

Patient and Public Involvement and Engagement in the Cardio- Vascular theme of NIHR Bristol Biomedical Research Centre 2017-2019: a strategy.

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The Cardiovascular theme of NIHR Bristol Biomedical Research Centre (CV-BRC) is committed to embedding Patient and Public Involvement (PPI) across all of its research.

Working in collaboration with People in Health West of England (PHWE), NIHR Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) NIHR Clinical Research Network, West of England, West of England Academic Health Science Network (WEAHSN), Bristol Health Partners, Health Protection Research Unit evaluations of interventions (HPRU) and public contributors, we have developed a set of core objectives that are central to our PPI/E strategy;

1. To develop and deliver an agreed collaborative strategy for PPI/E within the CV-BRC, coordinated with CLAHRCwest, WEAHSN and Bristol HP.
2. Ensure that public views are considered at all levels within the structure and work of the CV-BRC, including prioritisation of topics, identification of questions and so on.
3. Provide advice and support to CV-BRC researchers to develop effective PPI.
4. Identify and meet the needs of public contributors in relation to their contribution to PPI/E activities.
5. Engage with the wider public, raise awareness and provide opportunities for people to get involved.
6. Embed PPI across all phases of the research lifecycle.
7. Develop PPI/PPE methodology, in particular for involving and engaging young people and marginalized groups.
8. Seek public feedback to evaluate the quality and impact of PPI/E

This document sets out the vision and ambition we have developed, incorporating our 8 core principles, for high quality PPI/PPE across our work.

The strategy by which we will work to deliver this vision has been written in collaboration with Dr Noreen Hopewell-Kelly, Professor Barnaby Reeves, Associate Professor Andy Gibson

and in consultation with the members of the CV-BRC public contributor panel.

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DEFINITIONS (Developed by <http://www.planb-creativeonline.co.uk/phwe/wp-content/uploads/2015/10/PHWE-Strategy-2015-19.pdf>)

- **Public contributors**

Public contributors is an inclusive term to refer to patients, carers, service users, members of the public and so on who are contributing to the work of the CV-BRC.

- **‘Involvement’**

Activities in which contributors have an active role in influencing decisions; this may include, for example, early involvement in the development of proposals, where there is time for significant influence, or at a later stage in the contribution of ideas around dissemination of study results.

- **‘Engagement’**

The processes of sharing information and learning from research with the public and the promotion of participation in research.

1. Involvement

PPI should be embedded across all research taking place in the CV-BRC. Early involvement can benefit the research by widening the set of topics considered in the research, including initiating new ideas. Good facilitation and leadership is crucial for this activity and researchers will be supported by the PPI lead and offered training and development opportunities to promote effective facilitation. Researchers will also be encouraged to identify where and how PPI can be embedded across each stage of the research cycle; they can be supported in this task by the BRC PPI/E research fellow.

It is crucial that PPI at the CV-BRC be carried out collaboratively between the PPI lead, CV-BRC researchers and our partner stakeholders. Collectively we will work to:

- Develop and facilitate PPI across the research cycle.
- Ensure that appropriate funding is identified for PPI in research applications.
- Facilitate PPI contributions when prioritising research questions.
- Support the learning and development of both researchers and public contributors.
- Support researchers in the implementation of the strategy.

1.1 Public Advisory Group (PAG)

A panel of public contributors will be created to work collaboratively with CV-BRC researchers on all aspects of the research cycle. The public contributors on this panel will become involved in tasks relating to research, strategy and engagement. Tasks may include;

- Commenting on lay summaries
- Commenting on grant applications prior to submission,
- Developing patient information sheets for research studies,
- Sitting on the project steering board
- Developing, responding and commenting on research materials being produced.
- Developing, responding and commenting on promotional materials being produced.
- Undertaking activities between meetings as mutually agreed. This may include some or all of the following:
 - Reading and commenting on documents
 - Attending events (for example, a seminar or workshop).
 - Giving talks or delivering workshops.
 - Being involved in other relevant activities as appropriate.
 - When appropriate, providing support to new public contributors.

The panel will convene approximately once every three/four months to discuss the current research being undertaken within the CV-BRC. The format of these meetings will be developed to reflect the needs of the researchers and interests of the Public contributors. The group will be facilitated by the PPI lead. Researchers from the CV-BRC will be invited to meet with the group to present and collaborate on research ideas, discuss study designs and present results, develop and explore avenues for dissemination of findings (and so on). This will be a flexible forum in which researchers and public contributors can work together to discuss and develop research and the presence of PPI within the research cycle.

1.2 Training and support

The PPI lead will facilitate training and support for the public contributors on all aspects of their role. Public contributors will be invited to attend a PHWE learning event (such as 'Building Research Partnerships') to ensure they are appropriately prepared to undertake their role. Up to date PHWE training events can be found at <http://www.phwe.org.uk/event/building-research-partnerships-workshop>.

Public contributors will be able to access the learning and development programmes delivered by our PHWE partners as and when necessary.

1.3 Recruitment of public contributors

Working collaboratively with researchers, the PPI theme lead will recruit public contributors via social media, public engagement opportunities and partner databases. Recruitment leaflets have been designed for dissemination at public engagement events (appendix 2) and we are able to collaborate with PHWE in identifying potential PPI contributors through their database and their fortnightly newsletter 'Newsflash' (<http://www.phwe.org.uk/news/newsflash>). Recruitment to the PAG group will be ongoing.

The key requirements we are looking for in a public contributor are:

- Good interpersonal skills and the ability to listen and to express views about relevant issues in a way that respects the contributions of others and avoids jargon as far as possible.
- Ability to work as part of a group with people from a wide range of different backgrounds.
- Ability to focus on tasks and achieving outcomes.
- Ability to bring relevant knowledge from the perspective of members of the public.
- Ability to draw on personal experiences and work constructively with others towards a common goal.
- A commitment to promoting diversity and equality of opportunity.
- A commitment to prepare fully for meetings.
- Basic IT skills and access to the internet.
- Willingness to respect requests for confidentiality, to declare any conflicts of interest if these arise and to abide by an agreed code of conduct.

A job description has been developed for the recruitment process which will also be posted on the CV-BRC website.

3. Training for researchers

Researchers will periodically be invited to attend an in-house induction session to learn more about their role in PPI, the role of the public contributor, and to get practical advice on facilitating involvement in research.

The PPI theme lead will work collaboratively with the researchers in the CV-BRC on embedding PPI within the research cycle.

4. Patient and public advisory groups

Researchers will be supported to run individual PPI advisory groups for specific research projects. These will provide a forum in which researchers can speak to patients with specific health related conditions that relate to a specific research study.

All involvement opportunities to join an advisory group will be advertised on the CV-BRC webpages ([link here](#)) and via its twitter account ([address here](#)). Researchers will work with the PPI lead to identify and subsequently invite potential participants from CV-BRC databases. Recruitment opportunities will also be advertised on the PHWE fortnightly newsletter 'Newsflash' (<http://www.phwe.org.uk/news/newsflash>).

Payment guidance

In line with the guidelines set out by INVOLVE, it is generally agreed that public contributors should be paid for their time and travel. Reflecting the position of our PHWE partners, we will also follow the guidance from INVOLVE on rates of payment. Please see Table 1 for detailed breakdown.

Table 1: payment guidance

Activity	Rate
PPI advisory group (One off meeting for specific research activity)	£20.36 per hour or vouchers as agreed
PPI Strategy Group Meetings 4 per year	£20.36 per hour. This covers the time spent preparing for meetings such as reading minutes and associated papers).
Board Meetings	£20.36 per hour
Presentations, talks or facilitating at events, conferences and seminars- number of hours and preparation time to be agreed	£20.36 per hour
Research Activities; helping to run a stall; other activities as agreed	£14.44 per hour or vouchers as agreed
Essential training	As agreed

Please note that travel costs will be paid in addition to the rates for activities detailed in Table 1.

Please note that if a Public contributor is in receipt of welfare benefits and are offered payment for involvement they may need to consider how the payment might affect their benefits. This is a complex topic on which INVOLVE has set up a Benefits Advice Service to offer their expert knowledge. The advice is free, confidential, informed by the latest regulations and personalised (the advice is specific to the individual's circumstances). If a

Public contributor wishes to access the service, please email benefits@invo.org.uk or to phone on: 02380 651088.

5. Administration, resources and budget

There will be a central administrator supporting the CV-BRC PPI lead.

PPI resources will be made available to each researcher within the CV-BRC. A shared drive will be available for researcher to access the PPI strategy, PPI job description and all other relevant resources. A password protected database will also be kept in this file with details for the PPI contributors working with the CV-BRC.

6. Engagement

Our engagement objectives include communicating our work with the public through written communications, events, networks and social media.

- Engage and work with the dedicated Communications and Public Affairs Departments of each of the partnership organisations.
- Develop website and other communications with patient involvement.
- Identify PPI groups and interest groups and develop links/networks with these groups to promote access for patients and the public and dissemination of information about our work and events.
- Review opportunities for expanding and improving patient involvement including recruitment of additional patients.
- Learn from PPI research outcomes at CTRPS, NWL CLAHRC and Patient Experience Centre.

We will also look for novel and innovative ways to develop our engagement work, particularly in collaboration with other BRCs and interested parties.

7.1 CV-BRC website:

The website for the CV-BRC has a specific section for PPI. This hosts recruitment opportunities, links to resources, news and events, examples of PPI and so on. The website will be kept up to date and will be publicised widely to maximise potential traffic <http://cteu.bristol.ac.uk/ppi/home/>

7.2 Conferences and events: The CV-BRC will communicate its PPI work through attendance at conferences and events, but will also hold events of its own to showcase its work, to which patients and the public are welcome.