



## NIHR-HPRUs in Environmental Exposures and Health and in Chemical and Radiation Threats and Hazards

# Public and Community Involvement, Engagement and Participation (PCIEP) Strategy

This Strategy was drafted collaboratively by our Public Community Oversight Group (PCOG)

Strategy Working Group and our Joint Steering Committee (JSC)

March 2021





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#### **Abbreviations**

Abbreviation	Meaning
HPRU	Health Protection Research Unit
EEH	Environmental Exposures and Health
CRTH	Chemical and Radiation Threats and Hazards
PCIEP	Public Community Involvement Engagement and Participation
PCOG	Public Community Oversight Group
JSC	Joint Steering Committee
ECR	Early Career Researcher
YPAN	Young Persons' Advisory Network
PHWE	People in Health West of England





#### 1.Introduction

This document sets out the ambition, commitment and objectives of the National Institute for Health Research (NIHR)-Health Protection Research Units (HPRUs) in <u>Environmental Exposures and Health</u> (EEH) and in <u>Chemical and Radiation Threats and Hazard</u> (CRTH) for Public and Community Involvement, Engagement and Participation (PCIEP) between 2020 – 2025. It also sets our approach for involving the public and community in all stages of our research.

This Strategy was drafted collaboratively by our Public Community Oversight Group (PCOG) working strategy group and our Joint Steering Committee (JSC) (Appendix I) and was informed by the NIHR INVOLVE National Standards for Public Involvement in Research and the Going the Extra Mile Policy Review.

#### 2.Terminology

Throughout this document we use <u>NIHR INVOLVE</u> definitions for including the public in research, namely:

**Public** - includes patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.

**Involvement -** where members of the public are actively involved in our HPRU research projects e.g. in focus groups, providing feedback on information leaflets, acting as members of Advisory Boards etc.

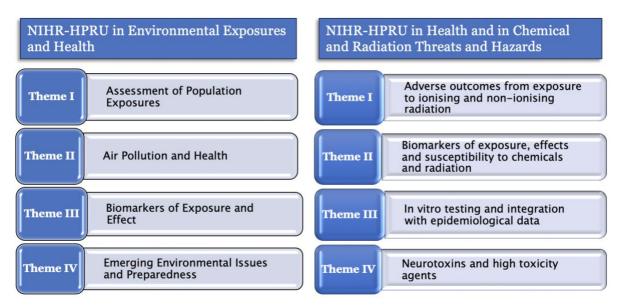
**Engagement/Outreach** -Where information and knowledge about the research of our HPRU is provided and disseminated e.g. through media stories, science festivals, newsfeed via social networking sites etc.

**Participation** — where members of the public take part in our research studies e.g. they are recruited into a cohort study as a participant.

#### 3. Background to this document

The NIHR HPRUs in Environmental Exposures and Health and in Chemical and Radiation Threats and Hazards are led by Imperial College London in partnership with Public Health England, King's College London and the MRC Toxicology Unit, Cambridge. The two HPRUs were inaugurated on the 1<sup>st</sup> April 2020.

The aim of these two closely clustered and collaborating HPRUs is to undertake the highest quality research on the health effects associated with exposure to a range of major environmental pollutants, including ambient and indoor air pollutants and other chemical and radiation threats. The themes covered by each HPRU are illustrated in Figure 1. The purpose of this research is to advance our understanding of how the contact with these environmental hazards leads to ill-health and produce evidence that will support the development of policies and regulations that will improve the long-term health of the population as well as to anticipate future unknown risks.



**Figure 1:** Thematic areas of research addressed by the HPRUs in Environmental Exposures and Health and in Chemical and Radiation Threats and Hazards

#### 4.PCIEP strategy vision

Our vision is to achieve meaningful public and community involvement embedded across the entirety of the two HPRUs with active consultation and collaboration with the various research Themes. To achieve this, we will ensure active public engagement is undertaken across the Themes with a proactive approach to make our work accountable, transparent and relevant to the public. An important aspect of our vision is to ensure that patient and public voice can impact on the development of our research strategies, it's effective delivery and the tailoring of key findings for dissemination across a range of stakeholder groups.

#### 5.Aim and objectives

To engage with and involve the public in a scientific dialogue on environmental health to ensure that the impact of our research extends beyond academic and policy realms and is responsive to the concerns of the public.

#### **Objectives**

#### Early milestones (6-12 months)

<u>Objective 1 to embed PCIEP</u> in the two HPRUs across all levels with active consultation, collaboration monitoring, reporting, evaluation and learning from the PCIEP activities undertaken in the various research projects.

<u>Objective 2</u> to ensure that the public and community voice impacts our research strategy, projects and functions through the establishment of a PCOG, with representation from vulnerable patient groups, public health practitioners, Non-Governmental Organisations (NGOs), government and industry.





Objective 3 to develop collaboratively a PCIEP Strategy with PCOG members and the JSC.

#### Medium term milestones (0.5-3 years)

<u>Objective 4</u> to expand on diversity by developing links and networks with interest groups to allow wider dissemination of information about our research and events to the public and community. We will also explore novel and innovative ways to develop our PCIEP programme.

<u>Objective 5</u> to build PCIEP capacity and expertise throughout the HPRUs by provision of training and regular meetings with other PPI networks in other NIHR funded organisations, to share examples of best practice.

<u>Objective 6</u> to develop, with consultation with the PCOG and other groups, educational and public health resources for the public to promote the level of understanding around the risks of environmental exposures to health.

<u>Objective 7</u> to communicate work directly to the public through high impact events such as New Scientist Live in London, and various science festivals at local and regional level.

<u>Objective 8</u> (evaluation) To continuously evaluate the process, implementation and impact of our PCIEP activities, in order to drive improvement and demonstrate achievements.

#### Long term milestones (2-4 years)

<u>Objective 9</u> to undertake research into the effectiveness of our communication strategies aimed at bringing about behaviour change to reduce exposures to environmental stressors, linked to HPRU-EEH-Theme 1, Projects 1 (indoor air pollution) and 2 (biomonitoring).

<u>Objective 10</u> to evolve the evidence base for the effectiveness of PCIEP in directing public understanding of environmental health issues. We will commission work, through seeking additional funding from year two (lead by the PCIEP coordinators) to investigate whether the HPRU's engagement and involvement activities have produced a frameshift in public perceptions of the importance of the risks surrounding environmental exposures.

#### 6. Resources

In order to develop a culture of PCIEP research, commitment to core resources is required. Costs for the PCIEP program have been factored into the HPRU awards. INVOLVE has an <u>Involvement Cost Calculator</u> for researchers to budget PCIEP in a research project. In addition, researchers' time will be taken into account to run PCIEP activities and events.

To fulfil the objectives within the strategy, a PCIEP Coordinator has been appointed for each HPRU. The coordinators will provide PCIEP support for researchers across the HPRUs. They will be the point of contact for researchers to liaise with the PCOG. The PCIEP Coordinators will also manage the delivery of all PCIEP engagement events, and in-house training for research staff, early career researchers, PhD students and members of the public. Additionally, a PCIEP Joint Steering Committee has been put in place. This committee includes the two PCIEP Coordinators and representatives from each of the partners in the HPRUs.





Training needs for PCIEP theme representatives and for PCOG members will be continually assessed for the duration of the HPRUs in order to be responsive to on-going and new training requirements. Bespoke training will be developed to meet the needs of individuals within specific research themes. There will be a mixture of in-house training offered by the Patient Experience Research Centre at Imperial College London as well as training offered by other related organisations, such as the NIHR and the MRC Centre for Environment and Health.

The NIHR Biomedical Research Centre (BRC) Imperial Patient Experience Research Centre (PERC) team, in collaboration with Imperial Clinical Trails Unit, have developed a series of public involvement training sessions, from basic training on what public involvement is and why we do it to more specific training on how public involvement can inform the last four stages of the research cycle. These training courses are available to all HPRU members.

We will also use the <u>NIHR Research Design Service (RDS)</u> (London) as a resource. This is led by King's College London in partnership with: Imperial College London, Queen Mary University of London and University College London. The NIHR RDS offers a free service that supports clinicians, health and social care professionals and academics to develop research proposals and grant applications, including the integration of PCIEP activities.

Finally, the HPRUs PCIEP Coordinators will be active members of the National HPRU Public Patient Involvement and Engagement Network, working together with other coordinators to share best practice, learn from each other and develop training opportunities across HPRUs.

#### 7. Payment and recognition for public involvement

Funds have been set aside in the budget for directly incurred costs for running PCIEP activities. The payment structure for our PCIEP has been informed from current INVOLVE guidelines (INVOLVE 2018), recognising the contributions of our PCOG members who are actively involved with the work of the two HPRUs is a very important aspect of PPIE in research. Members will be offered payment for their time as well as additional expenses such as meeting travel or childcare costs.

#### 8. Partners and collaborators

We will work with a range of stakeholders to ensure the effective communication of our research, particularly to vulnerable sub-populations, where the proposed research (across all of our themes) will have the most immediate impact. We will build on Imperial College London's strong link with local communities through the public and community engagement program.

**Public Community Oversight Group:** We have set up an advisory group which consists of members from the general public, industry, local government, NGOs and community and patient groups, who will advise on the broader context of the unit's activities and on the implementation of the PCIEP strategy. We currently have a total of 39 members, and we are looking at improving and maximising the diversity of this group. The PCOG aims to:





- Support the governance of public involvement and engagement approaches and activities within the HPRUs
- Identify research priorities addressing public concerns
- Advise on research plans, protocols and materials
- Identify and facilitate ways to involve members of the public in research
- Disseminate research results in lay summaries
- Support researchers to assess the impact of PCIEP in their work

The PCOG will meet approximately two/three times a year for two hours.

As part of the Imperial College London HPRUs, we have access to extensive public involvement and engagement resources in order to implement this strategy which are set out in more detail below.

- The <u>VOICE Digital Platform</u> provides opportunities for the public to get involved at all stages of research. This includes events, blogs, research summaries, discussion groups, polls and online courses; effectively building a national community of 'Research Active Citizens'. We will use the VOICE digital platform as an alternative resource to engage and involve other members of the public aside the PCOG. This will allow researchers to access a large and diverse community quickly and easily, use flexible methods of involvement from polls and surveys to discussion forums and public panels. Finally, it will enable researchers to gain insight from the general public as well as patients with specific lived experience.
- The Young Persons' Advisory Network (YPAN) advisory group comprising of 17–25-year-olds has been set up as a collaboration between the Imperial PERC, the Imperial Institute of Global Health Innovation and the Imperial Clinical Trials Unit. The YPAN enables young people to also get involve and influence current and future health research and it is available to support all HPRUs within Imperial College London who seek the input of young people into their research projects.
- The Imperial <u>Public Involvement training</u> which is aimed at researchers but is also suitable for patients and the public features how patients and the public can be involved across the research cycle.
- The <u>Imperial Patient Experience Research Centre Public Involvement Resource Hub</u> offers a broad range of resources for learning about public involvement in research.
- The <u>Imperial Patient Experience Research Centre blog</u> provides examples of public involvement case studies that our researchers can use for inspiration. The Centre's blog also offers the opportunity to share our PCIEP work with others to learn and share best practice.
- <u>Imperial Societal Engagement</u> offers access to a range of training sessions, support and ideas for engaging with wider society.

#### 9.Leadership and lines of reporting

The HPRUs will be directed by Paul Elliott and Frank Kelly (Imperial College London), with other members leading activities at PHE, KCL and UC. The Unit Directors have overall responsibility for the Unit's strategy and direction. Formal reporting lines of the Unit are through its Director to NIHR. We have established an effective governance structure for the HPRUs as follows:

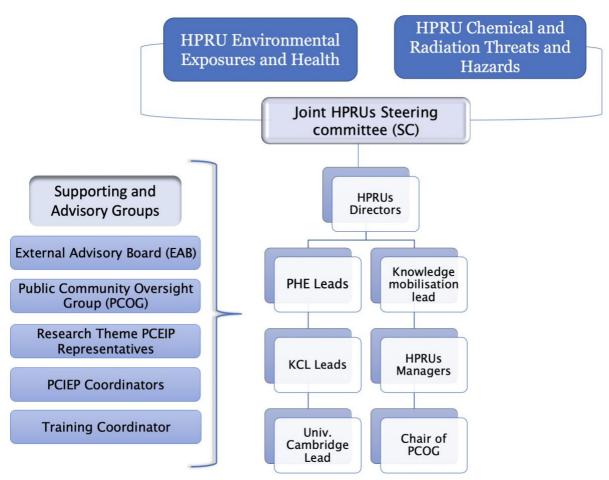


Figure 2: Governance structure

Steering Committee (SC) – the senior management, strategy and decision-making forum of the unit; it comprises the Unit Director, PHE, Kings College London (also representing the Theme Leads) and University of Cambridge leads, together with the Chair of the PCOG and the Knowledge Mobilisation Lead, ensuring direct representation of these core areas in the highest governance structure of the unit. The Knowledge Mobilisation is shared with the Climate Change and Health HPRU allowing for common aspects of the PCEIP strategy across these three HPRUs to be shared. The SC is the forum to identify research priorities and feed into PHE research and policy needs, supported by advisory groups and representatives from across the units' research areas and core areas of activity:

- External Advisory Board (EAB) an independent group composed of senior public health experts that advises the Directors on scientific strategy and research priorities, ensuring the units' strategy and programmes address and remain responsive to public health needs in the UK.
- Joint Public and Community Involvement, Engagement and Participation Committee this committee is comprised of representatives from each of the partners organisations and the two HPRUs' coordinators. The committee meets on monthly basis to oversee and provide advice on the development of the PCIEP program.





- Public Community Oversight Group (PCOG) its aim is to ensure that the research addresses the needs and concerns of the stakeholders and its results are appropriately communicated, by providing input at all stages of the research cycle and co-designing the Public and Community Involvement, Engagement and Participation (PCIEP) strategy and activities.
- Research Theme Leads responsible for implementation of the agreed research programmes.
- Research Theme PCIEP representatives responsible for the monitoring, reporting, and evaluation of the PCIEP program within their themes.
- *PCIEP Coordinator* we have appointed two PCIEP coordinators who are responsible for the design and implementation of the unit's PCIEP programme, and for the liaison between research themes, the PCOG, and other various community groups.
- *Training Coordinator* responsible for the implementation of the unit's training programme and representing the interests of the unit's early career researchers at all levels.

Our aim is to also ensure that the public voice is clearly present in our governance and leadership so that our decisions promote the public interest. We will involve the public in research management, leadership and decision making. We have appointed a non-professional Chairperson who will co-chair the PCOG meetings as well as represent the PCOG in the MRC Centre and HPRUs Joint Steering Committee meetings providing a public perspective in the highest governance structure of these units.

#### 10. Monitoring review and reporting

In order to evaluate the impact of the PCIEP strategy within the HPRUs (with the aim to allow for reflection and improvement), we will capture the impact that our activities have on our lay partners and researchers through the use of post event or activity feedback forms.

In addition to this, each theme will maintain a record of all PCIEP activities undertaken and provide updated information to PCIEP leads annually. This will be achieved through a reporting tool for reporting, reflecting and learning. This will allow us to access the impact of our PCIEP program in the long term. We will also use the <a href="MRIPP2 checklist">GRIPP2 checklist</a> which is the first international guidance for the reporting of patient and public involvement in health and social care research. This will allow us to ensure that PPIE practice is based on the best evidence.

Our PCIEP strategy will be reviewed on an annual basis with the PCIEP Joint Steering Committee and PCOG. The Joint Steering Committee will hold regular meetings to monitor activities including measuring, monitoring and evaluating of the PCIEP. These meetings will also be used to review progress against the objectives outlined in this report.





## 11. Rolling program of project and activities for the two HPRUs

	Project	Activity	Details	Status
		Early milestones (6- 12 months)		
Engagement	School outreach	Deliver engagement activities across primary and secondary schools to a) raise awareness of various environmental issues and b) promote Science, Technology, Engineering and Mathematics (STEM) subjects  This will be an ongoing activity, to be carried out by various Themes across the HPRUs	- Secondary school's engagement thorough the recording of short videos to support children online/home learning (summer 2020) - Chemistry for a cleaner world sessions:  Eco- Schools NI (part of Keep Northern Ireland Beautiful (Autumn 2020) Siglo Science festival (Autumn 2020) Northern Ireland Science Festival (Winter 2021)	Ongoing
	Local Community outreach	Deliver engagement activities to local families in the White City area London to a) raise awareness of various environmental issues and b) promote Science, Technology, Engineering and Mathematics (STEM) subjects  This will be an ongoing activity, to be carried out by various Themes across the HPRUs	Examples of topics for sessions:  - Air pollution causes, health effects and exposure reduction measures  - Microplastics - Brake dust - Biomonitoring - Chemical Incidents E-cigarettes	November 2020 – ongoing
Engagement	Social networks and online presence	Develop a variety of web-based engagement such as creating a social media presence (twitter) to disseminate our research and promote PCIEP opportunities	Develop and maintain our HPRUs websites Twitter	Ongoing
Engagement	Research communication	Use various media communication channels to increase the visibility of our research prevent the risk of misinterpretation and lead to meaningful engagement with the general public	Several of our researchers have been very active through various media channels (tv/newspapers)	April 2020 – Ongoing
	Embedding PCIPE	Establish a joint steering committee for PPI E	We set up a joint steering committee for the two HPRUs to manage PPI E across the HPRUs. Two PCIEP Co-ordinators have been appointed. This committee meets on a monthly basis	March 2020
Involvement	across the HPRUs	Identify representatives for each theme who will be responsible for PPI E activities within their theme	Two representatives have been identified for each theme: one from PHE and the other from the partnering universities (IC, KCL, UC)	November 2020
nvolvement	Establish an advisory group	The Public and Community Oversight Group (PCOG); chaired by a non-professional person. The PCOG will meet 2-3 times per year to advise on the HPRU's strategy, provide input into specific research questions and guidance on the implementation of the PCIEP strategy	The PCOG consists of over 35 members from 20 different organisations including (NGOs, industry, Government agencies, members of the public among others). The Chairperson was appointed in early 2021. The PCOGs inaugural meeting was held in November 2020	April 2020 - Ongoing
nvolvement	Embedding PCOG support across the HPRUs	Build relationship with PCOG members and theme representatives  PCOG members to help co-develop our PCIEP Strategy	Theme representatives to be invited to all PCOG meetings  Strategy drafted and shared with stakeholders	January to March 2021





		Medium term milestones (0.5 – 3 years)		
Engagement	High impact events	Hold Engagement events for the public and community e.g. Great Exhibition Road Festival, New Scientist live, the MRC festival of science and other various local and regional festivals. These events will offer an opportunity to engage with the public to share the work undertaken by the two HPRUs and MRC Centre	Participation in this year's Great Exhibition Road festival which will be held virtually this year Other festivals date TBC due to Covid-19 restrictions	September 2021
Engagement/ Involvement	Educational Resources	Develop with consultation with the PCOG educational and public health resources for the public as well as well as for primary age children to help better understand the risks of environmental exposures to health.		
Involvement	Public consultation	Expand and diversify group membership and opportunities for PCOG members and with other PPI groups both internal and external increase diversity of involvement as well as to identify training needs and opportunities		Ongoing
Involvement	Diversity, Inclusion and capacity building  Consider and implement new ways of engaging with group members including methods for virtual consultation		This will enable us to reach large numbers of people and particularly useful for members of the public who might not otherwise get involve such as those homebound, elderly people or parents	Ongoing
Involvement/ training	Sharing best practice across HPRUs	Build Capacity and expertise throughout the HPRU by holding regular meetings with PPI E networks in other NIHR funded organisations to share best practice	Active participation in the HPRU- PPI E network group which meets on a monthly basis	December 2020 – ongoing
Involvement		Refresh of all PCIEP communications materials for our advisory groups i.e., Terms of reference done with consultation with members	This will be done with consultation with the PCOG members	
Participation	Co- production of research questions and methodologies	Various projects across both HPRUs will hold focus groups and workshops to co-develop research questions and feasible methodologies for their research work		
Training		Skills audits will be carried out every year to identify the training needs of our lay members (PCOG).	Based on the audit findings, we will identify the right opportunities for our lay members to undertake the required training.	
Training		Explore methods to provide training, learning and support	We will organise or identify training courses potentially delivered in partnership with lay members of the public	
	Capacity building	Support researchers to actively involve members of the public in their research		
Training		We developed a session targeted to Early Career Researchers (ECR) on the subject of effective and engaging public engagement and educational outreach in the school environment	We successfully engage with over 15 early career researchers which are now better equipped to deliver educational sessions in various school settings. We will deliver a similar session in 2021	November 2020
Training		We will design and deliver a session emphasizing the importance of embedding public and community engagement and involvement in their training as early as possible.	To develop a position paper	Not commenced as yet





		Long term milestones (2-4 years)	
Engagement	PCIPE Publication	Publication of PCIEP impact in a journal to share best practice and lessons learnt	Not commenced as yet
Engagement	Imperial College HPRUs Event	Together with the other Imperial College HPRUs, we will deliver a big one- day event to showcase the College's HPRUs work.	Not commenced as yet
Engagement	Sharing best practice – Legacy	Use data generated to inform public engagement and knowledge dissemination.	Not commenced as yet
Engagement	Publications	Theme specific research studies will be published in peer-reviewed research journals.	Not commenced as yet





## Appendix I

Dr Diana Varaden	ICL	PCIEP Coordinator, HPRU in Environmental Exposures and Health
Ms Antoinette Amuzu	ICL	PCIEP Coordinator, HPRU in Chemical and Radiation Threats and Hazards
Dr Bethan Davies	ICL	MRC Centre & HPRU in Chemical and Radiation Threats and Hazards
Dr Ian Mudway	ICL	MRC Centre PCIEP Lead and HPRU in Environmental Exposures and Health
Ms Angela Lewis	ICL	HPRU in Environmental Exposures and Health & MRC Centre Manager
Dr Ed Seleiro	ICL	HPRU in Chemical and Radiation Threats and Hazards & MRC Centre Manager
Dr Emily Cheek	PHE	HPRU in Chemical and Radiation Threats and Hazards
Dr Liz Ainsbury	PHE	HPRU in Chemical and Radiation Threats and Hazards
Dr Liza Selley	UoC	HPRU in Environmental Exposures and Health and in Chemical and Radiation Threats and Hazards