul style="list-style-type: none"> • HEPE discussed organisation of November event
January 2016	Dr Ben Wheeler, Dr Ruth Garside Dr Kath Maguire	<ul style="list-style-type: none"> • Feedback from the November consultation event provided by Mr Des Prowse (HEPE member) and Dr Ben Wheeler • Nomination of Dr Andrew Green to HPRU External Advisory Board • Presentation and discussion on developing work with Cornwall Council on green space and health
April 2016	Dr Ruth Garside Dr Kath Maguire	<ul style="list-style-type: none"> • Dr Green provided feedback from the External Advisory Board • HEPE discussed how they could support developing public involvement and engagement in any future HPRU funding proposal • HEPE requested Dr Green and Dr Maguire to meet to produce a summary to encapsulate these discussions
July 2016	Dr Ruth Garside Dr Kath Maguire	<ul style="list-style-type: none"> • Dr Green and Dr Maguire reported on their meeting and the summary

Evaluation of Interventions HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.bristol.ac.uk/population-health-sciences/centres/nih-hpru/
PPIE web pages	http://www.bristol.ac.uk/population-health-sciences/centres/nih-hpru/ppi-pe/
PPIE Strategy	
Contact Name	Dr Noreen Hopewell-Kelly
Contact Email	noreen.hopewell-kelly@uwe.ac.uk
Contact Phone	

HPRU evaluation of interventions has continued to develop its PPI/E collaboration with People in Health West of England (PHWE) <http://www.phwe.org.uk>, the NIHR Collaboration for Leadership in Applied Health Research and Care West (CLAHRC West), NIHR Clinical Research Network West of England (CRN), West of England Academic Health Science Network (WEAHSN), Bristol Health Partners and the NIHR Cardiovascular Biomedical Research Unit.

Patient and public involvement:

Our new PPI strategy (<http://www.bristol.ac.uk/social-community-medicine/media/hpru/strategy-for-researchers-2017.pdf>) is in pilot phase, it has been developed in consultation with researchers across the HPRU, PPI leads from UWE and PHWE and two PPI representatives to “maximise impact of PPI within the research that is being conducted across the HPRU”. Whilst developing and piloting the strategy we have integrated PHWE’s “West of England Patient and Public Involvement Strategy 2015-2019” into all our PPI work <http://www.phwe.org.uk/wp-content/uploads/2015/05/PHWE-Strategy-2015-19.pdf>.

Impact

We have recruited a small number of public contributors to our PPI strategy group; the impact of this group has been in their involvement in the development of the core objectives of the strategy in addition to other areas of PPI including the co-production of lay summaries, contributing to study design and funding applications, advising on feasibility of study questions and piloting recruitment drives. Recruitment to this group continues; job descriptions have been developed in consultation with PHWE and are being advertised in the PHWE fortnightly newsletter, ‘Newsflash’, as well as on the HPRU website and at other engagement events.

***Communication and publicity**

We have continued to develop the presence of PPI on the HPRU evaluation of interventions website <http://www.bristol.ac.uk/social-community-medicine/centres/nih-hpru/ppi-pe/> We are working to make this user friendly and are advertising it widely to increase potential traffic. Researchers are being encouraged to contribute items of interest to include on the pages and to use this as a forum for PPI recruitment to their studies. In addition to our increased focus on involvement and engagement via social media, we have also introduced the HPRU PPI twitter feed; all researchers are being asked to contribute tweets in order for us to develop our social media presence.

***Case studies**

We have worked hard to increase the level of PPI being undertaken across our work. We are encouraged by increased numbers of researchers requesting PPI advice at an early stage in their research design, who are working to embed PPI not only at one stage of their research, but across the research cycle. With guidance, appropriate resources are subsequently being committed to PPI in funding applications to enable this greater focus on continued PPI. The EEPRIIS study continues to conduct highly successful ongoing PPI, other examples of our PPI work include:

- MRSA in people who inject drugs (PWID): A PPI group was run with service users to inform the design of the questionnaire being used in the study. The impact of this group was not only in the questionnaire being redeveloped to incorporate the group’s suggestions, but further PPI phases have now also been developed to include: a) informing service users of the study’s findings; and b) facilitating a discussion group to

enable context and guide further analysis to support interpretation and identifying potential interventions.

- EPIToPE: We have explored ways of embedding PPI into the study design. PPI contributors commented on lay summaries at an application stage and costings were included into the funding bid for ongoing PPI work that will aim to add context to research findings.
- Bovine tuberculosis in people: PPI has been embedded into the design of this research from its very beginning. The researcher has had PPI input on the funding application and its impact is evident in the development of summaries/adverts being used for PPI recruitment which were developed in consultation with public contributors. PPI has been costed into the funding bid and adverts have been developed for recruitment to a PPI discussion group to meet prior to the start of the study, to explore research priorities and approaches, and to an ongoing advisory group to work with the researchers throughout the course of the study on the management of the study, to discuss findings and to collaborate on potential means of dissemination.
- Evaluation of patient access to medical test result services in General Practice: A patient representative worked with the researchers to develop the lay summary for the funding application of this study. The impact of this work was in their comments being incorporated and the summary being reworked several times in collaboration with the PPI contributor. The PPI element of the application was subsequently comprehensive and costings included four PPI consultation events (to take place over the course of the study), plus the payment of two patient contributors to join the study advisory group for the duration of the study. A Public contributor was recruited prior to funding submission and PHWE were approached to advertise for the second role.

For further examples of our case study work please see <http://www.bristol.ac.uk/social-community-medicine/centres/nihr-hpru/ppi-pe/ppi-examples/> . We have also developed a newsletter for circulation across the HPRU evaluation of interventions and to our external collaborators. <http://www.bristol.ac.uk/social-community-medicine/media/hpru/ppi-review-nov2016.pdf>. This quarterly newsletter is being used as a means of maintaining communications, reporting our PPI/E activities, increasing awareness of our work and encouraging continued collaborative approaches to PPI/E from our researchers. We are working on developing a second newsletter to disseminate to the public.

Working collaboratively with researchers from PHE we contributed to the organisation of the Tuberculosis screening event aimed at homeless and substance misusing individuals in Bristol. Drop in sessions were arranged to take place at Bristol Drugs Project, where researchers were able to talk to service users about different aspects of the event, to help ensure its success. The service users' involvement was used to:

1. Address barriers to attending an event like this
2. Evaluate TB knowledge before and after the event
3. Develop TB educational material.

The PPI gained across the day was most helpful to the researchers in the development of the event itself.

We are working collaboratively with PHE staff on the development and facilitation of engagement activities. We are also collaborating with PHE staff on the design and dissemination of engagement materials, notably the HPRU newsletter and social media presence.

***PPI Evaluation protocol**

In anticipation of the implementation of the NIHR PPI standards across the HPRUS, The HPRU evaluation of interventions has commenced an evaluation of current PPI activity across each of the HPRUs. A protocol for the evaluation has been developed in collaboration with CLAHRC West, UWE and the HPRU evaluation of interventions. The evaluation will be a three-phase piece of work that will include a two-stage documentary analysis and a self-assessment questionnaire that each PPI lead will be asked to complete. We received ethical approval from The University of West England ethics committee to begin the evaluation at the beginning of April.

Public engagement:

In addition to the public engagement work referred to above which has been integral to our PPI, we continue to work with other HPRUs and external organisations to ensure that we share and learn from each other's best practice. We attended the INVOLVE national meeting for NIHR PPI leads (Nov 2016), have facilitated workshops with PHWE (Building Research Partnerships October 2016), chaired and presented in the PPI theme at the HPRU annual progress meeting (Dec 2016) attended an NIHR HPRU added value workshop, London (May 2016), and attended the qualitative health research symposium at UCL (February 2016) to engage with other researchers on the development of PPI in health care research.

We have also forged links with the established 'COMBACTE-MAGNET' PPI team who meet regularly to contribute to PPI in this European programme of antimicrobial research. Our researchers are now invited to attend their patient panel meetings to consult with the group on HPRU research. This is an excellent resource for researchers who frequently work to rapid response calls and thus can benefit from the input of an established HPRU-relevant patient panel.

Public participation:

We attended a number of events during the Healthy Cities week (Bristol) to publicise our PPI work (Oct 2016). A group of HPRU researchers have also begun working together to develop a more tactical approach to our Public engagement initiatives. The group are working collaboratively with outside agencies including @Bristol, Greenman, University of Bristol, Wellcome Trust and ACTA Community theatre to develop forthcoming PPE events.

Please also describe how you make patients and the public aware of the research being undertaken within your Unit, and signpost them towards appropriate information about participating in research.

The HPRU website (<http://www.bristol.ac.uk/social-community-medicine/centres/nihr-hpru/ppi-pe/>) and the PHWE newsletter 'Newsflash' are used to advertise PPI opportunities within the HPRU. We also look to recruit PPI contributors from collaborative sources, these have included PHE, Bristol Drugs Project, University Hospital Bristol and Bristol University. We are now working with PHWE and UWE to develop a more strategic approach to achieving greater diversity in the recruitment of our PPI contributors.

Our engagement activities are also used as opportunities to make patients and the public aware of the research that is undertaken at the HPRU; the website is signposted as the forum from which to get further information about our work. The PHWE and INVOLVE websites are also cited as links for further information about PPI at a general level

Gastrointestinal Infections HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.hprugi.nihr.ac.uk/
PPIE web pages	http://www.hprugi.nihr.ac.uk/patient-and-public-involvement/
PPIE Strategy	http://www.hprugi.nihr.ac.uk/media/9738/hpru-gi-ppi-pe-strategy-2016-17.pdf
Contact Name	Victoria Grimbly
Contact Email	grimblyv@liverpool.ac.uk
Contact Phone	0151 795 8317

We published our Patient and Public Involvement (PPI) and Public Engagement (PE) Strategy, which is now available at <http://www.hprugi.nihr.ac.uk/media/9738/hpru-gi-ppi-pe-strategy-2016-17.pdf>.

Patient and public involvement:

We aimed to recruit at least three lay representatives to the External Advisory Panel and ensure there is also representation at quarterly Research Steering Committee meetings

Four Lay Members attend meetings of the Research Steering Committee and External Advisory Panel, and have made considerable contributions to the panels and to the Research Themes.

Our aim is that HPRU management, including HPRU Director and Theme Leaders, will actively encourage research staff and PhD students within the HPRU to examine opportunities for public contribution in their research

Most of our Lay Members have been encouraged to adopt at least one research theme each, e.g. VB assists Theme 1 (“People”), and RG, who has long experience in managing major research and development programmes, contributes to Themes 2 (“Tracking”) and Theme 3 (“Pathogens”). GD, who has over 60 years work experience in health and safety contributes and puts forward a public viewpoint to the Committee and Panel meetings. CH, who has considerable expertise in coaching life skills, ethics, job finding, and developing presentations and grant applications, has worked with the HPRU GI Training Lead to develop life skills training for our PhD students; he kindly led a session on life skills at the NIHR HPRU in Gastrointestinal Infections PhD Students meeting held at Colindale on 23rd November 2016.

We aim to communicate with all researchers the importance of PPI in their research and provide training opportunities wherever possible and to share best practice, skills and expertise in PPI across the HPRU community

In September 2016 we organised a Public Involvement Day jointly with the NIHR HPRU in Emerging and Zoonotic Infections (EZI) and the University of Liverpool’s Institute of Infection and Global Health. It was organised for anyone involved in research, from post-graduate to professor. The aim of the day was to explain why public involvement is so useful.

We wish to inform and inspire researchers to undertake opportunities for patient and public involvement in their research

Evidence of the relationship between deprivation and GI infection is limited and the mechanisms underlying this relationship are not well understood. Some existing studies suggest that the trends in risk differ between adults and children, with children living in more deprived areas having higher risk of infection and hospitalisation. Qualitative research led by, Dr Rachael Eastham and Dr Alex Kaley, from the Division of Health Research at Lancaster University (Theme 1 (“People”)), aimed to deliver an in-depth understanding of GI infection within the wider social context and within households; and to characterise how these interplay to influence consequences of GI infection for families living in the North West of England. Using semi-structured interviews and participatory mapping techniques, this study recruited 21 people with children aged 0-11 who have had a recent experience of GI infection, in order to explore ways in which individual behaviours and experiences interact with the material, social and cultural environment (place) to influence the consequences of GI infection for families. Analysis of the material obtained from fieldwork, undertaken between September and December 2016, is currently underway.

Erica Kintz at the University of East Anglia (Theme 5 (“Pathways”)) has contacted local patient and public involvement representatives to help her design a case control study for risk factors for STEC infection.

Public engagement:

We aim to publicise the work of the HPRU through a range of communication channels in order to raise awareness and to foster public engagement

June 2016: Martin Maiden and Frances Colles were involved in the Wellcome Trust’s “The Crunch” activities to help people think about how our food, our health and our planet are all interconnected. They worked with Pearson to produce a script, and then did some filming with them at farm and laboratory locations to describe how *Campylobacter* isolates from broiler (meat) chickens and wild birds were collected and genotyped. The videos were incorporated as part of a larger education package created by the Wellcome Trust for school children aged 14-16. For more information on the module ‘Why cook your chicken?’ visit: (<https://thecrunch.wellcome.ac.uk/schools-and-colleges/its-the-small-things>). Watch the Farm Story at: (<https://www.youtube.com/watch?v=K7Nj7bVmCGA>). Watch the Lab Story at: (https://www.youtube.com/watch?v=6upV_PPHUbs)

January 2017: Blog post - Seun Esan (Theme 2 (“Tracking”)) published a blog post on the Nuffield Department of Primary Care Health Sciences website about ‘Unpleasant complications of gastroenteritis – unravelling the link’: <https://www.phc.ox.ac.uk/blog/unpleasant-complications-of-gastroenteritis-unravelling-the-link>

We aim to communicate about HPRU research and findings through attendance at conferences

June 2016: Sarah McGarrol and Suzie Rotherham (Theme 1 (“People”)) attended the

ENRGHI (Emerging New Research in the Geographies of Health and Impairment) conference at the University of Glasgow. Both researchers submitted posters: Suzie on 'Risk, vulnerability and consequences of gastrointestinal infections in disadvantaged neighbourhoods in the North West of England'; and Sarah on 'People and places: exploring and understanding factors influencing health inequalities in Gastrointestinal Infection (GI) in socially contrasting localities in the North West of England'.

June 2016: Miren Iturriza-Gómara (Theme 4 ("places")) gave her public, inaugural Lecture entitled "That familiar gut feeling... gone viral" at the Liverpool Medical Institution. She talked about how molecular detection methods have informed global disease burden estimates of the leading viral causes of gastroenteritis, while at the same time creating diagnostic challenges. She then addressed some of the problems we face in effectively controlling viral gastroenteritis in different populations.

July 2016: North West Zoonoses Group annual conference
Sarah O'Brien and Kevin Maher, Food Standards Agency chaired a session
Event was sponsored by HPRU GI and EZI.

September 2016: PHE 4th annual conference
Noel McCarthy (Theme 2 ("Tracking")) and Helen Hughes (Theme 1 ("People")) presented at the conference. Helen was awarded the Global Health Poster Prize as her work was considered to contribute positively to global health efforts.

We aim to present HPRU work directly to the public and seek their engagement at events

June 2016: Lee Kellingray (Theme 6 ("Microbiome")) gave a talk on gut microbiome and the importance of microbiome in health and disease to group from University of Third Age (an organisation which provides opportunities for retired and semi-retired people to get together and learn new things in a collegiate environment).

July 2016: Sarah McGarrol and Suzie Rotheram (Theme 1 ("People")) created a series of interactive activities for primary school children called 'Let's talk about poo and puke!' at a School's Science Festival in the World Museum in Liverpool and the aim of the day was for school pupils from four different local primary schools to take part in hands on science and learn more about research (<https://news.liverpool.ac.uk/2016/06/30/meet-the-scientists-successful-first-season/>). Around 55 children attended. The event was selected to be a case study for the Faculty of Health and Life Sciences (FHLS), and is published on the FHLS Public Engagement website (<https://www.liverpool.ac.uk/health-and-life-sciences/public-engagement/case-studies>).

August 2016: Arjan Narbad (Theme 6 ("Microbiome")) led a session open to the public entitled "Look after your gut bacteria" at St Andrew's Church Hall, Eaton, Norwich, with 150 people (<http://www.standrewseaton.org.uk/content/pages/documents/1465290545.pdf>)

September 2016: Arjan Narbad (Theme 6 ("Microbiome")) was interviewed on probiotics which resulted in a published article <http://www.nutraingredients.com/Research/UK-China-probiotics-centre-plans-GM-research>

October 2016: International Infection Prevention Awareness Week

Arjan Narbad and Lee Kellingray (Theme 6 (“Microbiome”)) launched a new treatment programme for *Clostridium difficile* using Faecal Microbiota Transplant. This news was published on the Norwich Evening News:

http://www.eveningnews24.co.uk/news/health/unusual_pioneering_procedure_to_treat_life threatening_gut_infection_being_carried_out_at_norfolk_and_norwich_university_hospital_14745856

March 2017: Infectious Science in the Pub - We held a joint event with HPRU EZI on 6 March 2017. Attended by 60 members of the public this free-of-charge evening event was held at the Everyman Bistro, Liverpool. The event featured six fast-paced scientific TED-X style talks from HPRU researchers including Miren Iturriza-Gomara (Theme 4 (“Places”)), who spoke about ‘rumbling guts’. The objective of the event is to encourage people from all ages and backgrounds to take an interest in emerging infections, and the event provides an opportunity for HPRU researchers to develop their public engagement skills.

<http://www.hprugi.nihr.ac.uk/about-us/news/infectious-science-event-update/>

Please also describe how you make patients and the public aware of the research being undertaken within your Unit, and signpost them towards appropriate information about participating in research.

Our website includes a Patient and Public Involvement page, for making patients and the public aware of the research in our Unit and inviting them to get involved

(<http://www.hprugi.nihr.ac.uk/patient-and-public-involvement/>). Our Lay Members have copies of our leaflet with information on our research, for distributing to interested parties. There is an active Twitter account for the HPRU GI. Three HPRU GI newsletters have been published - <http://www.hprugi.nihr.ac.uk/about-us/newsletters/>

Healthcare associated infection and antimicrobial resistance (Imperial) HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	https://www.imperial.ac.uk/medicine/hpru-amr
PPIE web pages	http://www.imperial.ac.uk/medicine/hpru-amr/patient-and-public-information/
PPIE Strategy	http://www.imperial.ac.uk/media/imperial-college/medicine/nihr-hpru-hai-antimicrobial-resistance/HPRU-HCAI-and-AMR-patient-and-public-engagement-strategy.pdf
Contact Name	Juliet Allibone
Contact Email	Head.ops@imperial.ac.uk
Contact Phone	0208 383 1280

Public Involvement

This year our patient/public representatives provided input into three NIHR fellowship applications, reviewed and commented on a research protocol and lay summary for submission to the Independent Scientific Advisory Committee (ISAC) for MHRA database research. They reviewed the revised HPRU website and provided input into Patient Information Leaflets and consent forms for one project. As reported last year, mindful of the

comments received about expanding the number of potential patient/public representatives beyond those on our Scientific Advisory Board, we established a “potential PPI/E panel” ready to be approached for input into specific research projects. In addition to sending the group our quarterly HPRU newsletter, this year we sent them copies of two peer-reviewed publications which had resulted from Patient/Public focus groups in which some of them had participated. They were invited to share any comments or thoughts with the research team and, for an incentive, to comment on the information leaflets developed. One of patient representatives, helped man our Antibiotic Amnesty stand again this year with researchers from the team and has continued with her outreach activity having “conversations” across the community landscape on medicine optimisation topics. She continues as a Lay Member on the English surveillance programme for antimicrobial utilisation and resistance (ESPAUR) providing an additional link with Public Health England. We remain committed to building researcher capacity for PPI/E through training. A bespoke 2.5 hour workshop was conducted by the Imperial College Biomedical Research Centre (BRC)/Joint HPRU PPI/E Officer in October 2016, to engage our PhD students and more junior researchers into finding ways to incorporate a patient/public perspective in their projects where possible. Training sessions on PPI provided by external trainers, which were personalised to the Imperial linked HPRUs were held on the 7th and 10th June 2016 and were attended by nine HPRU HCAI & AMR members. Further workshops were held again in December 2016.

Project level involvement: We reported last year that we were seeking further opportunities for patient/public involvement at individual project level. The award of a BRC funded PPI/E project (reported last year) and two new NIHR fellowships this year have allowed us to do this. A BRC funded project entitled SPIRIT allowed a focus group of 20 members of the public to look at four themes (1). a standard gamble methodology for information about usefulness of antibiotics for viral conditions in the primary care setting (2). a tool for involving patients and the public in strategic decisions on research funding (3). vignettes for engagement with decision making in the acute care setting and (4). a questionnaire for using an opportunity cost and structural framework to explore which factors influence decisions to seek antibiotics. In all cases patient and public representatives provided valuable input into the development of these by commenting on appropriateness and clarity of language and layout allowing these research tools to be refined and deployed in on-going research projects. The award of the two new fellowships has allowed the establishment of two new advisory committees each of which includes patient representation. CCG patient groups have been contacted to provide input for one and our “potential PPI/E panel” will be contacted for the other. In both cases we will use our patient role description which has been developed and is being used by other HPRU’s at Imperial. We will also hold a patient/public engagement event on invasive streptococcal infection, as part of a new Medical Research Council award on the Molecular dissection of England’s scarlet fever upsurge 2015-2016 and the impact on invasive infections, AMR and HCAI. Our close working with patient/public representatives in our research is demonstrated by the publication of four more papers co-authored by a patient representative during the year, with a fifth under review by Health Expectations.

Involvement in shaping strategy: The presence of our three patient representatives at Board level helps to ensure a patient and public voice is heard at a strategic level within our HPRU. Through the SPIRIT project we have also developed, tested and validated a tool for asking patients and the public about their research priorities. Our reproducible methodology provides a practical tool to capture public priorities for research and can be used by others to

involve patients and the public in making strategic decisions. While the HPRU's research direction is predominantly dictated by the priorities and needs of PHE, wherever possible the views of our patient representatives can and do shape the direction of research. We are currently advertising a research placement for a project on the Summary Care Record with Additional Information, championed by one of our patient representatives and one of our fellowship applications (outcome pending) includes a new sub-study to understand parents'/patients' views, which was suggested and developed with a patient representative.

Public engagement

We continue to consolidate the progress we have made in our public engagement activity by building on the successes of our first two years. Our website, including the extensive dedicated PPI/E section, has been reviewed and revised, by the BRC/Joint HPRU PPI/E Officer and our patient representatives. Our newsletter distribution list of over 250 members now includes representatives from patient organisations such as the Self Care Forum, British Infection Association, Patients Association, SURF, UK Sepsis Trust, Healthwatch, CLAHRC South London, Antibiotic Action and ReAct. Public engagement activities this year included HPRU speakers at the Royal Veterinary College (RVC) Global Health Society symposium "Disaster!" This was open to the public and aimed to highlight how big a threat AMR poses. This was followed by our speakers attending the RVC to talk as part of European Antibiotic Awareness day for which we also produced some hand-out materials "What can I do about AMR as a Vet" and successfully proposed the adoption of our Antibiotic Amnesty format, engaging with people via an information stand to make an Antibiotic Guardian pledge. Researchers have also given talks on the uses of routinely-collected data for AMR research to students at the University of Roehampton for European Antibiotic Awareness Day and to students at the Royal Veterinary College. The group has also been involved with the media; Professor Holmes appeared on Newsnight during a feature on AMR following the final report and recommendations of the Jim O'Neil review and assisted the Foreign Office, meeting Italian journalist from a leading Italian weekly to better inform Italian public opinion about AMR and to showcase the UK leadership and approach in tackling this global threat. Professor Sriskandan wrote an article for the New Scientist on Colebrook and the birth of antibiotics and Enrique Castro Sanchez was interviewed for Spanish radio on AMR. The Unit has also supported an art exhibition; Anna Dumitriu: Microbe Stories at the Blyth Gallery, South Kensington and held a free, hands-on practical art-science workshop with the artist exploring how art can creatively explore the complex issues around AMR and new technologies in microbiology such as whole genome sequencing and synthetic biology. We were also contacted by one of the researchers for Surgeon X, a comic book set in a post-antibiotic area and funded by the Wellcome Trust, and have hosted a fact-finding visit to the Unit and Imperial's Clinical Research Facility which will inform future episodes. In line with our PPI/E strategy, our core engagement activity remains focused on three main areas- the Antibiotic Amnesty held over World Antibiotic Awareness Week, the Imperial Festival and Schools Outreach.

Antibiotic Amnesty: Our Antibiotic Amnesty was again held in conjunction with Imperial College Healthcare NHS Trust and Lloyds Pharmacy. In addition, we were delighted that the initiative was taken up nationally, by the Centre of Pharmacy Postgraduate Education, in conjunction with PHE, and run through a number of pharmacies nationally. Over 267 people signed up to become Antibiotic Guardians during the event at Imperial and by the end of the week, 14 vials of ceftriaxone, 289 flucloxacillin capsules, 210 erythromycin tablets, 164 penicillin tablets, 23 amoxicillin capsules, 28 cefradine tablets, liquid preparations of

ciprofloxacin, metronidazole and erythromycin and antibiotic eye drops had been handed in. The initiative was “highly commended” in the innovation category of the Antibiotic Guardian Awards last year.

Imperial College Festival: At the time of last year’s report the Unit had made a successful application to participate in the Imperial Festival and was busy planning for the event. The HPRU had a strong presence over both days, with researchers from the Unit hosting a range of activities. These included making DNA bracelets, “[bacterial finger-printing](#)”, “[did you really wash your hands?](#)”, “the choice is yours” (public priorities for research spending) and Gambling with Antibiotics. The latter two activities have subsequently been developed as tools for research and refined in the SPIRIT focus group detailed above. In addition we also developed a “dicing with death” snakes and ladders game showing positive and negative antibiotic-stewardship behaviours and produced a large scale five panel “[illustrated history of antimicrobial resistance](#)”.

These last two resources have been made available as pdfs via our website as part of our schools materials. We have made another application for this year’s festival with some new activities and hope to have good representation again. In addition we are planning and developing an activity for the Schools preview day, along with the HPRU in Respiratory Infection and the HPRU in Modelling Methodology.

Schools outreach: The lesson plans described in last year’s report are finalised and are available on our new website. As part of World Antibiotic Awareness Week, we wrote to all schools in the local area to make them aware of WAAW, the resources which were available via our website and the lesson plan we could support in their school. We wrote to these schools again for British Science Week (March 10-19) and sent materials to encourage them to engage. The details of our lesson plans have been shared with the HPRU in Emerging and Zoonotic Infections who are interested in developing something similar.

Public participation:

Patients and the public are made aware of our research via the Unit newsletter or our website, which has recently been refreshed and re-launched. The Unit, as well as its individual researchers also continue to actively use twitter. Our work is also promoted via our engagement activities such as the Festival, Antibiotic Amnesty and Schools outreach. Material about our work including the PPI/E factsheets we have developed and a “Get involved” leaflet are taken to and actively distributed at each of these events and any appropriate fora attended by members of the Unit. We have written specifically to patient and public organisations with an interest in this area, including MRSA Action and the Patients Association making them aware of our work, website and newsletter.

Healthcare associated infection and antimicrobial resistance (Oxford) HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	
PPIE web pages	
PPIE Strategy	
Contact Name	Dona Foster
Contact Email	Dona.foster@ndm.ox.ac.uk
Contact Phone	01865 222790

Patient and public involvement:

In line with our strategy, we have continued to seek to involve our HPRU PPI representatives in the activities of the HPRU, to gain their perspective on priorities for research and opportunities for dissemination. Jane Binyon was invited to – but unfortunately unable to attend – our Programme Steering Committee meeting and Workshop in December 2016; Bob Butcher also had to send last minute apologies for the Workshop.

The broader MMM consortium – within which the HPRU sits – held a second open meeting on 30th June 2016, at which we presented on the ARMORD study, as well as a school PPE project on handwashing. While this was primarily a public engagement event (see below), the evening included time for discussion, at which we gained input from attendees. We also gave participants the opportunity to express interest in joining our core PPI/E groups, but unfortunately we had no uptake. We are currently considering how best to address this issue.

Public engagement:

We have several strands to our public engagement strategy, all of which are aimed at providing information and knowledge about the HPRU's research, as well as key issues in infection and anti-microbial resistance more generally.

- We have participated in a variety of public engagement events, including Science Museum Lates, Cheltenham Science Festival, and several events aimed at children at the Oxford Museum of the History of Science. We have developed a number of games and other resources for these events, e.g. bug 'Top Trumps'. Details of those aimed at primary school children will be included in a new book by Jules Pottel, and we also plan to develop standalone kits to allow others to create similar resources.
- Dona Foster has completed our handwashing project with a local school, which was presented at the Infection Prevention Society meeting in November 2016. We are now creating a standalone tool kit for teachers, to enable this to be rolled out in other schools.
- Taking a broader stance on raising awareness of infection and anti-microbial resistance, the MMM consortium continues to collaborate with artist Anna Dumitriu, and is developing a new project with a second artist, Lucy Turner, for potential public display at Oxford Brookes.
- To improve communication of our research to the public, we have updated the HPRU webpages and will expand these further over the coming months. The MMM website includes a regular 'blog', to which departmental members contribute and which also includes plain English summaries for key papers. We continue to utilise our two Twitter accounts #ModMedMicro and #MMMDDoingScience.
- As described above, we also held a second public engagement evening in June 2016, at which we shared some of the current work of the HPRU.

Public participation:

Please also describe how you make patients and the public aware of the research being undertaken within your Unit, and signpost them towards appropriate information about participating in research.

We have continued to recruit volunteers to our ARMORD (Antibiotic Resistance in the Microbiome OxfoRD) study, which is looking at how antibiotic use can make bacteria found in the gut more difficult to treat in future, through posters, flyers, and the assistance of a research nurse. As highlighted above, we have expanded our website and Twitter presence, and will add details of individual studies to this going forward.

Health Impact of Environmental Hazards HPRU
Annual Report 2016/17:
Patient and Public Involvement and Engagement (PPIE)

Website	http://hieh.hpru.nihr.ac.uk/
PPIE web pages	http://hieh.hpru.nihr.ac.uk/our-research/ppippe
PPIE Strategy	http://hieh.hpru.nihr.ac.uk/sites/default/files/private/secure/HPRU%20PPIE%20Strategy%20document%2005042016%20FV.pdf
Contact Name	Dr Mireille B. Toledano
Contact Email	m.toledano@imperial.ac.uk
Contact Phone	020 7594 3298

Our Patient and Public Involvement and Engagement (PPI/E) objectives are: (1) embedding PPI/E activities across each thematic area within the HPRU; (2) to build PPI/E capacity through training; (3) to provide support to patient/public representatives through educational resources to enable them to engage with scientists on public-directed research; (4) to present work directly to the public through science events; (5) to undertake research into the effectiveness of our communication strategies; (6) to develop PPI networks/forums to ensure a common approach to PPI/E, sharing of resource and best practice; and, (7) to evolve the evidence base for the effectiveness of PPI/E in directing public understanding of environmental health issues. These objectives and the rest of our PPI/E strategy document can be found on our website (<http://hieh.hpru.nihr.ac.uk/our-research/ppippe>), accessible to both researchers and the general public. Our PPI Strategic Oversight Group includes lay member(s) and PPI Leads from across each theme, under the overall leadership of Mireille Toledano: **Theme I** - Tony Fletcher (PHE) and Anna Hansell (Imperial); **Theme II** - Tim Gant (PHE) and David Phillips (KCL); **Theme III** - Mireille Toledano (Imperial) and Antony Young (PHE); and **Theme IV** - Ian Mudway (KCL) and Rachel Smith (PHE). Members of this board have met throughout the year to discuss progress and to receive guidance from invited experts within the field of PPI/E provision, including Dr Markella Boudioni (NIHR Imperial Biomedical Research Centre (BRC) & Patient Experience Research Centre PPI Lead) and Robin Clarke (Sciencewise). Below we have provided selected highlights of PPI/E over the last year by category and across the Unit's themes.

Patient and public involvement:

PPI training has taken place across themes, in line with our second PPI/E objective. This training includes a screening of 'People are Messy', a Theatre of Debate film that engages its audiences in an informed debate around PPI and the social and ethical issues that it raises (May 2016), and PPI training to address the challenges of HPRUs at Imperial College London (July 2016), led by a past director of INVOLVE. Researchers have also attended Experience Matters workshops to build understanding of PPI in research (November/December 2016); one-to-one PPI coaching was also offered through the Imperial College London NIHR Patient Experience Research Centre, particularly to lab-based projects, as well as via MRC sponsored training, as part of preparation for their Festival of Science Event in June 2016.

With regard to the third objective of facilitating public-directed research, members of **Theme III** (SCAMP study, July/August 2016) hosted two work experience pupils and gave science talks to a number of GCSE and A Level groups at SCAMP schools. Additionally, focus

groups with parents were held when first piloting the air pollution and traffic additions to the personal monitoring study. Focus groups and school Q&A sessions were also held to understand the effectiveness of SCAMP's communication strategies. In addition, we have recently received funding from the ESRC Impact Acceleration Account at Imperial College London to undertake a project aiming to identify barriers to study participation and provision of consent for data linkage in seldom-heard groups in the SCAMP cohort and initiate a dialogue on how to gain trust with seldom-heard individuals, and then to catalyse translation of this knowledge into practice at Imperial College London. This will involve focus groups with individuals from seldom-heard groups, with the objectives of a) establishing barriers to consent provision for data linkage and participation in the exposure validation assessment and bio-sampling in seldom-heard individuals/communities, b) co-producing specific, actionable solutions to increase consent and bio-sampling and exposure validation participation in the SCAMP cohort and c) discussing more widely how to address barriers to participation in research. A symposium will then be held for Imperial College London researchers. The symposium's objectives are to a) share results of the focus groups with other Imperial College researchers regarding engagement of seldom-heard groups and b) catalyse discussion and knowledge-sharing between researchers regarding engaging seldom-heard groups in research.

In **Theme IV**, the NIHR-funded Breathe London website (<http://www.breathelondon.org/>) continues to promote moderated citizen science projects based on the access to personal air pollution monitors, under the direction of the general public. This website allows members of the public to examine how to breathe cleaner air in different scenarios (eg. going for a run, on their commute and at work, and in their neighbourhood), enables easy access to the air pollution forecast and provides a route planner. If their concern is not answered through the website, they can propose a project of their own, with an easy and accessible form to fill in. Furthermore, a joint Community Advisory Board (CAB) with the MRC-PHE Centre for Environment and Health provides another forum for PPI/E and engaging the public with scientists to facilitate public-directed research. The CAB includes Paul Braithwaite (Ex Chancellor of Camden Borough and clean air activist), Monica Robb (Heathrow Association for the Control of Aircraft Noise), Andrea Lee (Healthy Air Campaigner, ClientEarth), Jacob Hayler (Environmental Services Association (Waste Industry)), Emily Jesper (Assistant Director of Sense about Science) and Danny Ruta (Director of Public Health, NHS Lewisham). We are currently looking to add representation from other groups including the British Lung Foundation and the British Heart Foundation, and through these links patient representation. This CAB is one of the ways we are developing a forum to ensure a common approach to PPI/E, sharing of resource and best practice (objective 6).

Public engagement:

In order to further engage the public, we have created a number of educational/information resources. The HPRU's website (<http://hieh.hpru.nihr.ac.uk/>) provides information about the HPRU's research activities, team, partners and events, and also has a specific page on PPI/E. This site has had 1,300 unique users since January 2016. Additionally, members of **Theme IV** launched the City Air mobile app at the end of 2016 as a tool for the public to try and reduce their exposure to air pollution; to date, the app has had over 4,700 users. Researchers across the themes have presented at science events including: From Black Cabs to Black Bogeys: Measuring London's Air Quality (May 2016), Pea Soup House – with Royal Institute of British Architects (June 2016), and Human Sensor – with Invisible Dust (July 2016). We also participated in the Environment and Health Question time at the MRC

Festival (June 2016), regarding emissions from waste incinerators (**Theme I**) and air pollution and noise around Heathrow (**Theme IV**). The Question Time Panel included David Pencheon (Director, NHS Sustainable Development Unit), Caroline Russell (London Assembly Member and Councillor for Highbury East ward in Islington, transport spokesperson for the Green Party), Frank Kelly (Chair of the Committee on the Medical Effects of Air Pollutants, Professor of Environmental Health at King's College London), Sile Lane (Chair, Director of Campaigns and Policy at Sense About Science), Andrea Lee (Healthy Air Campaigner at Client Earth) and Tony Halmos (Director of the King's Commission on London and a Visiting Professor at the Policy Institute, King's College London). Additionally, we presented at the Life Bank Science Exhibition (June 2016), which involved putting on an interactive science exhibition on waste noise, air pollution, the lung, electromagnetic fields and the exposome (covering all themes). The New Scientist Live event (September 2016) provided another opportunity to do engagement work across all HPRU themes, including radiation and epigenetics and UV, nanoparticles, environmental chemicals and air pollution to 22,000 people. This event was repeated this year on a larger scale led from **Themes II** and **III** (September 2017). Additionally, **Theme IV** researchers were involved in the Space to Breathe event (January 2017), presenting work on transport emissions and noise to the public through an event which championed creative action in response to London's air pollution crisis. Thus, we have presented at a number of science events, delivering objective 4.

Public participation:

Members of the public are taking part in and having access to research across all four themes. This to date has mainly been via the air pollution (**Theme IV**) and EMF (**Theme III**) research, but discussions are ongoing to promote greater engagement across all of the HPRU themes.

Therefore, this year we have delivered objectives 1-4 and 6, having made progress in embedding PPI/E activities across each thematic area within the HPRU; building PPI/E capacity through training; providing support to patient/public representatives through educational resources to enable them to engage with scientists on public-directed research; presenting work directly to the public through science events; and developing PPI networks/forums to ensure a common approach to PPI/E, sharing of resource and best practice. In the upcoming year, we will continue to expand our PPI/E in each of these areas, across all four themes. For example, we shall continue to achieve our goal of presenting our work to the public at prominent science events including the MRC festival, the Imperial festival and the New Scientist Excel event (including a confirmed lecture on air pollution and health). We also aim to build capacity, create educational/information resources and undertake research into the effectiveness of our communication strategies through our public engagement proposal: "Is waste rubbish for your health?" This bid will focus on waste industry studies on incinerators, breast milk and biocomposting (**Theme I**). Furthermore, we are developing a cross-HPRU proposal: "Evaluating Public Perceptions of Biomarker Research in Environmental Health". This will involve a Collaboration between the NIHR-HPRU's in Health Impact of Environmental Hazards and Chemical and Radiation Threats and Hazards, the NIHR BRC Patient Experience Research Centre (PERC) at Imperial, and the Imperial and Partners PPI Research Forum. This collaborative cross-HPRU proposal will achieve objectives 5-7.

Immunisation HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://immunisation.hpru.nihr.ac.uk/
PPIE web pages	http://immunisation.hpru.nihr.ac.uk/our-research/ppie
PPIE Strategy	http://immunisation.hpru.nihr.ac.uk/sites/default/files/js/wysiwyg/HPRU%20in%20Immunisation%20PPIE%20Strategy%20Jan2017.pdf
Contact Name	Pauline Paterson
Contact Email	Pauline.paterson@lshtm.ac.uk
Contact Phone	0207 927 2830

Patient and public involvement:

The strategic aim of our patient and public involvement is to improve the quality and relevance of research in immunisation by the HPRU. In alignment with this strategy we have carried out the following:

- Value of vaccination; a discrete choice experiment. In this project, we invited 1500 members of the general public to make choices regarding the benefit and dis-benefit of vaccination using a discrete choice experiment (see public participation – below). A discrete choice experiment consists of two parts; before administering the experiment it is important to make sure that we are seeking the right information and that the questions we pose will be understood. At this research development stage we consulted with the general public in two samples. The first was a small group consisting of lay members of the HPRU, colleagues, friends and family-members. In a second group, a wider group of end users (~60 people), we tested whether the questionnaire was well received and understood. The iterative public feedback improved the questionnaire considerably.
- Understanding and improving vaccination uptake and access to health services amongst recent migrants from Poland and Romania: A qualitative study. In the design of this qualitative study, which looks to explore vaccination uptake and health service access amongst Polish and Romanian migrants, we have sought input and feedback from key contacts involved in the management and delivery of the immunisation programme in England (e.g. members of Screening and Immunisation teams, Public Health consultants - PHE and Local Authority, health care professionals providing immunisations, Directors of Public Health etc.). Through these discussions, the underlying rationale for conducting this research project was established and recruitment areas/sites identified. We next involved a Polish community group (Lincolnshire Polish Society) in the development of the study documents, i.e. the participant information sheet/consent form/interview topic guide. This increased the relevance and usefulness of the study, and we hope it will promote study recruitment. Contacts were established with members of the Lincolnshire group, who are keen to be involved in the study, and we met with them in April 2017.
- Understanding the science relevance of Electronic Health Records. The Theme 1 PPIE and Research leads met with the London Data Science Facilitator and Public Engagement Coordinator of the Farr Institute, to plan to involve the public in electronic health record research on vaccination. Follow up meetings have been scheduled to discuss funding proposals for Involvement activities (May 2017)

Public engagement:

Our public engagement strategic aim is to raise awareness of our research at the HPRU and to share knowledge of research about vaccines. In alignment with this strategy and our PPE plan, members of the NIHR HPRU in Immunisation have participated in several science events open to the public with debates or discussions on research in Immunisation. These are listed below in chronological order:

- The Theme I lead represented the HPRU in the Pint of Science evening: “Are your Healthcare Records Transforming Research?”, presenting the case for the importance of healthcare records in vaccine research and engaging in the subsequent panel discussion. Pint of science events occur in pubs throughout the country, are open to the public and involve informal discussion. (05/2016) <http://ehr.lshtm.ac.uk/news/pint-of-science-are-your-healthcare-records-transforming-research/>
- A Theme 1 PhD student continued to deliver a short course to 24 high-performing school students on the study of vaccine safety, as part of the Brilliant Club (March-Sept 2016). The Brilliant Club is a charity dedicated to the reduction of inequalities in access to highly selective universities. (09/2016)
- A second Theme 1 PhD student met with a charity called South London Cares, along with some other LSHTM students, to talk about her work with interested older members of the public. (03/2017)
- A member of Theme 1 attended the Women in Science day at Tolworth Girls School and engaged approximately 300 students in discussion about immunisation research. This was a 'speed-dating' event, with 10 minutes to talk to each group of Year 7 and Year 12 girls over the whole day. (10/2016)
- Several members of the HPRU presented at the joint LSHTM and WHO meeting ‘Measles and rubella in Europe: A Process of elimination’ on ‘Understanding vaccine hesitancy’ and were interviewed on a video podcast (09/2016). <https://www.youtube.com/watch?v=KZ28ZTObj6A&feature=youtu.be>
- A member of Theme II represented the immunisation HPRU at the Science Museum Late (10/2016). As a part of the wider contribution by LSHTM, which was on Ebola, Theme II focussed on Ebola vaccination, herd protection and the ring vaccination.
- A researcher from theme 3 gave a pub talk in Canterbury (11/2016) about vaccine hesitancy during pregnancy. This was attended by around fifteen people and generated good discussions and feedback. (<http://blogs.kent.ac.uk/staff-student-news/2016/10/25/novembers-pubtalk-with-special-guest-speakers/>)
- The PPIE coordinator and researcher for theme 3 presented and was a panel member at ‘RISE - Re-Inventing Sanofi Pasteur in Europe Meeting’, Prague, Czech Republic (01/2017).
- Katherine Atkins, Mark Jit and James Munday collaborated with LSHTM’s Centre for Mathematical Modelling of Infectious Diseases (CMMID) to run a very well-attended stall at the “Science Museum Lates” at the British Science Museum, events that occur at night at the museum for adults. We co-ran the simulated “epidemic” during the evening and discussed vaccination with guests.
- The Royal Society is making a short film to promote the special issue on Ebola. Katherine Atkins will be interviewed for the film which will be available through the Royal Society website.

- John Edmunds gave a talk on epidemics and vaccine responses at Burnham Grammar School.

Several members of the HPRU underwent training in PPIE.

Public participation:

Our public participation strategic aim is to explore public perceptions and views of vaccines and immunisation programmes to help inform immunisation programmes in England. In alignment with this strategy we are in the process of undertaking the following research studies:

- *Value of vaccination; a discrete choice experiment*. In this project, we studied the preferences of the general public regarding the benefit and dis-benefit of vaccination using a discrete choice experiment. We sampled 1500 UK citizens using quota sampling to reflect all socio-economic strata, and 10 year age groups from 20 to 60+ years.
- *Reducing the incidence of vaccine preventable diseases in the Charedi, ultra-orthodox Jewish community, London, United Kingdom, through tailoring immunisation programmes*. To explore parental views of childhood vaccines and immunisation services and reasons why parents may delay or not vaccinate their children, we interviewed 10 parents and 10 key informants in the Charedi ultra-orthodox Jewish community in North London. We presented our findings in April 2016 to community members, a senior Rabbi, NHS commissioners and providers, General Practice staff, PHE, WHO, Government and LSHTM. We have incorporated findings from our analysis into a report on the implementation of the WHO Tailoring Immunisation Programme in the Charedi community, which has been published on PHE and WHO websites.
- *Vaccination in pregnancy: understanding the factors influencing uptake*. A PhD study involving in-depth interviews to understand factors influencing vaccination acceptance during pregnancy among women from minority ethnic groups in Hackney, London. The PhD student completed data collection in June 2016 (40 interviews and 1 focus group with pregnant or recently pregnant women, 10 interviews with health professionals, and a video recording of a pregnancy consultation)

Understanding and improving vaccination uptake and health service access amongst recent migrants from Poland and Romania: A qualitative study. This study uses qualitative interviews and focus groups to explore attitudes and behaviours towards recommended vaccinations amongst recent migrants to England from Poland and Romania. Following consultations with the Polish community in the UK (Lincolnshire) we intend to conduct qualitative interviews with Polish and Romanian migrants, recruited through community venues, that have lived in England since the accession of EE countries to the EU (EU8 countries, including Poland, in 2004 and EU2 countries, including Romania, in 2007). Following interviews, focus groups will be conducted with a sub-sample of Polish/Romanian migrants to discuss any identified barriers to health service access, delivery, and vaccination uptake. The aim of the focus group(s) is to facilitate the discussion of potential service improvements.

Modelling Methodology HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	https://www.imperial.ac.uk/hpru-modelling
PPIE web pages	http://www.imperial.ac.uk/hpru-modelling/involvement-and-engagement/
PPIE Strategy	http://www.imperial.ac.uk/hpru-modelling/involvement-and-engagement/
Contact Name	Maria Piggin
Contact Email	m.piggin@imperial.ac.uk
Contact Phone	0207 594 9774

Patient and public involvement:

PPIE Strategy: The existing PPIE strategy has been updated for 2017 with inputs from HPRU staff and the HPRU's Independent Advisory Board (IAB) lay member who is also a member of the Behaviour and Economics theme's PPI group (see below). The HPRU has also benefitted from the advice and support of a Patient and Public Involvement Officer, Maria Piggin, whose time is shared with three other Imperial College linked HPRUs.

Independent Advisory Board (IAB) Lay Members: John Phipps was appointed as a lay member of the HPRU's IAB and attended the IAB meeting on 16 March 2017. Once the Patient and Public Panel is established this year (as described in Objective 5(b)1) of the PPIE Strategy and the Forward Plan), we expect to recruit an additional lay member to the IAB.

Zika in Colombia - Characterisation of Exposure & Epidemiology in a Flavivirus Setting: Neil Ferguson, Christl Donnelly, and Pierre Nouvellet have been leading an in-country project in Colombia to conduct sero-surveys at four sites to assess exposure to arboviruses within the general population (including exposure to Zika). During the sero-survey, an information sheet was read to participants and questionnaires were completed. Prior to conducting surveys, we engaged with local community leaders and local health services as to how to best phrase - verbally - the content of the questionnaire and information sheet. Due to low literacy rates in many areas surveyed, a member of our team would typically read the content of information sheets and surveys to participants. Differences in languages are quite common in Colombia, therefore this consultation helped refine our protocol and use of language to best communicate with participants. This project has also received support from the Medical Research Council (MRC) and Wellcome Trust. Further public engagement and involvement is planned on this project as set out in the Forward Plan.

Behaviour and Economics Theme Public and Patient Involvement Group: A group of 8 members of the public were recruited through Public Health England (PHE)'s People's Panel and attended an Introductory Workshop at Skipton House in London on 30 September 2016. Richard Amlot, Katharina Hauck and Dale Weston asked the group to input on two of their current projects. Feedback was gathered on a literature review paper for the first project entitled "Understanding the Role of Human Behaviour in Modelling the Spread of Infectious Diseases". For the second project entitled "Influenza, Social Preferences and Attitudes to Risk: A Scoping Study", members of the public undertook an exercise to assess various questions relating to measuring risk, time and social preferences. The feedback provided by the group was incorporated into both the literature review paper and used to select questions used in an actual experiment on measuring risk, time and social preferences. An introductory

presentation by Ian Hall on infectious disease modelling at the workshop was recorded for future use in PPI projects and for it to be uploaded to the website as a public engagement tool. Members of this PPI group have since taken part in conference calls in January and March 2017 where they: received updates on how their involvement impacted the two projects; discussed the proposed PPI plans in another HPRU funding application; and reviewed a questionnaire concerning perceptions of and attitudes towards seasonal influenza and influenza vaccination to form part of Project 2. A further face-to-face workshop is planned for May/June 2016 to focus on completing input into Projects 1 and 2 and to discuss next steps in terms of both extensions to Project 2 and future PPI work on related projects. Members of this group will be invited to join the HPRU in Modelling Methodology Patient and Public Panel being established in 2017 for use as a resource by all themes across the HPRU (as described in the Forward Plan and in furtherance of Objective 5(b) of the PPIE Strategy).

LoL Lab 2017: Nathan Green secured a small grant from the Imperial Biomedical Research Centre to undertake a PPI project. In the spirit of the existing model of “Brightclub”, “Pint of Science” and “Science Show-Offs”, LoL Lab was a collaboration between 8 Imperial College researchers (5 of which are infectious disease modellers) and 7 local members of the public to create, rehearse and perform a series of comedy sets based on each scientist’s research. The sets were performed at a stand-up comedy event to a general public audience at a theatre local to St Mary’s Campus. Three evening workshops took place between 21 February and 7 March 2017, attended by researchers and the public and facilitated by an expert comedian and coach. The final event was held on 21 March 2017 at the Canal Cafe theatre in North West London and was attended by 48 members of the public. The workshops presented researchers with a unique opportunity to involve members of the public in the dissemination of their research (some of which is quite complex) in a way that was easy to understand and enjoyable. Evaluation of this project was undertaken (pursuant to Objective 5(c) of the PPIE Strategy) by asking a series of questions to the researchers and members of the public both before and after the series of workshops. One member of the public stated that they had learned more about how scientific research is carried out in the UK than they knew before the workshops and they were “glad attempts to make it more user-friendly and open it up to the public”. One researcher stated they had learned that “the language used by scientists doesn’t necessarily mean the same thing for non-scientists”.

Mixdiff Project – “Typo challenge”: In order to develop software to analyse epidemic data to estimate important epidemiological delays, infer missing dates and identify dates recorded in error and infer the distribution of potential “true” dates, Anne Cori and Marc Baguelin created a “Typo Challenge” to gather data about date typing errors from a large cohort of members of the public. To optimise the publicity material (a website and video explanation of the Typo challenge) for this project and to improve its dissemination to maximise the number of people who would participate, 9 members of the public were recruited to attend two evening workshops one month apart (in March & April 2017) to give input into the design of these materials. The feedback provided by the members of the public at the workshops is being utilised to upgrade the “Typo Challenge” and to create a video and a website explaining what the data collected will be used for and its importance in infectious disease modelling. This website will also serve as a public engagement resource. In accordance with Objective 5(c) of the PPIE Strategy, the PPI undertaken on this project is being evaluated through the use of benchmarking questions completed by both researchers and members of the public prior to and after taking part in the workshops.

Training of PPI Representatives: In furtherance of Objective 5(d) of the PPIE Strategy, on 10 April 2017, two members of the Behaviour and Economics PPI Group (including the IAB lay member) attended a one day course delivered by the Training theme of the HPRU entitled “Introduction to Infectious Disease Modelling to Inform Policy Making.” The IAB lay member, John Phipps also attended the Joint HPRU Research Meeting on 16 March 2017.

The Twitter handle is used to disseminate opportunities for the public to get involved in our work.

Public engagement:

Cosy Science 2016: On the 27th of September 2016, Modelling Methodology HPRU Modelling Lecturer, Dr Pierre Nouvellet hosted a ‘Cosy Science’ café-scientific evening talk to 50 members of the public on the epidemiology of the Zika virus. This was organised by Mickael Escudero from the Francis Crick Institute in the Cittie of York, London. He discussed the origins of the Zika virus, its transmission potential, some of challenges faced in combating the Zika epidemics, the ways in which public health policy can respond to the epidemic, and how research in our unit was actively engaged in characterising Zika epidemiology. The presentation was followed by a lively discussion where the public raised some thought-provoking questions and raised additional concerns.

Imperial Festival 2016: In August 2016, several Modelling Methodology HPRU members participated in the Green Man science festival, where they ran a stall focusing on outbreak response and how modelling can be used to inform crisis decision-making.

Green Man 2016: Modelling Methodology HPRU researchers have also developed lower-tech activities that are targeted at younger age ranges. Primary among these have been the development of a ‘Pandemic Potential’ Top Trump card game and ‘Sneeze Art’, an activity that uses food dye-filled squirty bottles to represent the spread of germs through sneezing. Both activities were launched with enormous success at the Centre ‘Einstein’s Garden’ stall at the Centre’s Green Man Festival in August 2016. Pandemic Potential has subsequently been expanded to double the number of disease cards in the deck and this larger deck will be trialled at the upcoming Imperial Festival 2017.

Collaboration with Emerging and Zoonotic Infections (EZI) HPRU. School Engagement: On 16 May 2016, Emma Bennett together with colleagues from PHE ran a “Tick Awareness Day” at Gomeldon Primary School (with which PHE has close contacts). This involved approximately 150 children (aged 4 to 11 years) rotating in small groups around three activities: tick identification; tick ecology and collecting, and tick bite risk and prevention.

On 18 January 2017, Emma Bennett, Hannah Williams and Adrian Pratt (EZI HPRU) also ran an “Epidemic Outbreak Day” at Gomeldon Primary School. A school-wide sticker epidemic illustrated the dynamics of an infectious disease, and Key Stage 2 students took part in two activities to demonstrate transmission of disease and the work undertaken by public health scientists.

Resources for schools: Ian Hall, Emma Bennett, Hannah Williams and Adrian Pratt (EZI HPRU) succeeded in securing a grant from HPRU (EZI) to collaborate with them to create educational resources and guidance for primary schools in order that they can hold their own “Tick Awareness Days” and “Epidemic Outbreak Days”.

Public participation:

Public engagement events such as Lol Lab and the Imperial Festival spread public awareness about research undertaken within the HPRU.

However, because much of the research undertaken in the HPRU is carried out on existing data sets there are not as many opportunities for the public to be participants in our research. The Mixdiff project (set out above) is an example of a project where data does need to be collected from members of the public. It is anticipated that the advice from the PPI group

working on this project will enhance the dissemination of the opportunity for the public to participate in the “Typo Challenge” and enhance this research.

New MM HPRU website and twitter handle launched in 2017:

Both of the following media will be utilised to promote and advertise opportunities for patient and public involvement, public engagement and public participation in the HPRU.

<https://imperial.ac.uk/hpru-modelling>

https://twitter.com/MM_HPRU

Respiratory Infections HPRU

Annual Report 2016/17:

Patient and Public Involvement and Engagement (PPIE)

Website	http://www.imperial.ac.uk/medicine/nih-hpru-respiratory-infections/
PPIE web pages	http://www.imperial.ac.uk/medicine/nih-hpru-respiratory-infections/engagement-and-involvement/
PPIE Strategy	http://www.imperial.ac.uk/media/imperial-college/medicine/nhli/nih-hpru-in-respiratory-infections/PPI-PE-Strategy---NIHR-HPRU-in-Respiratory-Infections_2015_2017.pdf
Contact Name	Aime Boakye
Contact Email	afua.boakye12@imperial.ac.uk
Contact Phone	020 7594 0884

Patient and public involvement:

Excellent progress with Patient and Public Involvement (PPI) has continued with the establishment of our Patient and Public Involvement Panel as per objectives 1 and 2 of our PPIE Strategy 2015-17. The panel will be a strategic PPI resource available to all members of our HPRU to provide them with continuous support and assistance with PPI and ensure our research is shaped by the patient and public voice. The Panel has been set up and is chaired by our HPRU-funded PPI/PE Lead Aime Boakye with support from the NIHR Imperial Biomedical Research Centre (BRC)/HPRUs Patient and Public Involvement Officer, Maria Piggin. Further details about the Panel are set out below. The NIHR Imperial BRC has offered a number of training opportunities throughout the year to improve awareness and understanding of PPI and Public Engagement for researchers and public representatives through training and resources which have been well-attended by our HPRU. The NIHR HPRU in Respiratory Infections continues to have strong partnerships with collaborators and 3rd sector organizations such as TB Alert and Doctors of the World.

International Scientific Advisory Board Lay Representatives

Since Michael Goold, our lay and International Scientific Advisory Board (ISAB) chair, has been inactive this year, we invited an additional Lay Member to join our ISAB, Zoe Portlock, who is Director of Services at the Bromley-by-Bow Centre. The Bromley-by-Bow Centre is an innovative community organisation in east London, working in one of the most deprived boroughs in the UK. They support families, young people and adults to learn new skills, improve their health and wellbeing, find employment and develop community-wide resilience. The Centre is recognised by PHE as a leading UK model for delivering sustainable health

and addressing health inequalities, particularly in immigrant communities and Prof Lalvani, our HPRU Director, is the Chair of the Centre's Board. We are delighted that Zoe has joined our HPRU ISAB and will input into our future research strategy and projects.

Public Involvement in Live Attenuated Influenza Vaccine (LAIV) Study Recruitment

Two work experience students joined us at the TB research centre from the 27th June 2018 for a week where they created a poster for the LAIV study to help recruit an unvaccinated group of study participants in the second year of the study. 17 students were subsequently enrolled into the unvaccinated group.

Patient and Public Panel

The NIHR HPRU in Respiratory Infections strives to ensure that the patient and public voice impacts our research priorities, strategies, projects and functions making sure our research is accountable, transparent and relevant to the public. Therefore, we have recruited a panel of patients and members of the public to help us identify, plan and design our research across all of our research themes. The panel currently consists of 7 patients affected indirectly or directly by Respiratory Infections and members of the public both with and without previous experience of PPI. We are endeavouring to recruit additional members with TB specific experience as this area of respiratory infections is not currently well represented on the Panel. We held our first panel meeting on 23 January 2017 which included undertaking an audit of PPI training needs of the members in order that we can address these in future meetings. Together with Panel members, we co-designed a Terms of Reference document (including a detailed Role Description) which governs the Panel. Our next panel meetings are planned for June and October 2017. Since the establishment of the Panel, we have had support from various Panel members to assist with two research projects.

1) Two members of the panel (one experienced in PPI and one not experienced in PPI) have reviewed patient information leaflets and consent forms to aid the recruitment and continuation of our TB diagnostics theme.

2) Two Panel members (one experienced in PPI and one not experienced) have reviewed an information leaflet which is going to be used in PPI interviews with patients who have previously been treated for Multi Drug Resistant (MDR) TB. These interviews helped support the application for MDR TB clinical, social and financial prospective cohort project. We intend to work with our Patient and Public Panel to initiate a variety of project-specific methodologies for measuring the impact of our PPI work. This is a new proposed objective in our PPIE Strategy 2017-19. We will also ask the Panel to review and update our existing PPIE Strategy 2015-17 so that it captures our aims and objectives to the current end of our HPRU funding in March 2019. Members of our Patient and Public Panel are rewarded for their contribution in accordance with the NIHR Imperial BRC Rewards, Payment and Recognition Guidance for Patient and Members of the Public involved in Research. Members were recruited to this Panel through our Twitter handle and by way of advertisement on the "People in Research" website.

Website and Social Media

Objective 4 of our PPIE Strategy 2015-17 addresses our website and social media plans. The website is being updated and upgraded this year to include PPI information about our work (and will soon include PPI opportunities and ways to get in touch). In addition, we have

established a twitter feed which keeps the public up-to-date with events being held with NIHR HPRU in Respiratory Infections, including PPI opportunities.

PPI Training

Nine members of the HPRU attended PPI training as per objective 1 of our PPIE Strategy 2015-17 provided by the NIHR Imperial BRC in June 2016 and delivered by external trainers. This HPRU-tailored training was undertaken with the Imperial HPRUs in Healthcare Associated Infections and Antimicrobial Resistance (HCAI/AMR) and in Modelling Methodologies.

Public engagement:

During this year, we have organised the following public engagement events as per Objective 3 of our PPIE Strategy 2015-17:

1) Two of our research theme leaders, Dr Richard Pebody and Dr Katja Hoschler, and our research nurse presented at a career in science evening at one of the LAIV study sites on the 15th September. They presented to parents and students aged 15-18 years old on influenza and vaccinations. The students were extremely engaged and asked appropriate questions to all three presenters. As a result, we have 2 students scheduled to come to HPRU for work experience in summer 2017.

2) Our quarterly research symposium series continues together with our Annual HPRU Research Symposium, with invitations extended to all our ISAB, patient representatives, collaborators and colleagues, to allow our researchers to disseminate and discuss their project findings.

3) Our Research Assistant/ PPI/PE lead and our Research Manager worked as “shop assistants” for the National Heart and Lung Institute Convenience Store at the Imperial Festival on 8/05/16. We talked to the members of the public about the various lung infections and heart diseases including Tuberculosis and Flu. The festival attendees asked questions and were actively engaged with our research. The NHLI Convenience store also used interactive demonstrations, exhibits and activities to show existing and future therapeutic interventions.

4) Professor Ajit Lalvani was a key member on the panel at the “Engagement to End” TB event at the University of East London. This was part of the Voices for London Festival which was attended by community members of East London. Helen Piotrowski (Clinical Research Nurse) also attended as an audience participant. 5) Members of the research team and theme leaders have an excellent track record in active engagement with patients and public. Professor Ajit Lalvani and Dr Luis Berrocal Almanza have presented ‘lessons learned’ from our stakeholder events with third sector organisations in the development of COMBAT, our study plan for community-based actions to control TB. This has been presented at The Well North Conference in Manchester on 01/07/2016 and Barcelona Public Health Service on 22/11/16.

5) Dominik Zenner (PHE Lead for TB screening) was interviewed by the TV presenter Victoria MacDonald for a Channel 4 News special edition on the National TB Strategy. Furthermore, Luis Berrocal Almanza (HPRU TB epidemiologist (studies patterns, causes and

effects of health and disease) and Helen Piotrowski (Clinical Research Nurse) had an informal discussion with Victoria MacDonald prior to this, and helped facilitate an interview with Dr Duncan Trathen, Lead GP at Newham Transitional GP Practice Trust, a GP practice in East London offering specialist respiratory services due to the high incidence of TB in the area. This was aired on Channel 4 news on the 20/10/2016.

7) Dr Oisin Wall, the leading Research Curator for the new £24m Medicine Galleries at the Science Museum, interviewed HPRU staff to use our specialist input and knowledge of TB and the history of respiratory disease to inform the development of the new galleries which will open in 2019. Helen Piotrowski facilitated a visit for Dr Wall to our collaborators at The Shrewsbury Road Surgery, a frontline GP clinic in East London which again treats patients with a high burden of the respiratory diseases we are researching. This visit enabled Dr Wall and our researchers to learn more about the real-life issues driving demand for NHS respiratory services. Further work and collaboration on this project is expected.

Public participation:

Current studies requiring volunteers have not been open to participation by the wider public, as the LAIV study is being conducted in two schools, Loughborough and Oakham, with existing links to Public Health England (PHE). Similarly, the “LAIV Immuno” study was restricted to GP sites in two counties only, Hertfordshire and Gloucestershire. The S-CAP study (**S**evere **C**ommunity-**A**cquired **P**neumonia) is open to patients fulfilling the eligibility criteria at any of the 7 hospitals with ethics clearance and nurses are trained to offer the opportunity to participate in studies to any suitable patients. In the future, the LCA60 monoclonal antibody (a new drug being tested) for Middle East Respiratory Syndrome (MERS) CoronaVirus phase 1 study (first in human) will be open to enrolment from healthy volunteers within reasonable travelling distance from London. We will advertise in London newspapers and through the NIHR/Wellcome Trust Imperial Clinical Research Facility’s (CRF) website to attract volunteers. This is likely to commence in late 2018. We also anticipate that our Patient and Public Panel will be able to advise us as to alternative and additional ways to recruit study volunteers and ways to increase the number of study participants and how to ensure study participants do not drop out over the course of the study.
