NIHR Health Protection Research Unit (HPRU) in Genomics and Enabling Data

Patient and Public Involvement and Engagement Strategy (PPIE) 2021

Section 1: Background and Purpose of the HPRU

Our mission is to provide the methodological backbone required to improve English public health using new rich data sources. In particular, recent and ongoing developments in whole-genome sequencing technologies have a widely acknowledged great potential to help us improve public health, but this potential is currently incompletely realised due to a lack of sound and scalable methodology to interpret the data in the correct epidemiological context.

In order to realise our HPRU mission we will create high quality, lasting partnerships with our researchers, practitioners, patients, public contributors and communities, collaborating together with the aspiration to co-produce research that creates public health benefit. The experiences and perspectives of patients, communities and the public provide important and unique insights that can enhance the quality of research and ensure the research, knowledge mobilisation and training undertaken by the Health Protection Research Unit (HPRU) is relevant, acceptable, appropriate, and more trusted from a public view. We plan to build strong foundations for PPIE, drawing on National Institute for Health (NIHR) policy including the *'Going The Extra Mile'* review that provides important context (NIHR 2015, Staniszewska et al 2018), NIHR guidance including the Standards for Involvement (NIHR 2018), NIHR Guidance on Co-production (Hickey et al 2018) and GRIPP2 (Guidance for Reporting Involvement of Patient and the Public Involvement) to develop our PPIE evidence to inform best practice (Staniszewska et al 2017).

Section 2: Our vision, mission for HPRU PPIE Strategy

Our vision and mission for PPIE in the HPRU is adapted from the vision and mission from '*Going the Extra Mile,'* which provides strategic direction for NIHR until 2025 (NIHR 2015, Staniszewska et al 2018).

HPRU PPIE Vision: "A population actively involved in public health research to improve health and wellbeing for themselves, their family and communities."

HPRU PPIE Mission: "The public as partners in delivering high quality public health research that makes a real difference to the health, social care and wellbeing of communities."

2.1 Co-Production: Our Underpinning principle

We will work towards co-production as an approach to public involvement, which underpins our vision and mission, embedding the key principles and features of co-production as set out in the NIHR Guidance for Co-Producing a Research Project and identified in the Going the Extra Mile Policy Review (NIHR 2015) and updated by Staniszewska et al (2018), recognizing that co-production requires significant change in research systems and cultures (Redman et al 2021) that will develop over time.

The key principles of co-production

Sharing of power – *the research is jointly owned and people work together to achieve a joint understanding*

Including all perspectives and skills – *make sure the research team includes all those who can make a contribution*

Respecting and valuing the knowledge of all those working together on the research – *everyone is of equal importance*

Reciprocity – *everybody benefits from working together*

Building and maintaining relationships – *an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential*

Hickey et al (2018). NIHR Guidance for Co-Producing a Research Project.

Section 3: Our strategic aims:

1. **Culture, governance, leadership and infrastructure**: We will embed patient and public involvement practices within the culture of the HPRU, our governance structures, across the four themes and within projects.
2. **Building on the experiences of the HPRU community:** We will build on the experiences of past HPRUs, collaborate with HPRUs nationally through the HPRU PPIE leads network and work with the wider NIHR and PHE infrastructure to share resources, learning and examples of best practice.
3. **Building capacity:** We will build skills, capacity and training within the HPRU for researchers, students and public contributors to deliver meaningful involvement in the HPRU including PPI within knowledge mobilisation.
4. **Embedding co-production and diverse voices:** We will facilitate high quality relationships and partnerships with diverse voices to co-produce knowledge, evidence and learning.
5. **Building evidence for practice:** We will develop an exploratory, evidence informed and evidence generating approach to public involvement, building evidence base for future public health PPIE practice, including published papers and case studies.
6. **Culture of evaluation and reporting:** We will develop a culture of gathering feedback, evaluating and reporting PPIE to ensure impact and contribution is captured as part of developing the evidence base.

Section 4: Our strategic objectives

Each strategic aim has several objectives. The objectives describe how we will achieve our strategic aims. Our next step will be to develop the implementation plan.

4.1 Objectives for strategic aim 1: Culture, governance, leadership and infrastructure: We will embed patient and public involvement practices within the culture of the HPRU, our governance structures, across the four themes and across projects.

1. We will aim to develop a culture that recognises patient, public and community involvement and engagement as an essential and vital component of public health research, by building knowledge, capacity and skills for involvement. We will encourage role modelling of leadership behaviours that support this approach.
2. We have established a Public Reference Group to guide involvement in the HPRU, using a hub and spoke model, with the hub as the entire Public Reference Group meeting 3-4 times a year and the spokes as smaller sub-groups, with public contributors involved at theme and project level, with meeting frequency decided collaboratively at project or theme level. Contact in between meetings will include commenting on documents, writing, talking to other public contributors.
3. The Public Reference Group will develop its own Terms of Reference with a public contributor as co-chair.
4. We will work with the Public Reference Group to develop the PPIE strategy, oversee its implementation and undertake an annual update.
5. We will undertake an annual review of our work against the NIHR Standards for Involvement to identify opportunities for strengthening our involvement.
6. We will ensure public contributors are included at all governance levels of the HPRU, including External Advisory Panel, the Steering Group and the Management Board and that all key meetings have a standing PPIE agenda item.
7. Depending on the nature of the theme, public contributors will either contribute to the theme or to selected individual projects within it.
8. We will implement a model of distributed leadership with theme and project leads responsible for delivering on PPIE in their studies, supported by the PPIE lead (SS).
9. We will identify opportunities for researchers to be mentored by public contributors experienced in PPIE.
10. We will develop ways of working that enable involvement, including virtual and face to face meetings and ensure expenses including contribution to mobile, broadband costs and childcare costs are met.
11. We will agree the nature, type and frequency of communications to ensure public contributors are aware of HPRU activity.

4.2 Objectives for strategic aim 2: Building on the experiences of the HPRU community: We will build on the experiences of past HPRUs, collaborate with HPRUs nationally through the HPRU PPIE leads network and work with the wider NIHR and PHE infrastructure to share resources, learning and examples of best practice.

1. We have adopted a leadership role as SS is co-chair of the HPRU PPIE leads group.
2. We will continue to work with other HPRUs to further develop the menu for strategy development to guide PPIE strategy development across other HPRUs in the future.

3. We will work collaboratively with other HPRUs on strategically important areas such as training, to enhance the offer to all HPRUs, to share resources, learning and examples of best practice.
4. We will actively explore collaboration opportunities with other parts of NIHR infrastructure including the ARCs, to share resources, learning and examples of best practice.
5. We will seek to work collaboratively with the Centre for Engagement and Dissemination and Public Health England to share resources, learning and examples of best practice

4.3 Objectives for strategic aim 3: Building capacity: We will build skills, capacity and training within the HPRU for researchers, students and public contributors to deliver meaningful involvement in the HPRU including PPIE within knowledge mobilisation.

1. We will work collaboratively with colleagues to ensure that PPIE is included in the training strategy which we will review annually with the Public Reference Group.
2. We will develop training resources tailored to the needs of researchers and public contributors, working collaboratively with other HPRUs, to develop cross HPRU training resources and opportunities.
3. We will develop an induction pack for researchers and public contributors which includes all key reports, key papers, the PPIE strategy and other items that researchers and public contributors require as links provided on the website.
4. We will identify opportunities for public contributors to be mentored by researchers in specific methodological expertise that a public contributor may need.
5. We will deliver training and support to researchers in the HPRU to help them develop their knowledge of PPIE, its evidence base, facilitation skills, capture and reporting of PPIE and publishing their PPIE. This will include lectures, seminars and workshops and informal support delivered through bespoke sessions. We will use feedback forms to identify further training needs.
6. We will deliver training and support for public contributors. We will ensure we include an item on training for the main Public Reference Group Hub meetings (3/4 times a year) which considers and reviews training needs.
7. We will work collaboratively with colleagues to ensure that PPIE is included in the knowledge mobilisation strategy and we will work collaboratively with our Public Reference Group to explore the public role in knowledge mobilisation.

4.4 Objectives for strategic aim 4: Embedding co-production and diverse voices: We will facilitate high quality relationships and partnerships with diverse voices to co-produce knowledge.

1. Our ambition is to embed co-production and its principles within the HPRU, drawing on the NIHR approach, supporting researchers to consider how they implement the principles of co-production.
2. We will work with other HPRUs to understand and build on their experiences of co-production.
3. We will plan prospectively for co-production in themes and projects. We will encourage researchers to work with public contributors to plan how they implement co-production.
4. We will ensure that our Public Reference Group and the project sub-groups aims to include diverse voices from different communities, built up over time as high quality relationships and trust develop between researchers and communities involved with projects. We

recognise the challenges of moving beyond usual ways of working in research to developing relationships and will focus on projects that enable high quality relationships to develop.

5. We will explore with the Public Reference Groups to identify opportunities to enhance diverse voices in the HPRU, particularly from groups under-represented in research.

6. We will work collaboratively with the PHE Public Panel as part of ongoing recruitment, seeking to recruit individuals who create more diverse voices in our research.

4.5 Objectives for strategic aim 5: Building evidence for practice: We will develop an exploratory, evidence informed and evidence generating approach to public involvement, building an evidence base for future public health PPIE practice.

1. We will encourage researchers to consider PPIE as an area of evidence-informed social practice that has the capacity to generate new evidence that can contribute to strengthening the PPIE evidence base. This includes more complex areas where PPIE is less common, but where exploration of potential is possible, e.g. modelling.

2. We will encourage researchers and public contributors to plan for PPIE at the start of projects by completing a PPIE Project Plan adopting a project life cycle approach that considers each stage of their study which they co-produce with their Public Reference Group.

3. We will deliver an annual workshop to help develop PPIE Project Plans that enable researchers and public contributors to share their ideas.

4. We will capture key contributions in PPIE meetings, in order to identify the potential contribution and impact of PPIE in public health research.

5. We will encourage researchers and public contributors to work together to publish their PPIE activity

6. We will encourage our researchers and public contributors to identify wider engagement opportunities, sharing results with communities, including as part of knowledge mobilisation.

7. We will aspire to explore collaborative possibilities with other HPRUs to work together to build evidence for practice, dependent on securing further external funding.

4.6 Objectives for strategic aim 6: Culture of evaluation and reporting: We will develop a culture of gathering feedback, evaluating and reporting PPIE to ensure impact and contribution is captured as part of developing the evidence base.

1. We will ensure that PPIE meetings are captured either as notes or transcripts to ensure contribution and impact are recorded as the building blocks of knowledge generation and co-production.

2. We will support researchers and public contributors to reflect and evaluate their PPIE with the use of evaluation forms and experiences logs.

3. We will encourage researchers and public contributors to contribute to the developing evidence base of PPIE in public health, including the use of GRIPP2 SF reporting guidance.

4. We will collect key information required by NIHR.

Section 5: Resources required to deliver the PPIE strategy

The delivery of the PPIE therefore requires a distributed leadership across the HPRU, with theme leads and project leads taking responsibility for the delivery of PPIE within the HPRU, supported by SS, PPIE lead at 10%fte.

With the PPI budget to support activity, each project lead will be able to apply for monies to support their PPI. This is to ensure there is a fair allocation. Project specific budgets will support contributor time at £20 per hour, £5 per meeting support for data and home costs plus any travel expenses in the future.

The HPRU GED is collaborating with the HPRU GI to fund a PhD student who will undertake a study that aims to develop the evidence base of PPIE in public health.

Section 6: Partners, stakeholders and communities

Our partners and stakeholders are likely to include both public members and community members with an interest in the subject areas or in the research studies. It might also include patients with specific conditions or who might benefit from the research.   There may also be charities or public advocacy groups with whom we wish to collaborate depending on the topic of interest. They could become members of theme or project specific activities. Each theme and project will be able to map their potential stakeholders.

Section 7: Implementing the strategy year 1-2

Our next step is to work with the Public Reference Group to agree a plan for implementation. Our approach to delivery will be to explore the potential for PPIE in each project within each theme. Each theme and project lead will have the opportunity to present their work in years 1 and 2 to the PPIE Reference Group in order to plan for potential PPIE. As such our implementation plan will become populated over the 1-2 years.

Section 8: Appendices

Appendix 1: Key strategy development steps

- The HPRU PPIE Leads Group met in November 2020 and identified the potential benefits of creating a HPRU PPIE Network, which could work together on a range of areas including PPIE strategy.
- Once established, the HPRU PPI Network met in December 2020 to discuss the key components of the PPIE strategy, with input from NIHR CCF colleagues. A 'strategy menu' was developed which included all the elements of strategy that a HPRU should consider. For example, the key Clinical Commissioning Facility (CCF) expectations were built into the new menu. This menu was refined following this meeting.
- A meeting in January 2021 of the HPRU PPIE Leads Strategy Planning group further refined the strategy menu which was then sent to the HPRU PPIE Network members to use as part of their strategy development.
- The strategy menu was piloted in the development of the PPIE strategy for the Applied Research Collaboration (ARC-WM) as similar research and policy trends exist across NIHR infrastructure.
- We worked collaboratively with our HPRU Public Reference Group to review each item from the PPIE menu and consider its inclusion in the strategy. As SS led on the development of the strategy for the HPRU in Genomics and Enabling Data and the HPRU in Gastrointestinal Infections, discussions from each of the Public Reference Groups have influenced this document at the generic level.
- Drafts of the strategy were reviewed by the HPRU Public Reference Group in two rounds of comments following the discussions.
- The final strategy document is presented here. Our next steps is to implement the strategy, working closely with the Public Reference Group and the wider HPRU.

Appendix 2: Definitions

We use the NIHR definitions for 'involvement', 'engagement' and 'public'.

'Involvement' is research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials and undertaking interviews with research participants.

'Public Engagement' is where information and knowledge about research is provided and disseminated. Examples of public engagement activity include disseminating the findings of a study to research participants, colleagues or members of the public, raising awareness of research through media such as television programmes, newspapers and social media and open days at research centres where members of the public are invited to find out about research.

When using the term **'public'** we include 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. Whilst all of us are actual, former or indeed potential users of health and social care services, there is an important distinction to be made between the perspectives of the public and the perspectives of people who have a professional role in health and social care services.

Appendix 3 – References

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