NIHR | Health Protection Research Unit Respiratory infections

Patient & Public Involvement, Engagement & Participation (PPIEP) Plan 2025–2030

Contents

Introduction

Over the next five years the HPRU will embed PPIEP across four research themes—Pandemic Preparedness, Surveillance & Analytics, Interventions, and Tuberculosis (TB).

Our goal is to build research-ready communities through:

1. Forming genuine partnerships with people and communities most affected by respiratory threats, giving a voice to the underserved
2. Ensuring public and participant feedback is systematically gathered and incorporated so that research remains relevant, equitable, and able to rapidly inform policy and practice.
3. Co-producing study design and materials to ensure the content connects to real needs, interests, and experiences.

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Core PPIEP Principles

- **Inclusive partnership**: Proactively reach multigenerational, marginalised, and high-risk groups.
- **Co-production**: Design protocols, consent processes, and communication materials with public contributors.
- **Accessibility**: Produce multi-format (print, digital, video), multilingual, British Sign Language, Braille resources; low-burden participation options.
- **Public Steering Committee**: A lay advisory group that holds HPRU Leadership to account, ensuring transparent, publicly understandable decisions. Members representing diverse and underserved communities advise on reducing health disparities and strengthening PPIEP, Knowledge Mobilisation, and Research Inclusion activities.
- **Ethical rigor**: Data safeguarding, and ethical review from appropriate research ethics committees. Ongoing ethics consultations with lay steering groups, and two-way dialogue with study participants. Recognise and proactively address fears around data privacy, especially among undocumented and marginalised groups. Ensure transparent communication about data use, storage, and participant rights. Provide anonymous participation options where feasible, and work with trusted community intermediaries to build confidence and reduce barriers to involvement. Participants and Public Steering Committee will be offered appropriate recognition and/or compensation in line with guidance.
- **Transparency & Trust in Data**: Actively address public scepticism by demystifying how data informs health responses. Share clear, accessible explanations of how data is collected, interpreted, and used to guide decisions. Use co-created summaries and materials, and community-led feedback to build trust and counter misinformation.
- **Sustainability**: Build lasting relationships with research-ready communities through consistent engagement across themes. Explore future funding routes to maintain interaction with communities to support long-term development of the research-ready communities we are building.
- **Training**: Embed PPIEP training into Early Career Researcher training plans.
- **Evaluation**: Feedback on how public involvement has shaped the research, will be shared within the HPRU through a newsletter and lay members through debrief sessions.

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Theme 1 – Pandemic Preparedness

Plain-language summary

The COVID-19 pandemic showed us how important it is to act quickly and gather community-level data to create effective public health policies. We're focusing on being better prepared - not for if another pandemic happens, but for when it does.

To be better prepared, we are developing a platform that can rapidly be activated in the event of a new respiratory virus outbreak. The platform will be designed to help us be able to answer important questions we would need to know early in a pandemic, such as how long people are infectious for and how do infections spread from person to person.

To make sure the platform works well, we'll test it over two winters using seasonal viruses. This will allow us to refine the study design while also learning more about how current seasonal viruses spread. Instead of inviting only individuals to test this platform, we'll invite whole households to take part, since most virus transmission happens at home. Studying households together will help us understand how infections start, spread, and affect people in everyday life. We'll also test the platform in care homes, where residents are especially vulnerable.

The COVID-19 pandemic also showed how crises can worsen existing health inequalities, with disadvantaged communities hit hardest. From the outset, this platform will work with these communities to make respiratory research and response more inclusive helping ensure future preparedness is fairer and that no one is left behind.

Objectives

1. Co-produce participant facing documents with underserved communities.
2. Pilot the platform in two consecutive winters (2026/7 and 2027/8) and iteratively improve the platform based on participant and community feedback.
3. Consolidate materials for rapid activation in response to a future pandemic.

Target communities

- Households in areas of socioeconomic deprivation.
- Care-home residents and staff via the VIVALDI network.
- Community members at outreach events (e.g., New Scientist Live, Great Exhibition Road Festival).

Overview of potential PPIEP activities depending on research outcomes and additional funding

1. **Community co-design workshops (Years 1–2):**
    - Partners: Local schools, community centres
    - Output: Plain-English protocol summaries, participant journeys, and mock-ups of sampling kits.

- New Scientist Live Exhibition: co-create study name and logo with the public (exhibition attendees)

2. **Ethics & materials feedback (Years 1–2):**
    - Invite lay reviewers to pilot participant information sheets.
    - Adapt based on readability assessments and volunteer feedback.
3. **Winter road-testing (Years 2–4):**
    - Recruitment via RCGP Research & Surveillance Centre (19 million-patient network), UKHSA FluSurvey and NIHR Be Part of Research.
    - Focus groups with study participants to refine instructions and logistics. Participants will be invited to share ideas about study aims for subsequent years.
    - Joint wrap-up sessions to ensure that participant feedback is incorporated into final study protocol.
4. **Protocol consolidation & community readiness (Years 4–5):**
    - Produce a "hibernation kit" containing all materials, SOPs, data-management tools, and community liaison contacts, ready for transfer to UKHSA for continual update and rapid activation in a future pandemic.

Anticipated outcomes

- Platform fully tested, ethically approved, and packaged for immediate use.
- Demonstrated engagement rates: High participation and sample-return rates across pilot sites.
- Community advisory group continues as "Rapid Response Community Panel" for future outbreaks.

Evaluation plan

- Metrics: Recruitment rates by IMD quintile; kit return rates; participant confidence ratings (pre/post surveys); community "readiness" drill performance.
- Methods: Brief online surveys and/or telephone interviews for participants that specifically consent to being contacted by the study team for study feedback/ evaluation
- Reporting: Biannual summaries to HPRU Director, UKHSA Lead and HPRU Managers; transparent publicly accessible annual study progress report and annual public feedback event. In addition, findings and updates on how public input shaped the research will be communicated through a newsletter. Lay summaries and debrief sessions to inform contributors how their input shaped research.

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Theme 2 – Surveillance & Analytics

Plain-language summary

Theme 2 (Surveillance & Analytics) focuses on understanding how respiratory viruses spread and how severe they are, especially among vulnerable and underserved groups. This research is essential for planning effective public health responses and ensuring that healthcare resources are used where they are needed most. By analysing large amounts of data collected in real time, researchers can detect patterns of infection, track new variants, and measure how well vaccines and other interventions work. The team will develop new methods to estimate how severe different respiratory winter viruses are and how they spread, using advanced techniques like Bayesian data analysis (a method that uses both new data and existing knowledge to make better predictions and decisions, even when information is incomplete or uncertain). This approach will help public health authorities respond quickly and effectively to respiratory infection outbreaks and best designing strategies to reduce the overall impact of respiratory infections. Importantly, this Theme also aims to address health inequalities by focusing on groups that are often overlooked, ensuring that no community is left behind when planning healthcare strategies. Ultimately, the insights gained from this research will support the development of more targeted interventions that protect public health and reduce the burden of respiratory diseases for everyone.

Objectives

1. Co-identify the data elements communities care about (e.g., hospitalisation risk, long-term symptoms).
2. Pilot at-home serology (finger-prick blood, oral fluid) and nasal-fluid sampling.
3. Produce equity-stratified severity and transmission dashboards with lay summaries.

Target communities

1. Residents of socioeconomically deprived communities.
2. Migrants and non-English speakers (co-recruited via Doctors of the World, Mosaic Community Trust).
3. Care-home residents and VILVALDI staff.

Overview of potential PPIEP activities depending on research outcomes and additional funding

1. **Engagement activities (Year 1):**
    - Engagement with underserved communities to inform surveillance design, including sampling strategies and communication approaches.
2. **Collaboration with community organisations for recruitment (Years 1–2):**
    - Doctors of the World, Bromley-by-Bow Centre, Mosaic Community Trust and local NHS Trusts to support inclusive recruitment and engagement.

3. **Workshops (Year 2):**
    - Community workshops with socioeconomically underprivileged groups
        - Partners: Doctors of the World; Bromley-by-Bow Centre; local NHS Trusts
        - Interactive sessions for community members to share experiences and barriers to accessing healthcare.
    - Key objectives:
        - Identify barriers to participation among vulnerable and disadvantaged populations.
        - Co-develop tailored recruitment strategies for future studies.
        - Inform public health interventions that address these communities' specific needs.
4. **Serological sampling (Years 2–3)**
    - Use of serological sampling (oral fluid, nasal lining, blood) and laboratory data linkage to assess immunity and transmission, with public input on acceptability and feasibility.
5. **Involvement of the Public Steering Committee (PSC) (Years 1–5):**
    - To guide the development of surveillance protocols and ensure relevance to priority communities.
6. **Feedback mechanisms (Years 2–5):**
    - Lay summaries and debrief sessions to inform contributors how their input shaped surveillance design and outputs.
7. **Data analysis (Years 3–5):**
    - Equity lens in data analysis and reporting, including stratification by ethnicity, deprivation, age, and other sociodemographic factors.

Anticipated outcomes

- Community-informed severity estimates guiding winter vaccination and antivirals.
- Improved trust in public-health data and transparent dashboard designs.

Evaluation plan

We will monitor the effectiveness of PPIEP activities through a mixed-methods evaluation strategy.

- Metrics: Community workshop attendance and participant diversity (Yearly review, led by project team); survey responses on clarity and usefulness of data summaries and dashboards (Years 2 and 4).

- Methods: Mixed-methods surveys of community participants after each workshop (led by community partners); structured debrief interviews with partner organisations (e.g. Bromley-by-Bow Centre, Doctors of the World) at mid-point (Year 3) and project end (Year 5); newsletter updates, will explain how public input has informed data design and outputs.

Input from the Public Steering Committee to assess whether community priorities have been reflected in research outputs.

Theme 3 – Interventions

Plain-language summary

This theme focuses on improving how we use available tools, like vaccines and other measures, to fight respiratory viruses. By optimising their use, we can save lives, reduce illness, and ensure resources are used wisely, especially for underserved groups. The approach is centred on three key goals: improving delivery, monitoring impact, and increasing uptake of interventions. These efforts target major respiratory viruses like RSV, influenza, hMPV, and adenovirus, while also preparing for future tools for viruses that currently lack treatments. This includes understanding pregnant women's awareness of RSV vaccination, their experiences of accessing information about RSV vaccination (including from healthcare workers they see during pregnancy), and their experiences of accessing RSV vaccines. This could help vaccine access and information to be tailored for different communities to address vaccine uptake inequalities.

Objectives

1. Identify beliefs and barriers to immunisation through public surveys and co-production panels.
2. Develop and trial culturally resonant messaging via social media, local radio, and faith-centre outreach.
3. Identify facilitators to enhance acceptability and uptake of maternal RSV immunisation.

Target communities

- Communities living in more deprived areas of London with historically low vaccine uptake.
- Ethnic minority communities with historically low vaccine uptake.

Overview of potential PPIEP activities depending on research outcomes and additional funding

- Initial public engagement work in North-West London has included:
- **Engagement events (Years 1–2):**
    - Meeting co-hosted with the Mosaic Community Trust to understand parents and carers current knowledge and awareness of RSV and the new vaccine and what questions they have about the new vaccine.

- **Public engagement (Years 1–2):**
    - Conversations and listening activities with parents whose babies have been admitted to hospital with Bronchiolitis.
    - In the first year since the new maternal RSV vaccine was introduced, initial public involvement work has included developing case-studies of currently pregnant women in London experiences of accessing the RSV vaccine.
- **Engagement with pregnant women (Years 1–2):**
    - Identify qualitative-research preferences, revealing a strong preference for one-to-one semi-structured interviews (phone or online) over focus groups.
- **Qualitative research protocol (Years 1–2):**
    - Informed by initial public involvement a qualitative research protocol is being developed for ethical approval. This project will interview pregnant women in London about their experiences of accessing the RSV vaccine. Recruitment will be via community groups with strong existing links such as The Mosaic Community Trust but also other public groups such as maternity voices, maternal Black advocacy groups, Tommy's maternity charity, maternity and community champions and other community groups in North-West London.

Anticipated outcomes

- Community-validated strategies to boost vaccine and antiviral uptake.
- Data-driven models of intervention impact informed by lived experience.

Evaluation plan

- Metrics: Vaccine uptake by postcode, hospital trust, deprivation level and ethnicity; social-media engagement statistics.
- Methods: Use routinely collected vaccine uptake data; evaluate the public engagement and participation using established methods such as the CUBE evaluation tool; attendance and engagement with the public engagement and public involvement activities and recruitment of target communities.
- Reporting: Lay summaries and debrief sessions to inform contributors how their input shaped research.

Theme 4 – Tuberculosis

Plain-language summary

Tuberculosis (TB) infection can happen after breathing in the microbe that causes it. Not all infections go on to cause symptomatic TB disease. People can have latent TB infection (LTBI) when they are not considered to be infectious and have no symptoms or disease. However, if not given antibiotic treatment approximately 10% or more of infected people will go onto develop TB disease. Some groups of people are at higher risk of being exposed to and developing TB disease. Swift diagnosis and treatment of active TB reduces the chances of

transmitting it to other people. We want to work with affected communities, employers and health care providers to improve TB prevention interventions that are tailored to different population needs. We also want to look at patterns in electronic health care records (EHR) to spot ways to improve care for people with TB. We will be using TB genetic information to understand patterns of spread. Finally, we will be using computer models of TB transmission to project the health impacts and costs of the interventions we consider.

Objectives

1. Map barriers to LTBI testing and treatment in high-risk populations.
2. Validate EHR-derived diagnostic-delay patterns with affected communities.
3. Co-design WGS-informed contact-tracing protocols for diverse settings.

Target communities

- Migrant communities
- People sleeping rough or in temporary accommodation.
- Newly arrived social-care migrant workers (adult social-care [ASC] sector).
- Healthcare providers including GPs.

Overview of potential PPIEP activities depending on research outcomes and additional funding

- **Focus groups (Years 1–2):**
    - Sessions with diverse patients, TB-affected households, and healthcare providers across prisons, hostels, hotel accommodation, and care homes in urban/rural and high/low incidence areas
    - Validate electronic health-record findings, ensure interpretations align with lived experience, and identify any missing perspectives.
- **Anonymous ASC migrant survey (Years 1–2):**
    - Online and WhatsApp surveys for new-entrant ASC workers to capture knowledge, attitudes, and practices around TB screening and LTBI offers.
    - Topics include barriers to GP registration, experiences of LTBI testing offers, and decision factors; findings shared in summary workshops with ASC employers and agencies.
- **EHR-validation sessions (Years 1–2):**
    - Panels of patients, TB-affected households, and clinicians reviewing electronic health-record analyses of diagnostic pathways and care delays
    - Identify misalignments with lived experience and refine intervention targets (for example, referral scripts)

- **WGS contact-tracing co-design (Years 2–3):**
    - Workshops with the UKHSA TB Unit, Health & Justice team, prison charities, and community representatives to adapt contact definitions and tracing strategies informed by whole-genome sequencing.
    - Engage patients, households, and providers from a range of settings to ensure protocols are realistic

- **Policy-creation forums (Years 4–5):**
    - Collaborative sessions with UKHSA policy teams, DHSC Adult Social Care, and HPRU behavioural-science partners to align emerging findings with priorities for the 2026–2030 TB Action Plan.
    - Use lived-experience insights and modelling outputs to co-develop proposals for future grant applications that test community-supported interventions (e.g. LTBI screening offers, contact-tracing protocols).
    - Integrate community feedback and stochastic-model outputs into final policy recommendations.

Anticipated outcomes

- Development of policy and process of LTBI testing to reach ASC and ensure high treatment completion as a high priority group.
- Development of interventions to reduce diagnostic delay which may be specific to different groups and community/healthcare settings.
- Validated contact-tracing SOPs reflecting WGS data and real community networks.
- Community-informed revisions to national TB policy (Next Action Plan).

Evaluation plan

- Metrics: Survey reach and completion rates; focus-group attendee diversity; policy update citations.
- Methods: Mixed-methods surveys; policy-impact tracking.
- Reporting: Lay summaries and debrief sessions to inform contributors how their input shaped research.

[This strategy has been read and endorsed by the HPRU in Respiratory Infections Public Steering Committee, with relevant feedback incorporated.]

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PPIEP Plans Summary

Timeframe	Theme 1 – Pandemic Preparedness	Theme 2 – Surveillance & Analytics	Theme 3 – Interventions	Theme 4 – Tuberculosis
Short-term (Years 1–2)	• Co-produce participant-facing documents with underserved communities. • Community co-design workshops with schools/community centres. • Ethics feedback via lay reviewers. • Pilot testing over winter seasons (planning phase). • Public engagement at events (e.g. New Scientist Live).	• Engagement with underserved groups to inform design. • Collaborate with community organisations (Doctors of the World, Bromley-by-Bow, Mosaic). • Workshops identifying participation barriers. • PSC guidance begins.	• Engagement events with Mosaic Community Trust. • Conversations with parents/carers about RSV awareness. • Engagement with pregnant women (1-to-1 interviews preferred). • Develop qualitative research protocol for RSV access experiences.	• Focus groups with TB-affected communities and clinicians. • Anonymous survey for migrant ASC workers. • Validate EHR findings with lived experience panels. • Identify barriers to LTBI testing and GP registration.
Medium-term (Years 3–4)	• Winter road-testing of pandemic platform (households, care homes). • Focus groups with participants to refine instructions. • Iterative improvements to platform materials.	• Serological sampling (oral fluid, nasal, blood). • Ongoing community workshops and feedback sessions. • PSC reviews ensure inclusion and relevance. • Begin equity-lens data analysis.	• Implementation of community-validated strategies to boost vaccine uptake. • Roll-out of tailored messaging and communication interventions. • Ongoing evaluation (CUBE tool, data monitoring).	• Co-design WGS-informed contact-tracing protocols with communities, UKHSA, and prison charities. • Validate and refine tracing strategies for multiple settings.
Long-term (Years 4–5)	• Consolidate all materials into “hibernation kit” for rapid future activation. • Community readiness drill and evaluation. •Maintain advisory “Rapid Response Community Panel.”	• Final equity-stratified dashboards and public-friendly data summaries. • Debrief sessions and evaluation reports. • Continued PSC oversight and feedback reporting.		• Policy-creation forums with UKHSA, DHSC, and ASC sector. • Co-develop future grant proposals for community-supported interventions. • Integrate lived-experience insights into next TB Action Plan.