

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

**Theme 1 Public and Patient Involvement Plan**

This document outlines the Public & Patient Involvement (PPI) plan for Theme 1. This plan will guide PPI activity for Theme 1 research projects. We will review this plan regularly, as the project develops 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.

Seven projects are being pursued within the theme:

* An experiment assessing whether different wording about the risk of side-effects reduces the chances of a volunteer experiencing side-effects after taking a tablet.
* A study to develop ways of supporting the psychological wellbeing of members of an organisation which is affected by a terrorist attack or disaster.
* A study to understand the apparent needs, worries and concerns for teachers in the recovery from deliberate terrorist incidents, when providing support to worried students and colleagues.
* A study which involves interviewing healthcare workers who assisted with the Ebola response in West Africa, in order to identify ways of supporting such workers better in any future deployments for a disease outbreak.
* A study tracking whether parental concerns about the flu vaccination predict whether a parent observes side effects in their child after vaccination.
* A study tracking whether rumours about the HPV vaccine predict whether children and their parents see side-effects in the child after vaccination.
* A study to assess whether patients caught up in an apparent chemical incident for which no chemical is ever identified are satisfied with the information they receive, and what additional needs they may have.

The activities we will engage in in order to pursue this plan are outlined in the table below:

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| **PPI activity** | **Aim** | **Schedule** | **Indicators of success** | **Completion** |
| ***Side effects of medication study****: Benefits from study are targeted at general public. PPI involves feedback from general public and participants* | | | | |
| Workshop with lay public | To discuss and obtain feedback on research plans, specifically regarding the presentation of the proposed study, clarity of the information sheet and questionnaires, information provided about the proposed intervention and the timing of participant information. | 4 March 2015 | Researcher feedback indicated that this workshop supported the research plans with suggestions for some changes to increase the clarity/conduct of the study.  Public feedback indicated the study design was appropriate. | Completed. Feedback identified multiple minor issues with the questionnaires and information sheets, all of which were addressed.  Discussion also endorsed the suitability and ethics of our proposed study. |
| Feedback from participants at the end of the study on the appropriateness of the study design | To identify ways of improving the design and conduct of future studies in this area | 1st February 2017 | Useful participant feedback received. | Completed. Several participants feedback their thoughts on the study which were positive.  Participant feedback identified support for the study design, and there was no negative feedback about the use of deception via omission. Participants thought the current design worked well and did not have any suggestions on how it could be improved. |
| Editorial on the ethics of deception in research | To disseminate the issues of deception faced in nocebo research and suggest ways to reduce the negative impact of deception by giving an example of how we achieved this in our study. | Submitted to British Journal of Health Psychology on 12th March 2018 | Promote the use of strategies (e.g. PPI) to limit the negative effects of deception in future research. And for researchers to think about the need for deception and ways in which they could be less deceptive. | Completed. The editorial has been published and disseminated among our research network. |
| Presentation on main findings from PhD to a group of academic and community pharmacists. | To disseminate PhD findings and propose the possible solution of reframing side-effect information in patient information leaflets positively to reduce side-effect reporting to medications. | 30th April | To get the audience to think about the way they communicate side-effects to patients as pharmacists and to get their thoughts on our proposed intervention. | Completed. Feedback from the audience was positive and they could see the potential of positive framing. In addition, one pharmacist said they were going to change the leaflet they go through with patients to the positive framing approach. We are in touch with them about a potential collaboration to test this in clinical practice. |
| ***Group Responses After Disasters and Emergencies:*** *Study will improve wellbeing in occupational groups following disaster (including GPs as an occupational group). PPI will include representatives of these target groups.* | | | | |
| A brain-storming session with Senior GPs | 1. To ensure the correct questions are being covered and that our language and key topic areas fit with the organisational culture and need. 2. To identify ways to recruit research participants | August 2014, November 2014, April 2015 | * Clarity and consensus on interview schedule. * New ways to recruit research participants identified | Completed – discussion identified several routes to recruiting participants and expanded the scope of the discussion guide. |
| Email discussions with members of target organisations | 1. To obtain feedback on literature review findings 2. To discuss and obtain feedback on research plans | Ongoing, since August 2014. | * Feedback suggests novel interpretations of the literature review and / or suggested changes to the plans. | Ongoing – key outputs to-date have included advice on best ways to recruit participants. |
| Meetings with representatives from target populations. | 1. To discuss suitability of using specific emergency service and commercial groups in the study. | Meetings held in February to April 2015 | * Identification of suitable groups of workers who are willing to participate in study. | Completed – discussion guided our choice of organisations to approach in order to recruit participants. |
| Practice interviews with members of target organisations | 1. To obtain feedback on first round of interviews/focus groups 2. To discuss and obtain feedback on design of communication intervention for the next stage of the research | April/May 2015 | * Feedback suggests changes to the wording of our interview / focus group schedule. * Suggestions are made for communication intervention. | Completed – there were several suggested changes for our intervention and discussion guides, some of which resulted in modifications. |
| Post-analysis discussion with individual participants from the qualitative study | 1. To ensure that they felt their views had been interpreted and explained appropriately | September 2017 | * Participant views supporting or changing the interpretation of data | Completed – two participants were emailed a copy of the final paper, and confirmed that their responses had been interpreted appropriately. |
| Discussion of intervention and piloting with business community representatives. Two meetings were held with our local Business Improvement District | 1. To identify challenges and solutions to recruitment for our pilot study  2. To identify additional needs from the community | September 2018 | * Challenges, solutions or additional needs are identified | Completed – representatives suggested several changes to our recruitment material to make clear who was being invited to attend, and helped to distribute the material.  An additional research need was raised (CCTV operators who view distressing scenes but might be missed in mental health interventions). We will consider additional work on this. |
| Post-interview/post-analysis discussions with target organisations | 1. To obtain feedback on our interpretation of research findings   To obtain advice on research dissemination activities | End of project | * Researcher feedback indicates that this method supported or changed research interpretation. * New avenues for research dissemination identified | Future activity |
| ***Psychological assistance for teachers and their students:*** *The study aims to understand the apparent needs, worries and concerns for teachers in the recovery from deliberate terrorist incidents, when providing support to worried students and colleagues.* | | | | |
| One teacher has been approached to provide feedback on the survey and make recommendations for questions | 1. To assess appropriateness of survey format  2. To gather feedback on survey questions | Ongoing | * Feedback indicates appropriateness of survey format * Changes are required to make question format, i.e. removal of open-ended questions, more suitable for teachers | Ongoing – feedback to-date has included advice on how best to structure survey questions. |
| Feedback from teachers and governors | 1. To assess appropriateness of survey format  2. To gather feedback on survey questions | Ongoing | * Feedback indicates appropriateness of survey format * Changes are required to make question format, i.e. removal of open-ended questions, more suitable for teachers | Ongoing – we have approached a school governor and discussion will take place soon; we are in the process of identifying other teachers and governors |
| ***Psychological Effects of Ebola on Responders:*** *Study will benefit those who deploy overseas for emergency response. PPI will include those who have deployed overseas and their managers.* | | | | |
| Discussion of proposed research topics and questionnaire / interview items with people deployed to West Africa | 1. To identify key areas of concern among responders  2. To test suggested wording for questionnaire items and identify possible items that needed to be added | End of February 2015 | * Development of acceptable qualitative interview schedule and on-line survey | Completed – initial discussion identified some areas of concern that we had not considered, which were added to the interview schedule and questionnaire. |
| Presentation of preliminary results to a mixed group of responders and managers. | 1. To gain feedback on preliminary results and check that our interpretation of the results seemed sensible.  2. To identify possible routes for dissemination of results (e.g. NGOs to engage with) | End of March 2015 | * Feedback that the presentation / contextualisation of the results required amendment or was satisfactory. * Researcher development of a list of possible agencies with an interest in our area. | Completed – participants broadly endorsed our interpretation of the results and suggest some routes for dissemination, including a conference attended by several NGOs. |
| ***Public health consequences of parental concern about vaccination: Two studies (one investigating the child flu vaccine and one investigating the HPV vaccine)*** *Studies will improve communication with parents and school children about vaccinations. PPI for the study investigating the child flu vaccine will involve parents of children aged 2 to 4. PPI for the study investigating the HPV vaccine will involve children aged 12-13 and their parents.* | | | | |
| Child flu vaccine: Two groups of parents of primary school children were involved in the development of this PhD application. | 1. To identify the best approach to recruit participants  2. To identify practices that would allow participants to visit our laboratory for a testing session (e.g. financial reimbursement, length of visit, crèche arrangements).  3. To inform the lay summary for our grant application. | End of December 2014 | * Feedback indicates supported or changed the timing of the questionnaires, the recruitment approach or the text for the lay summary. | Completed – the activity identified several additional questions to consider for the study, and helped us to reword the lay summary to make it more accessible. |
| Child flu vaccine: Presentation of interpretation of results to parents. Advice on effective dissemination of results of research. | 1. To gain feedback on results and check that our interpretation of the results seems sensible.  2. To identify platforms easily accessible to parents through which to disseminate the results of our research. | End of August 2019. | * Feedback that the presentation/contextualisation of the results required amendment or was satisfactory * Researcher development of a list of possible platforms through which to disseminate the results of the research | Future activity |
| HPV vaccine. Discussion with parents and adolescents about a new study on HPV vaccination | 1. To identify adolescent concerns about the vaccine and how to phrase these in a questionnaire  2. To assess suitability of proposed recruitment strategies | Ongoing | * Appropriate wording and strategies are identified | Activity is ongoing. Initial work has already identified unexpected adolescent concerns which need to be included. |
| ***Suspected chemical incidents with no identifiable toxin:*** *Study will improve communication to patients caught up in a suspected chemical incident where no chemical is found. These often occur in schools. PPI will involve school children and their parents.* | | | | |
| Children and parents of a school were asked to provide feedback on our recruitment paperwork. | 1. To assess appropriateness of recruitment materials | October half term 2014 | * Feedback suggests that materials are appropriate or identifies areas for change | Completed – discussion with children and parents noted that the material was broadly acceptable, and suggested that approaching potential participants was unlikely to cause concern. |
| ***Application for additional HPRU funding:*** *King’s College London have applied to the second round of NIHR funding for the HPRU competition. Although existing HPRU resources were not used for this, the PPI activity is recorded here for completeness.* | | | | |
| Four members of the London Bridge business community with experience of disaster preparedness and the 2017 terrorist attack were asked to review our lay summary | 1. To assess whether lay summary was comprehensible and compelling. | April 2019 | * Feedback suggests changes or appropriateness | The four PPI members provided written feedback. All independently noted that the summary made sense and appeared to reflect high quality work. |