

*The NIHR Health Protection Research Unit in Emergency Preparedness and Response at King’s College London*

**Theme 4 Public and Patient Involvement Plan**

This document outlines the Public & Patient Involvement (PPI) plan for Theme 4: Improving the evidence base for risk assessment and risk reduction. The research in this theme focuses on developing better understanding and tools to assist national to local level planning and response to direct the effective implementation of public health measures (including the distribution of medicines, support and advice) following deliberate (or accidental) releases into the atmosphere of biological or chemical agents, and also following other low probability but high impact incidents that are highly complex in nature. Current research strands include:

1. Developing complex statistical tools to analyse individual patient level data concerning symptoms of illness in the very earliest cases to report to healthcare, their time of onset of illness and their travel histories during the incubation period of the illness to infer the geographic region that might have been exposed to an airborne infectious agent. Such analysis would then aid the targeting of therapeutic public health interventions. Identifying meaningful Public and Patient Involvement in this very specialist mathematical research proved challenging, so the researchers are now keen to understand from PPI representatives themselves how they consider meaningful PPI could be best undertaken in the future under these circumstances. Research on the statistical tools is also being extended to try to reduce uncertainty and improve the accuracy of the analytical tools’ results for targeting interventions. One way of achieving this might be to use more precise location data for the early cases of illness, based on location data of their mobile phones. This research is being undertaken collaboratively with the Emerging Threats Theme of the NIHR Health Protection Research Unit in Modelling Methodology led by Imperial College London in partnership with PHE. There are potential important hurdles for research and applications aiming at utilising personal mobile phone data with regard to: Personal Identifiable Information (PII), data protection, ethics, commercial interests, etc. Public and Patient involvement will be explored as a means of facilitating the research to more widely consider the possible tensions between serving their health needs, the public good more generally and identifying the cause or the individuals responsible for the release versus the general population’s concerns regarding privacy and personal data protection. The PPI activities associated with this involved doing PPI on PPI to gather the public’s advice on how best to involve the general public in designing and conducting this type of potentially sensitive research. One significant outcome was insightful changes into the materials that will be used in recruiting participants into volunteer studies, as well as a better understanding of the blockers in public perception to such volunteering. It is hoped to do more work of this nature. In the meantime, an unplanned opportunity arose to undertake some cross HPRU PPI. This included some very positive involvement with school science teachers to develop two off-the-shelf resource packs, “Operation Outbreak” (infectious disease outbreaks) and “Tricky Ticks” (promoting tick awareness).. These enabled teachers and STEM ambassadors to deliver engaging science activities and public health messages for primary school Key Stages 1 and 2 (4 to 11 year-olds) in areas that are of relevance to all three HPRUs involved (Modelling Methodology, EPR and EZI).
2. The second strand considers complexity in emergency response, including patients with complex backgrounds in order to seek to reduce the impact of complex national/international emergencies on public health. How to focus the research and decide on priority topics was challenging given the nature of complex events. Applying a type of structured brain-storming, the researchers identified the ongoing UK, European and international migration crisis as both complex and worthy of deeper research. To focus and edify the research process, involving PPI representatives from a forced migrant community background was invaluable. The PPI advisors attended regular project meetings to insightfully advise on, help co-develop, and directly contribute to, the undertaking and dissemination of the research and hopefully have a longer term and direct involvement in its completion. The involvement of the PPI representatives tangibly guided the research planning. This comprehensive PPI process was written up in a peer-reviewed publication with the PPI reps as co-authors (Brainard et al (2017) Forced migrants involved in setting the agenda and designing research to reduce impacts of complex emergencies: combining Swarm with patient and public involvement. Res Involv Engagem. 2017 Nov 6;3:23. doi: 10.1186/s40900-017-0073-z. eCollection 2017). Research in this strand has now moved on to investigate other complex situations in this case arising from the public’s reporting behaviour to gastrointestinal outbreaks. The research will capture data about public response to gastrointestinal illness (GI), and is undertaken in collaboration with our colleagues in the GI and Modelling methods HPRU. The value of this work is to better understand what symptoms trigger health care seeking after GI illness. This may inform service planning, especially in the context of an emerging disease illness which may present suddenly, be subject to public awareness campaigns and/or involve specific known illness progression.

We will review this plan regularly, as new projects start and based on feedback from the HPRU central management, our researchers and the members of the public who take part in the activities.

In line with EPR HPRU PPI policy, this plan only focuses on activities where the public are actively involved in our research projects and does not include public engagement or research dissemination activities.

The activities currently planned in order to pursue this are outlined in the table below:

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| **PPI activity** | **Aim** | **Schedule** | **Indicators of success**  | **Completion / Outcome** |
| STRAND 1 |
| Engage with Modelling Methodology HPRU cross- theme panel as an early “pilot” on how to best to undertake PPI on “use -cases” involving mobile phone data for research and health protection purposes. | 1. Identify opportunities for PPI in future research on mobile phone data.
2. Inform the development of a research questionnaire on mobile phone data usage for the public
 | 26th Oct 2017 | * Public feedback indicates that (1) aims overall were clearly explained and they were given sufficient opportunity to express their views, (2) they found the involvement interesting, and (3) they would be willing to be involved in future research activities
* Researcher feedback indicates that this workshop supported or changed research plans and the shaping of the types of work and outputs that might be relevant for different audiences/purposes
 | This activity was completed and resulted in better volunteer recruitment materials for future research using location data based on mobile technology usage of the volunteers. |
| Engage with teachers, local school children and STEM ambassadors to design some outreach materials based on ongoing research | 1. Identify interested schools and teachers.
2. Inform design brief for materials
3. Test materials for utility
4. Iterate with teachers and children
 | 2017 | * Materials designed to be suitable and actively taken up and utilised by schools and teachers via STEM ambassadors.
 | Completed. Materials were very suitable, involvement of the teachers and children invaluable and materials, both physical and on-line are shortly to be available via STEM and tes (Times Educational Supplement). This was also a highly successful collaborative venture between 3 HPRUs (EPR, MM and EZI) |
| Seek further PPI to extend materials to older year groups | 1. Identify interested schools and teachers.
2. Inform design brief for materials
3. Test materials for utility
4. Iterate with teachers and children
 | 2018 (funding permitting) | * Materials designed to be suitable and actively taken up and utilised by schools and teachers via STEM ambassadors.
 | Ongoing and seeking resource |
| STRAND 2 |
| Engagement/ Attendance of 1 or 2 members of the public at regular Theme meetings | To generate suggestions on the thematic areas to be covered, and methodologies that might be used by the research on complex emergencies.  | From March 2016 PPI partners contribute to regular project meetings  | * Public feedback indicates that (1) aims overall were clearly explained and they were given sufficient opportunity to express their views, (2) they found the involvement interesting, and (3) they would be willing to be involved in future research activities
 | Completed. Two representatives of forced migrant communities were invited to join the project team as patient and public (PPI) representatives. They attended regular project meetings, insightfully contributed to and advised on practical aspects of potential research areas. The representatives identified cultural obstacles and community needs and helped choose the final research study design, which was to interview forced migrants about their strategies to build emotional resilience and prevent mental illness. |
| Role play as practice interviewees, part of research delivery (subsequent to previous PPI in 2016-2017 related to Identifying and prioritising) | To prepare interviewer for original study interviewing refugees about resilience (to practice methods & techniques with example interviewees) | Summer 2017, to be repeated before end 2018 if 2nd interviewer required | * Public feedback indicates that they felt that they have refined the interview approach and tried to identify any issues to resolve
* Researcher feedback indicates that they find the public feedback helpful and will alter their manner, methods or techniques in response
 | Initial interviewer training was completed in summer 2017. Comments about practice interviewee and interviewer experience were positive and reported elsewhere. |
| Role in management, by co-representing Theme 4 at HPRU advisory group (and receiving their critical comments) | To participate in research oversight process  | June 2017 | * Public feedback indicates that they felt that they benefited from the meeting and were given constructive feedback about their role in the research design.
* Researcher feedback indicates that the PPI representative was able to co-present well with the lead researcher attending the meeting.
 | Attendance at advisory meeting was on 11 June 2017; feedback was positive. |
| Undertaking part of the research (recruitment activities) | To help with recruitment by disseminating recruitment leaflets at British Red Cross Centre in Norwich | Summer 2017 and onwards later | * Public and Researcher feedback is that the materials for recruitment were easily exchanged, easy to distribute
 | Completed |
| Identifying, prioritising, Designing and Managing: Co-authorship of academic report on PPI | To have public contribution to description and analysis of the PPI experience | Summer 2017 | * Public representatives approve of the publication, and are satisfied to be collaborative authors on a written report (for peer review journal) about our PPI process
* Researcher feedback indicates that they find the public perspective helpful in understanding the merits and challenges of PPI
 | Article submitted and accepted and published Nov 2018 [Brainard et al (2017) Forced migrants involved in setting the agenda and designing research to reduce impacts of complex emergencies: combining Swarm with patient and public involvement. Res Involv Engagem. 2017 Nov 6;3:23. doi: 10.1186/s40900-017-0073-z. eCollection 2017] |
| Undertaking: Evaluation of thematic mapping that researchers created | To provide qualitative & verification feedback about data collected  | 2018 | * Public feedback indicates that they felt that they have confirmed or modified interpretation of themes initially suggested by the investigators after reading the interview transcripts
* Researcher feedback indicates that they find the public feedback helpful in better analysing & understanding what the collected data mean
 | Regretfully this work was not possible to complete due to recruitment problems. |
| Evaluation and impact: Presentation of study results to Norwich people involved in service delivery to forced migrants  | To provide service provider perspective on both our interpretation of collected data; but also to identify any contrasts with how services are delivered or how people find support they need | 2018 or 2019 | * Public feedback indicates that they feel that they have contributed their “on the coalface” perspectives
* Researcher feedback indicates that they find the public feedback helpful in better analysing & understanding what the collected data mean
 | Completed; Positive Feedback that indicates success (as indicated left) from PPI advisors was reported separately to PPI coordinator (Julia Pearce). |
| Pilot testing of data collection questionnaire; opportunity to comment on research objectives and acceptable parameters for data collection methods for research into gastro-intestinal illness | To obtain feedback and suggestions on research plans and types of outputs | Consultation took place on 15.3.18 | It is anticipated that the necessary PPI to inform our research plans in 2018-2019 will be completed before 1 April 2018. However, some processing of this feedback may continue into 2018 and be reported more fully in the Annual report for 2018-2019. | Comments were used in application for ethics approval to run survey; ethics approval is still pending and may later confirm that the PPI input was useful and relevant. |