

CLAHRC Wessex

Collaboration for Leadership in Applied
Health Research and Care



***National Institute for
Health Research***

Embedding Patient and Public Involvement Champions within Applied Health Research Programmes

A Practical Manual based upon the observations and experience-based
learning of NIHR CLAHRC Wessex



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Definitions

By 'PPI' (patient and public involvement) we refer to research (and implementation) carried out 'with' or 'by' patients and members of the public, rather than 'to', 'about' or 'for' them.

We refer to 'public contributors' as those who carry out involvement work in a 'lay' capacity (i.e. as patients, members of the public and / or their families / caregivers).

Within this Guidance, we highlight the contribution of 'PPI champions'. These are public contributors invited by virtue of their experience, skills and characteristics to contribute to strategic involvement work within applied health research and implementation programmes.

By the term 'applied health research', we are referring to research aiming to answer clinical or practice-based health research questions, rather than basic science questions.

In reference to 'strategic PPI involvement' work, we mean the contribution made to helping the organisation identify longer-term PPI aims and interests, and appropriate means of achieving them.

Background

Since the origins of patient and public involvement (PPI) in the 1960's, there has been consistent growth in recognition of its importance. Today, it is accepted as a critical part of successful research and research bids.

"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well."

Professor Dame Sally Davies, Chief Medical Officer

"As well as the practical benefits of helping to ensure research quality and relevance, the underlying reasons for involving members of the public in research are also informed by broader democratic principles of citizenship, accountability and transparency. The reasons for involvement might not always be clearly defined and at times will overlap each other. However understanding why you want to involve members of the public in your research will help you think who you want to involve and how you want to involve people"

An excerpt from INVOLVE (www.invo.org.uk/)

Introduction

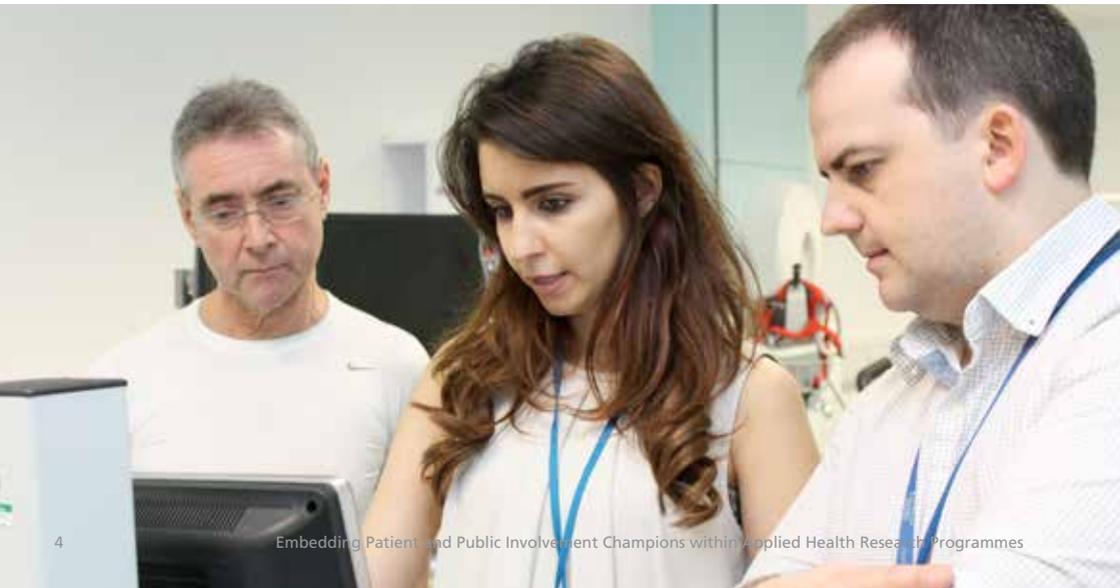
Since we were founded in 2014, NIHR CLAHRC (Collaboration for Leadership in Applied Health Research and Care) Wessex has sought to embed PPI through identifying, supporting and empowering more experienced PPI contributors ('PPI champions') to work strategically with staff across our six research and implementation themes (see www.clahrc-wessex.nihr.ac.uk/). The learning associated with this work has informed this guidance, which has mainly been drafted for:

- » Researchers seeking a blueprint towards embedding PPI within their applied health work
- » Experienced PPI contributors wishing to assume a more strategic role within programmes of applied health research
- » Health research organisations aiming to enhance the sustainability and effectiveness of their own PPI model

Collaborative working with experienced PPI contributors has been a major factor in the successful development of NIHR CLAHRC Wessex. We recognise that our proposals represent just one of a number of possible PPI models. However, it is our hope that through sharing our experiences and the learning associated with introducing a new apex PPI role, to further embed PPI at an organisational level, we can make a positive contribution to this rapidly evolving area of work. This document therefore aims to share our learning from the PPI Champion implementation process, to support other organisations wishing to employ a similar model.

How was it made possible?

NIHR CLAHRC Wessex funded both the project worker and the public involvement time. The organisation also supported the project with expert guidance, communications and administrative support.



Section 1: Appointing PPI Champions

'PPI champions' at CLAHRC Wessex are PPI contributors invited by virtue of their skills, experience and characteristics, to contribute to strategic involvement work within applied health research and implementation programmes. In many ways positioning these individuals in apex PPI roles, this section considers how other organisations may identify and recruit effective individuals for similar roles, and how they might operate within the organisational structure.

Our experience at CLAHRC Wessex:

We acknowledge here that, at times, luck may have played a part in our ability to recruit effective PPI Champions. However, reflection has indicated that getting to know our PPI contributors as they were recruited was critical to successful appointment. Understanding sometimes hidden skills, experience and motivations, as a mechanism for identifying those contributors with the capacity and/or interest to move on into a more strategic role, has proven pivotal.

At CLAHRC Wessex we have examples of PPI champions with significant former PPI health research experience with other organisations, or with significant third sector knowledge and experience. Some retain a clinical background and/or experience, are very well-networked in this area of work, or have chronic conditions of relevance to our specific research themes. We also appointed PPI Champions with none of the aforementioned skills, experience or background, on the basis of their significant interest and/or motivation to make a greater, more strategic contribution. Regardless of the motivations, background or reasoning for their appointment to PPI Champion roles, all our experience demonstrates the importance of investing the time, energy and effort to meet and get to know new PPI contributors as they register to join the programme; without such investment these individuals could not have been identified from the PPI resource pool.

As has been suggested, rather than formally advertising externally to recruit our PPI champions, the identification process was far more informal, and based upon direct approach following the identification of desirable qualities and characteristics. At CLAHRC Wessex, the associated process highlighted the following as appropriate examples:

- » Curiosity and/or a keen interest in health research
- » Experience as an advocate, representative or worker with community groups (e.g voluntary organisations or health charities)
- » Confidence, tenacity and resilience
- » Flexibility and a willingness to learn
- » A belief in the difference that their own singular contribution can make
- » A basic understanding about the operational processes within the host organisation
- » The ability to work well within a team environment

This list was co-developed with one of our PPI champions. Some or all of it may be useful in other organisations, but consideration should be given to identifying their own, bespoke index.

Section 2: Refining the PPI Champion role

The 'PPI Champion' role, and the associated activities, will be varied and organisation-dependent. However, at CLAHRC Wessex our experience of implementation at an organisational level contributed to the development of a 'PPI Champion Role Descriptor' that worked for us. Detailing the types of activities in which PPI champions would engage, this next section covers some of the constituent elements.

Our experience at CLAHRC Wessex:

We believe at CLAHRC Wessex that PPI champions can adopt a wide variety of roles. It has been our experience however, that it is of importance to identify elements of the role of primary relevance to our own organisation. The following provides a summary:

- » Acting as a role model for other PPI champions
- » Providing a PPI perspective on research proposals - both during and following the design phase
- » Contributing as core team members to research projects; which further helps us track - through direct contact with our champions - how PPI is being implemented across the organisation
- » Sharing their ideas about new innovations or new ideas with the potential to improve health care experiences
- » Representing PPI for NIHR CLAHRC Wessex at regional/national specialism meetings
- » Disseminating theme-based PPI activity and contributing to PPI branch matters centrally, through active involvement at quarterly WISeRD (Wessex Involvement in Service Research and Delivery) Advisory Group* meetings
- » Speaking out about the patient experience at internal and external events

** At CLAHRC Wessex, upon appointment, each PPI Champion is automatically enlisted to the WISeRD Advisory Group - a forum for PPI information exchange and theme-related PPI activity dissemination. For more information about WISeRD see <http://bit.ly/2o35NYI>.*

Section 3: Supporting PPI champions

Ensuring the provision of adequate support for 'PPI champions' is important, even if it has been our experience that, as more experienced PPI contributors, they will often proactively seek support when necessary. With this in mind, developing an awareness in 'PPI champions' of where to source such support has been important. The chosen approach will vary between organisations, in response to organisation structure and role descriptions, but what follows outlines the approach adopted by CLAHRC Wessex.

Our experience at CLAHRC Wessex:

There are several advertised routes through which our PPI champions can look for support towards fulfilling their remits, including a central administration team with a PPI Coordinator, through which questions, concerns or queries may be channelled. Of particular importance is a nominated member of staff who sits within a specific research theme, offering support to the associated PPI Champion. At CLAHRC Wessex, these individuals are termed 'PPI staff links'.

A critical part of identifying appropriate individuals from within the existing staff pool to fill these roles, has been the determination of desirable personal characteristics. Based upon the role descriptor for PPI champions, and co-produced with two of our PPI champions, the following details those desirable requirements identified for our PPI staff links:

- » Be comfortable with collaborative working, and with sharing power in decision-making with public contributors
- » Understand/support participation with the limitations caused by chronic conditions
- » Be confident liaising with researchers
- » Operate at a strategic level within the organisation
- » Create ongoing rapport and dialogue towards supporting PPI contributors in their work and development
- » Be flexible to the needs of the PPI contributors
- » Understand the theory and background to PPI
- » Facilitate awareness of, and where appropriate, involvement with local and national PPI resources, and the associated networks (virtual, social media etc)
- » Clarity of reporting lines and accountability to senior levels within the organisational structure
- » Be contactable

In our view, and with specific reference to the use of a 'staff links' model, many of the desirable qualities detailed above are translatable to other organisations/organisational structures, given that individuals operating within a 'PPI Champion' role should have access to support, regardless of their remit.

Section 4: Setting the ground rules

With increased responsibility and involvement, we felt it was necessary to develop a set of guiding principles and values which 'PPI champions' would be expected to follow. Designed to ensure the promotion of respect, participation and integrity in our PPI champions in their interactions across the wider organisation, and collaboratively developed with our WISeRD Advisory Group (WISeRD is a forum for PPI information exchange and theme-related PPI activity dissemination; see <http://bit.ly/2o35NYI> for more information), what follows outlines what we produced. Co-production with PPI input has proven really important and is something we would advocate - but different organisations may pursue different approaches.

Our experience at CLAHRC Wessex:

A set of guiding principles and values which PPI champions are expected to follow was developed with, and agreed by the WISeRD Advisory Group. The subject of several experience-based iterations, the constituent elements are captured by the acronym 'OSCARS', and underpin how we all work together (see Table 1). While we recognised the importance of being very clear about these principles, we also recognised the need for flexibility and opportunity for learning.

O wn	WISeRD members will each have a sense of and accept responsibility for the collective activities and decisions of the group
S hare	Members will listen and talk to partner organisations and interested people beyond the WISeRD group to widen its reach and impact
C ontribute	Each member will take an active and constructive part in the activities of WISeRD
A ttend	Members will attend meetings whenever possible
R espect	Members will treat each other with dignity and respect
S ecurity	Members will respect and abide by ethics and governance requirements

At times there have been differences of opinion or insensitivity in the offering of viewpoint, but reflection has typically identified appropriate training opportunities or afforded a positive revision of process to the benefit of all. However, it has been important to ensure we retain a willingness in researchers to incorporate PPI into their work, and that PPI contributors and champions know that their views are valued and make a tangible contribution.

Section 5: Resources to support 'PPI champions'

Beyond the support afforded by the 'PPI Staff Link' role (or equivalent), providing resources to support the work of 'PPI champions' - both financial and practical - is in our view, very important. As is detailed below, we have incorporated experiential learning, applied with guidance from elsewhere, to develop resources we believe to be appropriate to the remit of our own PPI champions. Essential to helping them operate effectively, the desired approach to provision will again vary between organisations - depending on the task(s) that the organisation in question wants their 'PPI Champion' equivalents to deliver - but that which follows details our approach.

Our experience at CLAHRC Wessex:

Broadly following the '4Pi Standards' (<http://bit.ly/2naTDhU>) that categorise 'support' under four primary facets (practical issues; engagement; communication; support & training), we incorporated the views of our PPI champions towards enabling their participation.

As with all of our PPI contributors, PPI champions are reimbursed for their time and expenses in line with national guidance (INVOLVE 2012: <http://bit.ly/219OPSZ>). Additionally, with an awareness that the many organisational acronyms can be confusing, we also co-produced an online 'Jargon Buster' with our PPI champions: <http://bit.ly/2nXDOs9>.

To help us support engagement, and provide means for effective communication and dissemination, we use a variety of media platforms to share and promote the work of NIHR CLAHRC Wessex; our PPI champions have been at the forefront of developing these. Our website - a dynamic and ever-evolving resource - is also a broad portal for the communication of current research and engagement; again our PPI champions have actively collaborated with the Communications and Marketing Manager to ensure that content is engaging and universally accessible. With a growing social media presence (for current list of platforms visit www.clahrc-wessex.nihr.ac.uk/) - driven in-particular by an experienced blogger within our PPI Champion ranks - we have also employed a PPI Contributor to design and produce a 'PPI Guide to Tweeting', which has been made available to our PPI contributors. Indeed, this provides a valuable exemplar of the benefits of PPI contribution to the development of such resources - drafted and reviewed by PPI, for PPI, the document is inherently accessible by its very nature.

We have followed a number of different approaches to ensuring we provide adequate education and training opportunities for PPI champions and contributors. For example, we created a 'Guide to Lay Reviewing'. PPI champions are also routinely invited to participate in events, such as our NIHR CLAHRC Wessex Annual Stakeholder Day, away days and some other more general CLAHRC training opportunities (e.g. Impact Case Study workshop, Presentation Skills workshop). In line with national recommendations (INVOLVE 2015: <http://bit.ly/2oCUA2t>), we also offer PPI champions the opportunity for an annual review which is conducted by the PPI Lead or the PPI Coordinator. A simple format, Box 1 (overleaf) illustrates the details.

Box 1: Format for the PPI Champion annual review

- » Name;
- » Reviewer;
- » Date;
- » What is going well?
- » What is not going so well?
- » What would you do differently?
- » What are your learning needs?
- » What are the organisation's PPI learning needs?
- » Agreed actions.

The annual review process identifies specific learning needs. It also offers insight into learning around PPI that may be required by the organisation, and in our view helps to evidence in our champions, the value we place on their contributions. Health research theme staff can be involved in the discussion if the PPI Champion requests their input.

Affording resources that promote 'PPI Champion' effectiveness is important, but equally important in our experience, is ensuring PPI input to the resources we offer, and that they know how/where to access the resources. After all, having resources that the PPI team do not know about is of little benefit to anyone! This provides another example of the positive influence that clear communication lines provide - in the example of our own organisation, this gap is filled by our PPI staff links.



Section 6: PPI Champion feedback & evaluating impact

The 4Pi 'Process' (<http://bit.ly/2naTDhU>) also promotes reflection towards understanding how contributors feel about the involvement process; an important constituent in establishing the effectiveness of PPI within an organisation, and therefore something that any organisation should consider towards PPI implementation at any level.

Our experience at CLAHRC Wessex:

In response to these requirements, and with reference to the PPI Champion model we elected to employ, CLAHRC Wessex initiated a project called 'Mapping PPI' in our first year of operation. The project sought perceptions and opinions on the involvement process (specifically about PPI contributions made to research prioritisation activities over this period) from our PPI champions. The preferred approach to evaluating the level of involvement in PPI champions will vary between organisations, but the act of enquiry alone, contributes to an overall sense of involvement and engagement with the organisation and its objectives. Certainly, we believe our PPI champions have had a very positive impact. Box 2 provides a brief sample of the comments that arose as a consequence of the project:

Box 2: A brief sample of the anonymous comments arising from the Mapping PPI project, designed to qualitatively assess PPI Champion impact with our research themes.

"...she is very involved at all levels - highly engaged in our meetings and our work... helps in recruiting others in our areas of study, attending meetings and working with others. Very reliable and helpful."

"She has a good knowledge of how things work in her local area and knows some of the key people involved in the implementation. Practically, she understands about the local context and travel and communication difficulties which are helpful to researchers. We have used her background in film-making and her knowledge about the technology involved to help us in filming our case-studies - e.g. in finding appropriate gadgets and software."

Conclusions

This manual aims to disseminate a roadmap for the implementation of a new PPI organisational model, using the observations and experiential learning gleaned by our organisation - CLAHRC Wessex - during implementation, as an exemplar.

The 'PPI Champion' role - as we implemented it - has made a significant contribution to embedding PPI at a strategic level within the organisation. This document details the processes we have undertaken towards appointment, support and establishing the subsequent impact of individuals operating within this capacity. It is drafted in support of a full guidance document which may be found under 'Useful Documents' [here](#).

Arising are a series of general recommendations (see below) enabled to aid organisations seeking to embed strategic PPI within their own programmes of health research; our continuing goal is to promote PPI within both health research organisations and experienced public contributors.

Guidance summary & key recommendations

Recommendation 1:

Clarify where PPI fits strategically within the applied health research programme, and how it will exert influence.

Recommendation 2:

In identifying PPI champions, consider what characteristics, skills and experience are required / will best-complement the research programme, staff and other PPI contributors (where applicable).

Recommendation 3:

Involve PPI champions in identifying values and principles which inform how they and others work, and review adherence to these in practice.

Recommendation 4:

Create policies, resources and learning opportunities which will support PPI Champions to work within health research programmes.

Recommendation 5:

Work together with PPI champions and other stakeholders to co-design evaluation of PPI champion impact, using credible and meaningful methods.