Patient and Public Involvement & Public Engagement: Summary of Mapping (2011-2014)

NIHR Imperial BRC

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Introduction

The NIHR Imperial Biomedical Research Centre (BRC), as part of the Imperial Academic Health Science Centre (AHSC), aims to transform health outcomes locally and internationally through translational research. Patients are central to our work. In February 2014, Dr Markella Boudioni was appointed in the role of Patient & Public Involvement (PPI) Manager for the NIHR Imperial BRC, to work across both the BRC and the Patient Experience Research Centre (PERC). Since then, a detailed exercise has been carried out to map ongoing PPI and PE activities within the BRC and its 19 research themes (Appendix 1).

NIHR INVOLVE definitions are used at this document, namely that patient and public involvement is where patients and members of the public are actively involved in the activities, organisation and governance of research projects or Themes, while public engagement is where information and knowledge about research is provided and disseminated to the public.¹ These definitions, values and approaches will be referred to throughout this document.

Mapping

Patient and Public Involvement (PPI)

The mapping identified good patient and public involvement practices, examples and activities linked with certain themes, though within other BRC themes no PPI activities were identified. The ways of involvement, the research stages, range of activities as well as the PPI approaches all varied across BRC Themes and research teams.

Ways of involvement

- The commonest ways of involvement utilised through the PPI-active BRC themes were through:
  - alliances with charities and other organisations (15 themes), and
  - patient and public representation in steering committees (12 themes).
- Less common ways of involvement were:
  - generic patient groups/panels offering advice and support for all research projects within a team (4 themes), and
  - patient and public steering committees or groups for specific projects (7 themes).

Research stages and range of activities

- Patients and members of the public were involved in the whole research process in a few occasions only (5 themes). They were involved across a range of activities, from discussing the initial idea to the dissemination of findings or setting up strategic priorities for the BRC theme.
- Charities/charity representatives, patient and public groups and individuals, were mostly involved in specific stages of the research process.
  - Many involved in the designing and managing activities, i.e. designing research tools such as PIS and consent forms and commenting on grant and ethics applications (14 themes).
  - There were some good examples of involvement in commissioning (12 themes), and disseminating findings (8 themes).

¹ Further definitions: participation: where people (patients, public, carers) take part in a research study (as subjects / participants); public: an inclusive term used for members of the public, including all subgroups of population, community groups, ‘communities of interest’, ‘communities of place’, networks, organisations and healthy volunteers; patient: those individuals who receive healthcare. The term carer is not used explicitly in this report, but it is included in public and patients (NIHR, 2013, INVOLVE, 2014).
However, there were very few examples in identifying or prioritising topics (3 themes) and involvement in undertaking research (1 theme).

**PPI approaches**
- The majority of the PPI approaches in research could be described as consultations (15 themes) and very few as collaborative projects (5 themes), although the distinction is not very clear.

**PPI Examples**
- A good example of PPI across all research projects is presented in cancer with an active generic cancer patient group being involved in reviewing material for clinical trials and providing insight into information and publications.
- Good PPI consultative and collaborative examples are evident in specific infection projects.
  - ‘Views of new migrants in screening’. A collaborative qualitative project with ethnic community charities explored the views of new migrants on screening. It utilised public consultation at an ethnically diverse borough in London, at the initial design to refine the research questions, but to also identify appropriate ethnic groups to invite for further involvement and collaboration. Two migrant members of public were collaborators in the initial NIHR proposal and members of the project steering group overseeing the study.
  - CHERUB Collaboration. The Collaborative HIV Eradication of Viral Reservoirs: UK BRC (CHERUB) collaboration, works to provide a unique experimental medicine approach to new HIV therapeutic strategies. It includes representation from peer experts, close interaction with Non-Governmental Organisations (NGOs), and working with people living with HIV in protocol development, TSC and trial management groups. Although this is a consultative project, it has strong elements of collaboration with NGOs, people living with HIV, and local community organisations to design information leaflets, written articles for peer community publications and patient feedback meetings (http://www.cherub.uk.net/).
- Two other examples of **PPI consultative projects** are the LOLIPOP study (biobanking) and a project around Type 1 Diabetes (obesity).
  - The LOLIPOP -a population bioresource cohort- study has established a patient and public participant group/steering committee of 8 people with input into study design, progress, discussion of results, dissemination, etc. which meets formally and informally. In addition, there is a wider interest group of 70 people, which comments on the study electronically. The study is based in General Practice and includes feedback of results to patients and GPs.
  - Development of a Novel Microprobe Sensation-Less Continuous Glucose Monitor for Type 1 Diabetes study. An advisory and steering patient group has been established and meets 2-monthly to discuss study progress, development and strategy for further funding. Although, it is a consultation project, the patient group is involved in the strategy for further funding.

**Public Engagement (PE)**

**PE Activities**
The mapping exercise also identified good public engagement practices, examples and activities.
- Most of the BRC themes are involved in PE activities, such as:
  - festivals and public events (13 themes),
  - media coverage and publicity (6 themes),
  - public talks and seminars (6 themes).
- Recent productions of videos informing lay audience about research were identified (5 themes).
- There are also dedicated and public access project websites within a few themes (3 themes).
• Other activities include research laboratories tours and patients and public visits (2 themes), production of publications and newsletters reflecting research (2 themes), public meetings and coffee mornings (2 themes).

**PE Examples**
Good examples of public engagement spanning across the BRC are:

• the Imperial Festival, an event that many BRC teams present and interact with the public every year ([http://www3.imperial.ac.uk/festival](http://www3.imperial.ac.uk/festival)) (8 themes in 2011-2014), and

• the NIHR Imperial BRC and partners’ video showcasing patient involvement in research ([produced in 2013](http://imperialbrc.org/our-patients)).

Examples linked with specific BRC teams are:

• the public events associated with the work of Professor Roger Kneebone ([surgery and surgical technology](https://www.youtube.com/watch?v=dWtILWOYwpQ));

• the short animated MOSAIC ‘How to Catch Flu’ film ([respiratory](http://www3.imperial.ac.uk/newsandeventspggrp/imperialcollege/newssummary/news_24-7-2014-12-51-33));

• the 17 short videos explaining the importance of clinical trials ([cancer](http://www.imperial.nhs.uk/research/research-centres/imperial-cancer-research-uk-centre/index.htm)); and

• the innovative ‘Heart and Lung Repair Shop’, a pop-up interactive hub for heart, lung functions and research ([cardiovascular](http://www1.imperial.ac.uk/nhli/public_engagement/the_curious_act/heart_and_lung_repairショップ/)).

**PPI/PE barriers and gaps**
PPI/PE barriers and gaps were also identified; these should be addressed in order for PPI/PE activities to be more effective. The main ones were:

• lack of PPI/PE knowledge and approaches,

• lack of strategic/organisational support for PPI/PE,

• limited PPI/PE network across Imperial and NWL, and

• lack of evaluation or impact mechanisms.

**PPI/PE mechanisms and facilitators**
On the other hand, the mapping exercise identified PPI/PE mechanisms and facilitators that should be utilised:

• developing and sustaining productive partnerships,

• PPI leads within each theme,

• PPI strategies,

• job/role descriptions for patient representatives,

• PPI/PE funding, and

• theoretical or PhD work for PPI/PE.

**PPI/PE quality and impact**
Although evaluation or impact tools are not yet in place, some indications for the quality and impact of PPI/PE were given.
Patient and Public Involvement

- Most of the projects with PPI can be described as consultative projects with little involvement from the public.
- Although some teams are involved in very few or none PPI activities, there is commitment and proactive approach to the PPI values and principles by other BRC teams and investigators.
- Patients and the public are increasingly involved in research organisation, governance and commissioning, which has the greatest impact in research.
- PPI activities in research have also impacted on implementing, i.e. information delivery and services co-design.

Public Engagement

- Most BRC teams demonstrate a proactive approach to the PE principles.
- There are rich, varied and innovative ways that the BRC themes are engaged with the wider society or specific population subgroups.
- The PE activities have increased substantially over the last years, reached a big number of people and offered them the opportunity to interactively learn about research.

Conclusions

This mapping shows a variable picture of PPI/PE activities across and within each of the BRC Themes, with an encouraging breadth and variety. There are many good examples of PPI/PE activities and many enthusiastic and knowledgeable facilitators, but there are also gaps and barriers.

Based on the above and in order to address the PPI/PE gaps and barriers, the NIHR Imperial BRC PPI/PE (2014-2017) strategy was drafted. This was approved at the AHSC Research Board meeting in January 2015. The strategy draws from the initial NIHR Imperial BRC strategy (2011) and includes the general approach, objectives and activities linked with the objectives.

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Appendix 1 - Figure 1. NIHR Imperial BRC Themes, 2014