

Health Protection Research Unit
in Gastrointestinal Infections


*National Institute for
Health Research*

Patient and Public Involvement (PPI) and Public Engagement (PE) Strategy

2016-2019 Strategy

Background

The National Institute for Health Research (NIHR) Health Protection Research Unit (HPRU) in Gastrointestinal Infections at The University of Liverpool is a partnership with Public Health England and brings together internationally leading researchers from the University of East Anglia, University of Oxford and Institute of Food Research. We work in partnership to exploit synergy, world-class facilities, and breadth and depth in relevant research between these institutions.

Its overarching strategic aims are to:

- explore and explain the distribution of diarrhoeal diseases in the population, establishing for whom the disease burden is greatest and why
- generate new strategies for control to reduce disease burden and associated health inequalities

Through these aims this integrated, inter-disciplinary research programme will meet Public Health England's main objectives of addressing inequalities, protecting the country from infectious diseases, and being an evidence-led organisation that provides answers to public health problems.

The research undertaken by the HPRU is encompassed in six thematic areas:

- Theme 1: People
Exploring socio-economic and behavioural factors in gastrointestinal infections
- Theme 2: Tracking disease in the population
Developing novel methods for disease surveillance and outbreak investigation
- Theme 3: Pathogens
Exploiting recent advances in genomics
- Theme 4: Places
Elucidating the role of environment in gastrointestinal disease outbreaks
- Theme 5: Pathways
Understanding transmission of gastrointestinal infection to and between people
- Theme 6: The Microbiome
The role of microbial communities in gastrointestinal disease

Vision

The NIHR HPRU in Gastrointestinal Infections is committed to ensuring that patient and public involvement and engagement are reflected within their research. Patient and public involvement is important as our researchers are able to listen to the public's views and ideas on Gastrointestinal Infections, which in turn helps to shape and improve HPRU research. Public engagement is important as it enables us to share HPRU research news on a local and national level which in turn leads to a greater understanding of research in general and of public need.

Our vision is to ensure that there are opportunities for patients and the public to make valued contributions to our HPRU at all levels; from the strategic level at the External Advisory Panel and Research Steering Committees, to the individual level at the project stage. We aim to ensure that all themes consider the viability of public contribution at project level. All themes are expected to contribute to public engagement activities. We aim to communicate with the

wider community across the different regional areas of the HPRU, informing diverse stakeholders about our work and opportunities to engage.

Definitions

Throughout this strategy we will use the definitions adopted by the NIHR for including the public in research, namely:

- Involvement – where our HPRU research is being carried out **by** or **with** members of the public. The ‘public’ includes: patients, potential patients, carers, service users, and those organisations that represent people that use services.
- Engagement - where information and knowledge about our HPRU research is disseminated **to** the public. For example, at science festivals, open days, talks at schools, and through social media sites etc.
- Participation – where members of the public take part in a HPRU research study. For example, a member of the public could be recruited to a clinical trial, into a cohort study as a participant, help by completing a questionnaire or take part in a focus group etc.

Audience

We wish to engage members of the public with our research through a mix of activities, with attention to the regional areas of our partner institutions, including: the North West of England, the East of England and the South East of England. This will also include reaching diverse groups that are under-represented. Further to this, we hope to encourage relationship building between researchers and community groups, so that all partners can usefully contribute to collaborative research projects. A key part of this will be to build on the existing capability of our scientific community to increase the public’s knowledge and understanding of the HPRU’s work on Gastrointestinal Infections over the term of the HPRU, until March 2019.

Objectives

We have developed six strategic objectives for PPI and PE. These objectives are listed below along with some of the important activities and projects that will help us meet these objectives:

Involvement

1. Enable patients and the public to input at a strategic level into the direction of the HPRU and its governance
 - Recruit at least three lay representatives to the External Advisory Panel and ensure there is also representation at quarterly Research Steering Committee meetings

- Ensure all representatives are able to contribute by developing a clearly defined role description, with induction and training provided
 - PPI/PE lead to assist with travel arrangements, prompt payment of expenses and other support as required, to enable ease of participation at requested meetings
 - Patient and public representatives to feed back into their own networks and panels the work of the HPRU, thus generating wider debate
2. Inform and inspire researchers to undertake opportunities for patient and public involvement in their research
- HPRU management, including HPRU Director and Theme Leaders, to actively encourage research staff and PhD students within the HPRU to examine opportunities for public contribution in their research
 - Communicate with all researchers the importance of PPI in their research and provide training opportunities wherever possible
 - Share best practice, skills and expertise in PPI across the HPRU community

Engagement

3. Embed public engagement across all themes within the HPRU
- PPI/PE lead to conduct a desk-based benchmark study on public engagement activities across all 13 HPRUs and their partner institutions to inform decision making and facilitate planning of future collaborative engagement activities within the HPRU
 - All researchers to collaborate with Theme Leaders, lay representatives and PPI/PE lead to plan, develop and facilitate effective engagement activities related to their research
 - Provide training opportunities wherever possible in order to develop engagement skills and build on the capacity and PE expertise of the HPRU researchers
4. Publicise the work of the HPRU through a range of communication channels in order to raise awareness and to foster public engagement
- Develop a HPRU website with user friendly and engaging information, including: a patient and public involvement section that explains the work of the HPRU in layman's terms, detailing latest highlights of public engagement activities and offering ways to get involved
 - Manage communications via social media platforms, such as through our twitter account, in order to inform the public of our PE activities and direct the public to the HPRU's research
 - Disseminate information about the HPRU via a regular newsletter for HPRU members, GI patient groups and other key stakeholders, with a focus on public engagement activities

- Utilise the University of Liverpool, PHE, NIHR and partner institutions press offices to develop articles for new stories and announcements in order to engage with a wider audience via digital and traditional media, such as television and radio
 - HPRU researchers to register with the national Science Media Centre to develop links with the national media to utilise when announcing research findings to the media
 - Produce a leaflet that introduces the public to the HPRU and the ways they can get involved
5. Communicate about HPRU research and findings through attendance at conferences
- All HPRU researchers and PhD students to attend relevant academic conferences to maximise opportunities for press and other coverage of HPRU work
6. Present HPRU work directly to the public and seek their engagement at events
- Pro-actively participate in public engagement events that are run by the University of Liverpool and its partner institutions, as these events are able to reach wider audiences than the HPRU would be able to achieve on its own
 - PPI/PE lead to circulate national awareness initiatives in Gastrointestinal Infections, such as Love your Gut week, and for HPRU researchers to use this as a catalyst for their own public engagement activities

Support

The HPRU has a central administrative team to support sustainable patient and public involvement and public engagement work by research staff and PhD students. The team consists of a Project Manager, a part-time Project Officer (the PPI/PE lead) and a part-time Research Administrator. The team take a central role in planning and co-ordinating any engagement activities and manage the day-to-day activities needed to deliver the strategy.

As a member of The University of Liverpool the PPI/PE lead will continue to network and share expertise on Public Engagement at various levels within the University, including: the Public Engagement Working Group run by the Faculty of Health and Life Science's Public Engagement Officer; and the Public Engagement Forum organised by the University's Public Engagement with Research Manager. To maximise resources we will also work with the NIHR on any joint HPRU initiatives. We will utilise the Public Health England's People's Panel, established as a way to engage with the public about health priorities, information and services and has 1,000 people across England as members. Further to this, we will make use of the NIHR's Involve initiative, a national advisory group that supports public involvement in research, in order to embed public involvement as part of the full HPRU research cycle.

Governance and Reporting

Each theme will maintain a record of the training courses attended by their teams and any PPI or PE activities undertaken. Information will be provided as a regular update to the HPRU's PPI/PE lead on a quarterly basis. This information will be disseminated more widely via the HPRU Gastrointestinal Infections newsletter, the website and twitter account. In addition the HPRU are required annually to report all progress, including its progress in delivering its PPI/PE strategy, to its funder NIHR.

Every quarter at the HPRU's Research Steering Committee, attended by the HPRU Director, PHE Lead, four lay members and the Theme Leaders, PPI/PE activities are monitored and reviewed. These meetings help to facilitate additional development of good practice and ensure that activities are appropriately monitored and involvement evaluated. Beyond this, the HPRU External Advisory Panel, which includes the four lay members, review the Unit's overall direction and progress.

Evaluation

This strategy represents a renewed strategic commitment to patient and public involvement and engagement from the HPRU, and recognises excellence in planning, delivering and assessing public engagement activities.

Evaluation is essential to achieve the best possible outputs, outcomes and impact, as well as to inform future work. HPRU Researchers will use the Medical Research Council's Public Involvement Impact Assessment Framework (PiiAF) to assess the impact of involving members of the public in their research. Evaluation of the effectiveness of involvement and engagement will become part of the HPRU's culture, supported by the PPI/PE lead. Furthermore, we aim to highlight the importance of sharing and disseminating best practice and learnings.

The effectiveness of this strategy will be reviewed and assessed annually during its lifecycle to assess progress towards delivering the ambitions set out here.

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- PPI/PE Strategy created: 31 March 2017
 - Strategy reviewed by lay representatives and senior management before uploading to the HPRU GI website: <http://www.hprugi.nihr.ac.uk/patient-and-public-involvement/>
 - Proposed review date: 31 March 2018.