

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

**Theme 3 Public and Patient Involvement Plan**

This document outlines the Public & Patient Involvement (PPI) plan for Theme 3: Enhancing syndromic surveillance for early detection and assessing the extent of incidents. The research in this theme focuses on evaluating existing, and exploring new and evolving, syndromic surveillance systems (such systems monitor in ‘real time’ the symptoms people report to Emergency Departments, GPs and other health care services). The aim is to better understand where such systems are able to provide early warning about deliberate or accidental exposures to biological or chemical agents, particularly those spread by air, food or water. There are two particularly challenging aspects for Theme 3 in relation to PPI. The first is the potential sensitivities (national security) associated with some but not all of the subject matter. The second is the highly specialist surveillance and statistical techniques that are central to much of the work.

The main research strand employed in this research project is:

1. Explore public perceptions of data use in public health with a specific focus upon the work of syndromic surveillance. These outputs will feed directly into public facing communications relating to research outputs

This plan will guide PPI activity for Theme 3 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.

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| **PPI activity** | **Aim** | **Schedule** | **Indicators of success** | **Completion/Outcome** |
| Public Perceptions of syndromic surveillance systems | | | | |
| Science Café presentation | 1. To determine public perceptions of the use of big data within public health 2. To explore whether the activities undertaken by syndromic surveillance are viewed as acceptable by the public. | Nov-2015 | * Information on public views in relation to big data and syndromic surveillance that can feed into communication about our work. * Details on methods and theme that can be explored further in questionnaire survey. | Completed. Nearly all respondents (92%) thought that SS was important and upon being presented with information about the working of syndromic surveillance 70% felt reassured. 64% saw big data analysis as part of public health work. |
| Questionnaire survey | 1. To explore views on whether syndromic surveillance is viewed as part of public health. 2. To quantify and explore public concerns about the use of specific datasets for syndromic surveillance (e.g. GP records, pharmacy records) | May 2017. | * An understanding of people’s views on whether PHE should be undertaking syndromic surveillance. * Information on the types and characteristics of datasets whose use raises most public concern. An initial understanding of the reasons behind these. * Information of public perception that can feed into the communication of syndromic surveillance work. Information on perception that can be used to guide future focus group discussions. | Completed. The questionnaire was completed in early 2017 and the results presented and discussed at a face to face HPRU meeting in July 2017. This activity indicated that there was slightly more unease about the use of GP records and NHS111 within syndromic surveillance in comparison to ambulance and emergency department data. Most unease was felt in relation to the use of novel sources (e.g. internet / twitter). However, the qualitative responses indicated that this unease was related to concerns about the usefulness of such data as opposed to privacy etc. These themes will be explored more fully in the focus groups. |
| Workshops to be held with two PHE panel focus groups | 1. To understand fully the concerns expressed re the use of  social media and google search data for surveillance as opposed to the apparent contentment with the use of the health consultation data | December 2018 | * To understand the apparent concern re the use of social media and to integrate these into the reporting of research results. * To include the factors highlighted in an overview paper re the ethics of social media/ internet search data for syndromic surveillance, so that others can learn from this | Completed. Two focus groups were completed by the end of 2018 and the results presented and discussed at a face to face HPRU meeting in January 2019. The focus groups were designed so that the first focus group was notable older than the second.  Within the first focus groups privacy was a greater concern and there was a lack of awareness of how privacy could be controlled on social media. Both groups recognized that privacy was of greater concern for older participants. Within both groups there was broad trust in the use of NHS data for syndromic surveillance.  In the first focus group there was a thirst for more information about the work of PHE and its use of data. The second focus group was more interested in knowing that the information was accessible if they wanted it rather than being “bombarded”. |