

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

**Theme 5 Public and Patient Involvement Plan**

This document outlines the Public & Patient Involvement (PPI) plan for Theme 5: Decontamination. This theme focuses on optimising the technical and psychosocial aspects of decontamination. Work will be conducted in two strands:

* Strand 1 focuses on optimising the physical process of decontamination, using in vitro approaches. In particular, research will examine the effect of disrobing, dry decontamination, and the use of novel agents such as diphoterine, on decontamination efficacy. The findings from this research will be used to inform volunteer studies carried out as part of Strand 2 (described below).
* Strand 2 focuses on understanding the psychosocial impact of incidents involving mass decontamination. The first stage of this research will involve a review and synthesis of existing guidance and evidence relating to the psychosocial aspects of mass decontamination. This will inform the development of guidance on the management of psychosocial aspects. Following this, a series of focus groups will be carried out to gain a greater understanding of likely public acceptability of decontamination interventions. The findings from this research (and the research carried out as part of Strand 1) will inform volunteer studies.

This plan will guide PPI activity for Theme 5 research projects. 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 we will engage in in order to pursue this plan are outlined in the table below:

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| **PPI activity** | **Aim** | **Schedule** | **Indicators of success** | **Completion/ Outcome** |
| ***Strand 1*** |  |  |  |  |
| Appoint a panel of 6 - 8 lay members to review project outcomes | 1. To identify whether optimum decontamination strategies identified within laboratory research are perceived as acceptable to panel of lay members. 2. To understand ways to potentially improve the perceived public acceptability of optimum decontamination strategies. | Share research outcomes once they are available (March/ April 2016).  Arrange a series of discussions with lay members about the findings, specifically relating to perceived acceptability of interventions. | * Identification and involvement of a panel of 6 – 8 lay members who are interested in and engaged with the research. * Improved understanding of factors which may affect perceived public acceptability of proposed decontamination strategies, and identification of ways in which acceptability of interventions can be improved. | Completed. A panel of members of the public have been recruited, who are interested in the subject area, and available to review project plans and outcomes. The panel were appointed near the start of the project (September 2015), and have provided (and will continue to provide) feedback on study materials and outcomes. |
| ***Strand 2*** |  |  |  |  |
| Panel of lay members to review new guidance document | 1. To obtain feedback on the proposed guidance. 2. To identify any areas of the guidance which could be improved, in terms of information which is missing or which should be included, or information which requires clarification. | Following development of new guidance (July, 2015). | * Public feedback suggests that the proposed guidance is clear and contains relevant information. * Public feedback facilitates clarification and improvement of guidance, where necessary. * Information gathered through discussions with members of the public informs the development of a plan for carrying out focus groups (see point below). | Completed. The public panel reviewed the new guidance document, and suggested areas for clarification and improvement. The guidance document was subsequently updated, based on these suggestions. One example of this was the suggestion by the public panel that information on the possibility of providing pre-incident public education should be included within the guidance document; the guidance document has now been updated to reflect this. |
| Panel of lay members to inform the development of focus group plan, facilitated by discussion with lay members about new guidance document. | 1. Information obtained from discussions with lay members about newly developed guidance will inform the development of a plan for focus groups. 2. In particular, discussions will focus on any aspects of the guidance which may be perceived as being less acceptable (e.g. certain decontamination methods may be perceived as being less acceptable than others), and how to optimise responder management strategies. | Between guidance development (July, 2015) and focus group study (October/ November 2015). | * Public feedback enables the development of a plan for focus group studies, which takes into account any public concerns about acceptability of different decontamination methods and management strategies, and allows these concerns to be examined further within the focus group study. | Completed. Following discussions about the guidance document, the public panel were engaged in a series of discussions about the nature of the planned focus group study. Based on these, a plan for the focus group study was developed, taking into account aspects of decontamination that may be perceived as less acceptable than others, and examining different responder management strategies. |
| Panel of lay members to review focus group research outcomes | 1. Review by PPI panel will identify any areas where research outcomes need to be clarified, and any areas of interest which require further information. | May 2016 | * PPI panel feedback on focus group outcomes enables the focus group report to be updated, and facilitates development of a plan for the human volunteer field trials. | Completed. The PPI panel suggested areas in which the focus group report required clarification (e.g. additional information provided regarding focus group sizes, the coding scheme used, and the fact the population was London-based). The PPI panel discussed the plans for the two proposed human volunteer trials, and suggested changes in regards volunteer recruitment and methods used; these suggestions were used to inform subsequent versions of the trial plans. |
| Identify Muslim PPI contacts to assist with recruitment of Muslim participants for focus groups, and design of focus group materials. | 1. To establish avenues of recruitment for focus groups, and ensure that cultural sensitivity is maintained during recruitment and running of the focus groups.  2. To generate a discussion guide for use during focus groups with Muslim participants. | Prior to running focus groups with Muslim participants (Jan – March 2016) | * Engagement with Muslim PPI contacts facilitates identification and recruitment of participants for focus groups. * Discussion with PPI contacts facilitates the development of a discussion guide for focus groups with Muslim participants. * Engagement with Muslim PPI contacts ensures that cultural sensitivity is maintained during the running of the focus groups. | Completed. A PPI panel of Muslim contacts was set up, and two meetings were held. The PPI contacts were very helpful in providing advice on participant recruitment, particularly in terms of the need to recruit a sample that would fully represent the diversity of the Muslim population in Britain, and the importance of running focus groups with a same-sex facilitator. Contacts provided introductions to their communities in order to facilitate participant recruitment. PPI discussions also ensured that the focus group guide was developed in a culturally-appropriate and sensitive way. |
| Appoint a panel of members of the public with previous experience of taking part in decontamination field trials/ exercises to inform the development of a plan for volunteer studies. | 1. To engage with the panel about plans for the volunteer studies, and to identify any areas for improvement (e.g. ways to improve volunteer welfare during volunteer studies, ways to optimise data collected etc.).  2. To establish new ways to identify and recruit participants for the volunteer studies. | During planning for volunteer studies (after April, 2016). | * Discussion with members of the public ensures that participants’ welfare is protected during volunteer studies, and that data collection is optimised. * New ways to identify and recruit participants for volunteer studies are established. | Ongoing. |
| Panel of members of the public from the PHOENIX Public Advisory Group to review research protocols for three studies to be conducted as part of Work Package 7 of the DH Policy Research Programme funded PHOENIX project. WP7 of the PHOENIX project is centred on psychological factors involved in decontamination, specifically the effect of different communication strategies on casualty behaviour; this therefore relates to the aims of Strand 2. | 1. To work through an interview schedule for an interview study with members of the lay public about non-expert perceptions of the risks of chemical contamination and the steps that can be taken to reduce these risks.  2. To discuss protocols for two randomised controlled trials to identify, from a lay perspective, whether there are any areas for improvement. | During planning of data collection activities (May, 2017). | * Discussion with members of the public ensures that participants’ welfare is protected during volunteer studies, and that data collection is optimised. * Working through the interview schedule will ensure that the schedule is applicable to the sample to be recruited (i.e. people with no expertise in the subject of decontamination or CBRN). | Completed. Two additional outcome measures have been added to one of the RCT’s as a result of discussions and a scenario will be developed for use in the interview study and RCT’s, based on feedback received from the panel. |