

Patient and Public Involvement/Engagement strategy for the National Institute of Health Research, Health Protection Research Unit, Behavioural Science and Evaluation (HPRU BSE)

Vision

We believe that Patient and Public Involvement/Engagement (PPIE) should be at the core of the work of the HPRU. Not only because this is the right ethical approach but because public involvement improves the quality and relevance of our health research.

The HPRU BSE public involvement team, Associate Professor Andy Gibson and Dr Noreen Hopewell-Kelly have worked with our public contributor strategy group to develop our Patient and Public Involvement/Engagement (PPIE) strategy; and to deliver our vision for how patient and public involvement can provide a strong consistent voice throughout the work of the HPRU.

Section 1 –

Our aims and objectives have been broken down into a series of plans for the short, medium and long term as follows.

Short-term aims

- To establish the public involvement needs of each of the HPRU BSE Work Themes.
- To establish and formally launch the HPRU Public Advisory Group (PAG) as part of the HPRU BSE.
- To identify the training needs of researchers, HPRU BSE affiliated students, academics, PHE staff and trainees which will provide them with the skills to undertake PPIE confidently and effectively.
- To identify the training needs of public contributors to ensure they can participate fully and effectively in PPIE; and are supported to have their voices fully heard.
- To establish how to best use the resources available through our strategic partner, People in Health West of England (PHWE).
- To identify suitable research project(s) to access our Community Involvement fund to enable meaningful engagement with underserved communities.

Medium-term aims

- To establish mechanisms for efficient and effective communication between researchers and public contributors.
- To develop and deliver training for public contributors to be able to undertake their role effectively and with confidence.
- To establish policies, procedures, and resources to support the appropriate and timely delivery of PPIE.
- To collect feedback from researchers and public contributors on their experience of our training programmes.
- To further develop and refine the training programmes to fully meet the needs of HPRU BSE affiliated students, academics, PHE staff and trainees.
- To work to achieve greater diversity in PPIE, diversity that is appropriate and relevant to research.
- To work with the successful research project teams to develop and undertake the community involvement Project(s).

Long-term aims

- To develop public involvement evaluation tools to test whether we have successfully created the conditions and processes to enable impactful public involvement.
- To review and evaluate our model of PPIE.
- To complete delivery of the Community Engagement Project(s).
- To work with the National HPRU PPIE lead network to identify opportunities for collaboration on PPIE, including knowledge mobilisation, training workshops and publication opportunities.

Our Public Engagement aims are:

- To work with HPRU Knowledge Mobilisation and Communications Officer to identify opportunities for collaborative working to encourage public involvement.
- To generate opportunities for the public to input knowledge, ideas and experiences to help shape future research.
- To capture skills and knowledge beyond conventional academic and public office channels.
- To use relevant channels to push out information about opportunities to get involved in HPRU research.
- To support effective dialogue between the public and researchers to create a cycle of collaborative dissemination, leading to public involvement, and lead to collaborative dissemination.
- To support the effective dissemination of research findings to non-academic audiences, exploring novel and innovative channels to achieve this.

Section 2 -

This is how our short-, medium-, and long-term aims will be implemented.

- A. [By working actively to make PPIE integral to research across the HPRU BSE. The PPIE team will:](#)
- Ensure that there is a strong public voice in the governance of the HPRU BSE.
 - Promote an awareness of the NIHR PPIE standards to HPRU BSE researchers and work with them to embed the standards into the PPIE activity within their work.
 - Provide guidance, resources, and support (including support with grant applications, budget developments, role specifications, recruitment, facilitation, reporting) so that researchers and public contributors can carry out effective public involvement in their work.
 - Target support to develop, and facilitate PPIE in priority projects, as agreed with the HPRU BSE programme manager and other appropriate leads.
 - Support the ongoing monitoring and reporting of PPIE activities and outcomes.
 - Provide training on PPIE to ensure that researchers have the skills and confidence to undertake their own PPIE work, under the guidance of the PPIE team.
- B.1 [Provide inclusive opportunities for involvement by building on planned and existing work focused on specific communities and groups relevant to the HPRU.](#)
- The HPRU BSE have committed funding for Community Engagement Project(s) to support the delivery of this aim.
 - Researchers from across the HPRU BSE will be invited to submit expressions of interests for this funding; and a small number of projects will be selected for funding.
 - The HPRU BSE Executive Group (HEG), PPIE team and the strategy group will work together to identify the most appropriate project(s) from those submitted.
 - The PPIE team will continue to work closely with the researchers involved to deliver, and evaluate the Community Involvement project(s).

- HPRU BSE PPIE team will promote researcher engagement using with public facing events to promote health research opportunities.

B.2 Increase diversity in our PPIE by:

- Increasing the diversity of the public contributors engaged in our research projects and in the governance structures of the HPRU BSE.
- Building links with people and groups who experience the effects of health inequality in collaboration with our PHWE partner organisations, to better involve these groups in our work.
- Supporting researchers to develop approaches to PPIE appropriate to their work and accessible to people from a wide range of social, cultural, and economic backgrounds.

C: Provide appropriate information about opportunities to be involved in HPRU research

- Use a wide range of public contributor networks to advertise opportunities to get involved in research including our electronic newsletter, Newsflash. (<http://www.phwe.org.uk/news/newsflash>). Seek new networks to improve the diversity of people aware of opportunities to become involved with the HPRU BSE.
- Support people to access and use the evidence on which their care is based through opportunities including:
 - Delivery of two 'Using and Understanding Research Evidence' workshops each year, across the region, in conjunction with PHWE.
 - Develop content for the HPRU BSE and PHWE website based on the Using and Understanding Research Evidence workshops to help people to find evidence on specific issues.
 - Use the Discourse on-line platform,¹ to enable public contributors to communicate and share ideas; and to improve access opportunities for community organisations.

D: Evaluate Public involvement quality and outcomes in NIHR HPRU BSE through:

- Working collaboratively with the University of West England and PHWE to develop effective processes for ongoing quality assessment of PPIE work at the HPRU.
- By developing a simple but effective process for reporting PPIE outcomes. By developing case studies to illustrate successful PPIE.
- By developing resources such as templates, topic specific guides and videos of our training workshops on the HPRU and PHWE website.

E: Disseminate research findings to relevant service user and patient groups by

- Working with the HPRU BSE Knowledge Mobilisation and Communications Officer to ensure that research findings are written in an appropriate language or where possible developed in appropriate alternative mediums.
- Making the HPRU BSE website an accessible and useful site for PPIE with recruitment opportunities, links to resources, and news and events. The website will show examples of public involvement and list opportunities for public contributors to get involved with our work. The website will be publicised widely to maximise potential traffic.
- Contributing to the HPRU twitter account to ensure that our work and involvement opportunities are widely disseminated.

¹ Discourse is an online platform developed in our collaboration with PHWE. It enables public contributors to communicate with each other freely and share developments and ideas on their involvement, with each other and with the facilitator.

Structural information

Resources

Public contributors

Our greatest resource at the HPRU BSE are our public contributors. Meeting their support and development needs and recruiting new contributors is a central priority for our team.

Collaborative partnerships

The partnership between HPRU and PHWE enables collaborative development of and access to a portfolio of resources that includes

- Providing a programme of learning and development for public contributors and staff across the collaboration.
- Developing and providing public involvement resources and policies to facilitate the PPIE process, for example advice on payment rates for public contributors.
- Providing a single point of communication, with information on PPIE opportunities, events, and resources for the West of England. This includes showcasing good practice in PPIE through a website and social media.
- Helping to build an evidence base on public involvement by developing tools and approaches to support evaluation.

The PPIE lead for the HPRU BSE is part of the national HPRU PPIE lead network. We have led on the development of the national PPIE strategy which includes a commitment to collaborative working and learning.

Finances

We have a policy and budget, which allows the Public Involvement team to pay for the time and expenses of the public contributors involved in each work theme.

We have a non-pay budget for PPIE costs of £11,000.

We have an engagement budget of £20,000 for the Community Engagement Project (Year 2 and 3).

Leadership and reporting.

- The HPRU PPIE Strategy Group will set and deliver the strategy for PPIE, reporting progress to the HEG. The Strategy Group will meet quarterly to review progress made in meeting the PPIE strategic aims.
- The academic lead, Andy Gibson, attends the HPRU BSE annual Strategic Advisory Board meeting; two public contributors from the Public Advisory Group, will also be invited to join the board.

- Members of the HEG will be invited to attend the PPIE Strategy Group meetings. This will ensure the group have the opportunity for regular engagement and open dialogue with the HPRU leadership team.
- Two members of the PPIE strategy group will attend the HPRU's annual Strategic Advisory Board to represent the interests of the Strategy Group. They will be supported by the PPIE academic lead at the meetings.
- PPIE at the HPRU BSE is delivered by an academic lead (Associate Professor Andy Gibson) and a PPIE lead (Dr Noreen Hopewell-Kelly). The HPRU BSE is a partner of PHWE and our PPIE lead attends the PHWE Operational Group. Our academic lead chairs the PHWE Operational Group, which meets four times a year. Two members of the HPRU BSE PPIE strategy group also attend the operational group meetings to represent the HPRU BSE.

The Public Involvement team meets monthly with the HPRU Programme Manager to review progress.

The HPRU BSE PPIE team (as it stands at time of writing), Associate Professor Andy Gibson and Dr Noreen Hopewell-Kelly have written the public involvement/engagement strategy for the HPRU BSE in collaboration with the HPRU PPIE strategy group, (this group will form the basis for our permanent Public Advisory Group (PAG). The members of this group are:

Sarah Blake
Melanie Fearon
Mike Frost
Sue Geary
Dermot McCann
Penny Morgan
Lorelei Hunt
Christina stokes (Co-Chair of the HPRU BSE PPI Strategy group.
Mina Tanna
Heather Thomas
Adele Webb

Definitions

By **'Patient and Public'** we mean patients, potential patients, carers, service users, and members of voluntary, community and service user groups.

By **'Involvement'** we mean having an active role in influencing decisions, particularly early in the development of proposals, so that there is still time for significant influence.

'Engagement' is sometimes used synonymously with Involvement, but here Engagement is used to describe the related processes of sharing information and learning from research with the public (including access to evidence that might inform their individual treatment), and the promotion of participation in research.

'Participation' is also sometimes used synonymously with 'Involvement', but here is used to describe the role of patients or the public as the subjects or participants in research studies.

'Research Ambassador' is someone who, from a public perspective, promotes the benefits of involvement and participation in health research.

The PPI team The HPRU BSE provides the public involvement team with administrative support. The team consists of an academic lead, a PPI lead (0.5) and a PPI facilitator (0.5)

Glossary

PHWE = People in Health West of England

PPIE = Patient and Public Involvement/Engagement

NIHR = National Institute for Health Research